The Sentinel Stroke National Audit Programme:
An improvement tool for community stroke care?

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Abstract

Background

The Sentinel Stroke National Audit Programme (SSNAP) is an established quality improvement tool for hospital-based stroke care. It is the only national stroke audit that collects data detailing stroke care beyond hospital discharge. However, its role in driving quality improvement in the community setting was unexplored.

Aim

To understand the role of national clinical audit in driving quality improvement in community stroke care.

Methods

This thesis consists of four phases of study, each informing the next. Phases used distinct research methods as part of the overall realist evaluation.

i. A scoping review of the literature exploring the contextual features that influence the contribution of externally initiated, multidisciplinary clinical audits to quality improvement.

ii. A mixed-methods online survey investigating stakeholder experiences of SSNAP in the community setting.

iii. Realist interviews exploring what influences the ability of SSNAP to contribute to quality improvement in the community setting.

iv. National clinical audit data was used to explore the use, and interpretation of a patient reported outcome measure (EQ5D-5L) as part of quality improvement in community stroke care.

Results

The scoping review identified important features pertinent to audits that are multidisciplinary and externally initiated. The findings suggest individual engagement to be influenced not only by a perception of the audit and its purpose, but also by perceptions regarding credibility and organisational culture. Findings were used to develop an online mixed methods survey.

The survey captured the perspectives of a broad range of stakeholders in different roles from across England, including administrative, clinical, management and commissioning (n=206). Participants reported being engaged in the audit and using feedback to inform a variety of quality improvements. Teams were described as committing significant resources to audit participation, despite facing a number of barriers. Challenges to audit participation were highlighted such as the administrative support available, the inflexibility of the online audit platform and the ability of the audit to reflect the services delivered in this setting. Findings were used as a framework for subsequent realist interviews.

Interviews were undertaken with a broad variety of stakeholders in different roles from across England (n=20). The findings generated greater understanding of the contextual features in community stroke care and the mechanisms by which these influence the ability of the audit to drive quality improvement in this setting. Four theories have been proposed that seek to explain the mechanisms by which SSNAP contributes to quality improvement in community stroke rehabilitation.

Firstly, organisational support such as leadership interest, the fostering of champions and dedicated administrative support legitimizes audit activity. This provides opportunities for skill sharing which motivates team engagement with the audit. Secondly, an accessible audit feedback report enables leaders to be confident in using the information to inform strategic conversations such as commissioning. Thirdly, channels of communication across the stroke pathway provide opportunities for collaboration around shared goals such as the curation of complete datasets. Finally, audit feedback is more likely to be used for quality improvement if stakeholders perceive it as reflecting the services they deliver and capturing the impact of these services for stroke survivors.

Participants described frustrations with the perceived limitations of existing outcome measures and proposed the collection of an alternative patient reported outcome measure the EQ5D-5L. Statistical analysis of national clinical audit data (n=3,813) confirmed that for community dwelling stroke survivors in England, the characteristics collected by SSNAP were significantly associated with the majority of EQ5D-5L outcomes at the level of domain, EQIndex and EQ-VAS. Characteristics included age, gender, comorbidities, relative deprivation, stroke severity and disability. The EQ5D-5L was found to be more reflective of physical, rather than psychological components of health-related quality of life. However, individual EQ5D-5L domains and the visual analogue scale of overall health provided additional information regarding pain and anxiety, to that already offered by measures collected in SSNAP.

Conclusion

Findings in this thesis add to the existing literature, providing transferable insights into the role of national clinical audit in driving quality improvement in community services. These include the importance of organisational support, such as dedicated administrative support, leadership engagement and the fostering of audit champions in this setting. There was a recognition of the importance of accessible audit feedback to enable its strategic use and the role of collaboration-based approaches along a clinical pathway which span organisational boundaries. The metrics collected should be interpreted by stakeholders as reflecting both the service they deliver and the populations they serve. The collection of EQ5D-5L at commencement of community rehabilitation and again at six months offers additional insights into the needs of stroke survivors at what can be a challenging time in their recovery.

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List of abbreviations

AF	Atrial fibrillation
CHERRIES	Checklist for reporting results of internet e-surveys
CHF	Congestive heart failure
COREQ	Consolidated criteria for reporting qualitative studies
CP-FIT	Clinical performance feedback intervention theory
CQR	Clinical quality registry
CMO	Context mechanism outcome
CPT	Candidate programme theory
DARF	Data access request form
ESD	Early supported discharge
FUPS	Flawed, uncertain, proximate and sparse
GRAMMS	Good reporting of a mixed methods study
HIC	High income country
HQIP	Healthcare quality improvement partnership
HRQoL	Health related quality of life
IPT	Initial programme theory
ISDN	Integrated stroke delivery network
IT	Information technology
MDT	Multidisciplinary team
MRC	Medical research council
mRS	Modified rankin scale
NCA	National clinical audit
NHS	National health service
NICE	National institute for health and care excellence
NIHR	National institute for health and care research
NIHSS	National institutes of health stroke scale
NQR	National quality register
NSRPG	Nottingham Stroke Research Partnership Group
PICO	Patient, intervention, comparison and outcome
PREM	Patient reported experience measure
PRISMA	Preferred reporting items for systematic reviews and meta-analysis

PROM	Patient reported outcome measure
PT	Programme theory
RE	Realist evaluation
SPSS	Statistical package for the social sciences
SSCA	Scottish stroke care audit
SSNAP	Sentinel stroke national audit programme
STROBE	Strengthening the reporting of observational studies in epidemiology
UK	United Kingdom

1 Introduction

This chapter introduces audit, its development over time and role as a tool for quality improvement within healthcare. An established national clinical audit, the Sentinel Stroke National Audit Programme (SSNAP) is detailed. Subsequently, the clinical pathway across which SSNAP is implemented is described and differences between the hospital and community settings are highlighted. Quality, and how this is measured in the context of stroke care is discussed, as are the limitations to the measures currently used. Finally, a rationale for further enquiry into the role of SSNAP in driving quality improvement in the community setting is presented.

1.1 What is Audit?

The Oxford English Dictionary defines audit as:

> "*To make an official systematic examination of accounts,*
> *so as to ascertain their accuracy*"[1]

Audit can be used to satisfy a number of objectives such as financial efficiency, procedural efficacy and quality assurance[2]. Despite the potential variety of functions, there are common key features of an audit. These include a clear purpose, agreed indicators against which performance is measured and a report detailing an analysis of the data[3].

1.1.1 A brief history of audit

Audit can be traced back to ancient civilizations where records of financial transactions were reviewed for accuracy. Auditing became more formalised in medieval Europe, where stewards were appointed to verify the accounts of landowners[4]. The rise of large corporations with increasingly complex financial transactions during the industrial revolution generated a need for more systematic auditing. By the mid-20th century audit had become a critical tool in fraud detection in the financial sector[4]. In the early 1980's, following the establishment of the National Audit Office and the Audit commission, there was a considerable increase in the use of audit in the UK. These organisations facilitated the scrutiny of new areas outside finance including health, education and the criminal justice system[3].

A vocal proponent of audit, Power suggested three causes for what he described as an "*explosion*" in audit activity during the 1990's. Firstly New Public Management, which used private sector management models to run public services in a more business-like manner[5]. In the context of spending reforms which prioritised transparency, audit was proposed as the tool by which services would demonstrate public accountability[6]. Secondly, the rise of governance within institutions and the drive for internal systems of accountability, for example, the significant investments made by the National Health Service (NHS) in risk management. Finally, the shift from purely *accounting* for practices, to *assurances of quality* through the specific indicators that were selected as reflecting acceptable levels of performance[6].

Despite an intention for audit to affect organisational change, Power acknowledged the potential for "*games of creative compliance*" whereby systems shift from having performance audited, to performing to the audit[6]. This was evident in UK education at the end of the 1990's. Teachers were reported as changing practice to "teach to the test" in response to planned inspections by the Office for Standards in Education. This reportedly resulted in an erosion of trust in the audit and its findings[7].

Maltby argues this blinkered pursuit of primary outcomes and lack of consideration of the potentially unintended consequences to have inherent risks[8]. This was illustrated in a study by Catlow et al. who explored the unintended consequences of clinical audit in endoscopic surgery. Findings suggested that the desire to achieve key performance indicators pushed individuals towards "*gaming behaviours*". These included inaccurate documentation, falsely claiming to have met targets and completing unnecessary interventions[9].

Power has pointed to examples of audit restoring trust in financial institutions through public accountability[6]. However, critics have argued that audit transparency is not tantamount to public accessibility[10]. Whilst the public may be reassured by an audit taking place, if the criteria for success are unclear, public scrutiny is difficult[8]. Power concedes that although idealised as a transparent activity, audit may appear intangible to many stakeholders. If findings are inaccessible they will lack leverage for their intended purpose[6].

The following section focuses on the application of audit in healthcare settings and provides an overview of national policy initiatives which have shaped the use of clinical audit in the UK.

1.1.2 National policy and clinical audit

In 1989, the NHS Review "Working for Patients" proposed reforms that would divide organisations into those who provide, and those who purchase healthcare services[11]. These proposals were operationalised through the NHS and Community Care Act 1990[12]. Underpinning these reforms was the premise of an internal market within the NHS. Instead of individual NHS Trusts receiving fixed incomes to meet their population needs, money would travel with the patient to the organisation providing a service. Individual NHS Trusts were incentivised to adapt services to local demand in order to attract patients, who in return would be offered greater choice as providers competed for business[11].

This white paper, amongst others, acted as a catalyst for health sector reforms, signalling a shift towards New Public Management in the early 1990's[2]. New Public Management had distinct private-sector characteristics and an overarching aspiration to reduce the "bureaucratic load" of public services. These included retaining managerial control, targets of reducing costs, incentivising competition and performance monitoring[5]. These principles were manifest in the Community Care Act[12], for example, the compulsory participation of NHS Trusts in clinical audit, overseen by an external independent body[2].

Critics have identified tensions in attempting to use audit to satisfy diverse policy objectives such as financial efficiency, procedural efficacy and patient outcomes[2]. A lack of shared understanding regarding the purpose of clinical audit may create barriers to implementation; for example clinicians may be apprehensive to engage in audit if they perceive its purpose to be financial efficiency rather than improving patient outcomes[13].

Dixon highlights concerns regarding this lack of shared strategic understanding regarding an audit's objectives, specifically whether it is for quality assurance or quality improvement purposes[14]. As described earlier, the origins of audit may lie in financial assurance, however its current purpose within healthcare is primarily quality improvement[15]. For clarity, Table 1-1 summarises the key characteristics that distinguish Quality Assurance from Quality Improvement (adapted from Dixon, 2011)[14]. *Quality* and *quality Improvement* are discussed in more detail later in this chapter.

Table 1-1: Comparison of Quality Assurance and Quality Improvement

Characteristic	Quality Assurance	Quality Improvement
Purpose	To ensure quality requirements are met	To bring about change, resulting in improvement
Focus	Using standards to ascertain compliance	Using standards to change practice
Data use	Data used for reference and comparison	Data used to identify focus and drive improvement
Outcome	Actions intended to remedy deviation from standards	Actions involve change to improve practice
Repeat data collection	Not always required	Regular cycle

Audits may be initiated either externally by an organisation, or internally by individuals involved in the activity being audited. The source of initiation influences how it may contribute to quality improvement[14]. Internally initiated audits are often in response to poor performance locally. It is suggested that audits initiated internally may foster collaboration and engender a perception of "ownership" that can lead to sustained improvement[16]. Externally driven audits are commonly undertaken to satisfy conditions for accreditation or certification, using retrospective data on an annual or biannual basis[16]. Mandated audits may face barriers in engaging individuals and therefore lead to quality improvement via different routes[17].

1.1.3 Contemporary clinical audit in the UK

In the UK, the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England, commission 28 National Clinical Audits (NCAs) across a range of health conditions[18]. These audits are usually governed and managed by recognised centres of excellence such as Royal Colleges and consequently their outputs are held in high regard by both providers and commissioners of healthcare services[19]. Clinical audit is defined by HQIP as:

"*A quality improvement cycle that involves measurement of the effectiveness of healthcare against agreed and proven standards for high quality*."[15]

This four-stage process is illustrated in Figure 1-1[15]. It consists of preparation and planning, measuring performance, implementing change and sustaining improvement.

Figure 1-1: The clinical audit cycle as proposed by HQIP

National clinical audit programmes in the UK have significant overlap with what are termed Clinical Quality Registries (CQRs) elsewhere in the world. These large-scale national registries collect data for the purposes of benchmarking, feedback and quality improvement in healthcare organisations[20]. For the purpose of this thesis, the term clinical audit will be used as an umbrella term where the description matches that provided by HQIP.

National clinical audit programmes in the UK collect a variety of information, based on evidence-based standards. These include patient characteristics such as age, sex, and comorbidities, patient outcomes including measures of functional ability or quality of life and provider performance measures such as length of stay in hospital[21]. In England, Wales and Northern Ireland audit data is publicly available and can be used to highlight discrepancies between practice and evidence-based key performance indicators. Comparisons can also be made between providers of similar services and benchmarking against national averages data[22]. These features are designed to prompt and facilitate behavioural and organisational change for quality improvement purposes[23].

1.1.4 What evidence is there that clinical audit is effective?

Despite being an established quality improvement tool, the most recent Cochrane review found audit resulted in only small improvements in clinical practice[19]. Of the 140 randomised trials included, the median absolute improvement was reported as +4%. The interquartile range varied from +1% to +16%, which demonstrated a degree of variability between studies. Larger effects were found in audits where baseline performance was poor, feedback was provided more than once from a supervisor or colleague and was delivered in multiple formats[19]. Those critical of clinical audit suggest this to be meagre return on investment and therefore an unjustified use of time and resources[24]. However it is important to understand the constraints of the research included in the review and how this may have contributed to variations in the outcomes reported.

Substantial heterogeneity was evident in the studies included in the Cochrane review such as the setting, the conceptualisation of audit, how outcomes were defined and captured[19]. Authors called for improved reporting of study design in future research. In addition, it was proposed that subsequent studies should include the explicit use of theory in audit design, to better understand how and why audits are effective. This concurs with previous research suggesting trials alone may be limited in their ability to explain how and why audits are more or less effective[25].

Historically, audit and feedback research has focussed predominantly on single-discipline activities, commonly those undertaken by doctors. These have either been situated in inpatient or clinic settings, where individual performance feedback comprised either rates (e.g. vaccination or prescribing), or compliance with documentation standards or clinical guidelines. As a consequence of limiting studies to settings, interventions, participants and outcomes that are *relatively* standardised, it has been possible to aggregate results. However findings may not be readily applicable to situations where greater complexity exists. For example, many of the NCAs commissioned by HQIP in England and Wales are multidisciplinary. These may be heterogenous in the nature of the activities audited, the healthcare professionals involved or the settings in which they are undertaken.

In an attempt to advance understanding, various studies have explored the underpinning theories used when designing and studying audit and feedback interventions[26-29]. In 2019, Brown et al. published the Clinical Performance Feedback Intervention Theory (CP-FIT)[30] building on a number of these theories, as well as existing implementation frameworks. This meta-synthesis of qualitative research offered what Brown et al. described as a comprehensive healthcare specific feedback theory. The CP-FIT proposes a number of factors that influence the success of audit feedback and offers guidance to enhance its effectiveness.[30] However, in the quest for a single broad overarching theory there is a risk that explanatory power may be reduced.

The new Medical Research Council (MRC) framework acknowledges this trade-off between the focus of enquiry and specificity of findings[31]. MRC guidance recommends that research into complex interventions such as clinical audit go beyond whether an intervention is effective. These include, establishing underpinning programme theories and investigating how an intervention interacts with its context[31]. Despite the CP-FIT identifying a core set of common contexts and explanatory mechanisms, their interactions are not explored in detail.

More recently, studies have used qualitative approaches to investigate a variety of aspects of these NCAs. Antonacci et al. used qualitative interviews to explore how healthcare providers use NCA data for improvement[32]. Findings highlighted an inequitable distribution of quality improvement skills at a variety of organisational levels resulted in NCA use being sub-optimal. Using qualitative interviews to explore how hospital boards view NCA, McVey et al.[33] described an imbalance between the burden of data collection and perceived benefits. This was reported as impacting the legitimacy of, and therefore engagement with the audit. Alvarado et al. used a realist evaluation to explore variation in the use of feedback from NCAs[34]. Findings suggested several mechanisms influenced healthcare provider interaction with NCA feedback, including competition and incentivisation[34]. Although this study had a broad focus in terms of contexts and type of audit included, the depth of interrogation offers detailed insights into why, how and in what context national audit may lead to quality improvement. The proactive use of feedback for quality improvement, was found within clinical services that were resourced to collect and maintain local databases. This provided feedback that was both trusted as accurate and customisable for the needs of the service.

1.2 Setting the scene: Stroke care in the UK

1.2.1 What is stroke?

Stroke is a clinical syndrome caused by an interruption to the brain's blood supply and subsequent cell death. It is characterised by a rapid onset of neurological impairment affecting one or more function such as movement, communication or swallowing, depending on the location of damage[35]. Between April 2022 and March 2023, 91,162 individuals were admitted to hospital with a stroke, in England, Wales and Northern Ireland[36]. Almost 73% of the 89,081 patients who survived their stroke, were discharged from hospital with a level of disability that would require ongoing rehabilitation[37].

1.2.2 Organisation and delivery of stroke care

The organisation and delivery of stroke care in the UK has been informed by a variety of guidance. This includes the National Clinical Guidelines for Stroke[38], The National Institute for Health and Care Excellence guidance[39,40], and in England the National Stroke Service Model[41] and the National Service Model for an Integrated Community Stroke Service[42]. For the purposes of this thesis, the term "care" describes any healthcare support including rehabilitation. The following section provides a simplified overview of the stroke pathway in England as outlined in the above guidance and is illustrated in Figure 1-2.

Integrated Stroke Delivery Networks (ISDNs)

As highlighted in the National Service Model[41], ISDNs are responsible for designing and delivering optimal stroke pathways and are key to delivering on the NHS Long term plan commitments for stroke[43]. These networks include multidisciplinary stakeholders from ambulance, acute and community services alongside patient representatives, individuals from the voluntary sector, commissioning and social care. ISDNs have four key objectives. Firstly, they provide clinical leadership and coordinate resources across the pathway. Secondly, they collaborate strategically with existing integrated care systems to manage capacity and demand for stroke care. Thirdly, they ensure services are optimally configured for local populations, facilitating cross-boundary collaborations between providers and agencies. Finally, they ensure provider engagement with SSNAP, monitoring performance and recommending actions if required. Consequently, ISDNs support the monitoring and reporting of high quality stroke care, through the delivery of evidence-based best practice[41].

For the purpose of this thesis, the stroke pathway has divided into four distinct components, hyper-acute, acute, community and six-month reviews. In reality these elements often overlap, and services may be provided by the same organisation. However it is uncommon for community-based services or six-month reviews to be delivered by acute hospital trusts.

1. Hyperacute

Most individuals with acute stroke (95%) experience symptoms outside of hospital. Early medical treatments are time-critical therefore patients with a suspected stroke are admitted to hospital via Accident and Emergency departments or directly by ambulance to Hyper-Acute Stroke Units. Guidelines recommend patients should receive brain imaging within one hour of arriving at hospital and be admitted to a stroke unit (hyperacute or acute) within four hours. If appropriate, patients should receive thrombolysis, thrombectomy or neurosurgery. These are medications to break up a clot, surgery to remove a clot and surgical interventions to address bleeding in the brain respectively. In addition to specialist nursing assessment, patients should receive assessments from members of the multidisciplinary team (MDT) e.g. speech and language therapy if indicated.

2. Acute / Stroke Unit

Once medically stable, stroke patients may be transferred to a stroke unit for ongoing assessment and rehabilitation if required. Often based in acute hospitals, stroke units are staffed by MDTs of skilled nurses, therapists and support staff. Teams are commonly led by a stroke physician and have access to a variety of healthcare professionals outside the core MDT such as Dieticians, Orthoptists or Psychologists. Langhorne et al.'s 2020 Cochrane review highlighted the impact of stroke units organised in this manner, on patient outcomes. They concluded that patients admitted to organised stroke units had more favourable outcomes in terms of mortality, disability and discharge destination in comparison to other inpatient settings[44].

Once able, stroke patients participate in rehabilitation to facilitate their recovery and enable discharge from hospital. The NHS operates a "*Home First*" approach whereby supporting individuals to return to their own residence is prioritised; if this is not feasible then patients may be transferred to a care home[45].

3. Community

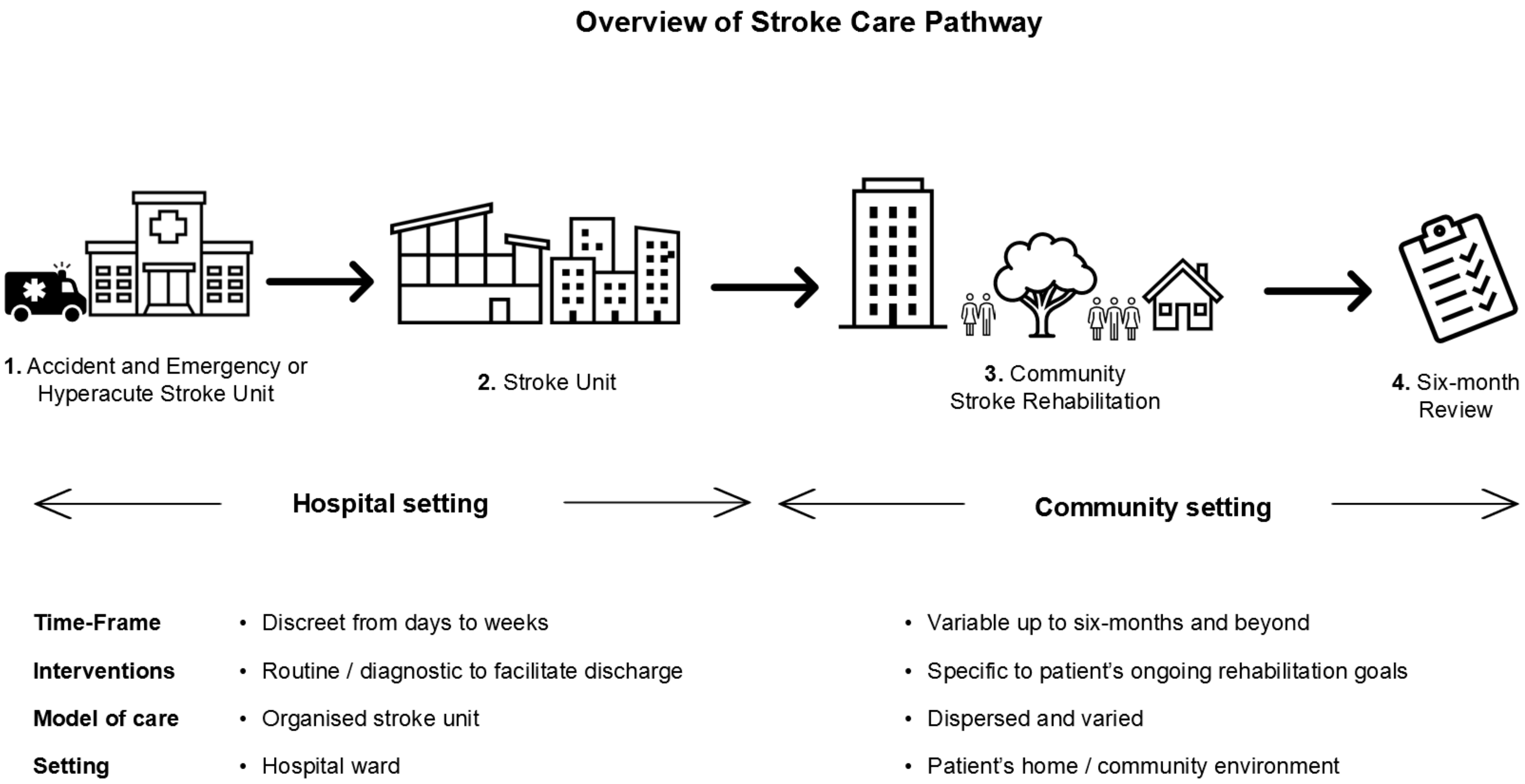
Following discharge from hospital, over 60% of stroke patients currently receive ongoing stroke care in the community, including those who are discharged to care homes[36]. This care is delivered by MDTs of predominantly skilled therapists, nurses and support workers. Commonly led by a senior Nurse or therapist, the staffing and skill-mix of these teams varies greatly between areas. Although some teams have input from Stroke Physicians, medical support is most commonly provided by General Practitioners in the community. In comparison with acute services, there are fewer nurses and an increased proportion of rehabilitation support staff[46,47]. Due to the dispersed nature of their work, community services are often based in multiple separate locations and may share office space or administrative support with other teams within their organisation.

Members of the MDT travel to patients' homes, usually working alone or in pairs. They provide tailored input and support patients to participate in rehabilitation in order to optimise their function and achieve their rehabilitation goals. Where patient needs cannot be met by the community stroke team, referrals may be made to other healthcare providers. This may be necessary if the team lacks a specific discipline or expertise, for example referrals to regional centre for spasticity management.

According to the latest annual clinical audit report for England, Wales and Northern Ireland, community teams provided rehabilitation over a median period of 42.3 days between April 2022 and March 2023. In contrast, the median episode of care in acute hospitals was 7.6 days. In addition to a longer episode of care in the community there was also greater variation in the length of the episode (interquartile range of 22.9 – 80.5 days compared to 2.9 – 24.6 days in acute hospital). These figures highlight the relative variability in episodes of care within community stroke services.

4. Six-month review

All stroke survivors in England are entitled to a review of their needs between four and eight months after a stroke[48]. However the proportions of stroke survivors receiving reviews at six-months vary[37], and are often dependent on local commissioning arrangements. This can be in-person, telephone, online or by post. Reviews can be delivered by a variety of providers, including healthcare professionals, suitably trained support workers or third sector organisations such as The Stroke Association[37]. Approximately 40% of stroke patients currently receive a six-month review[36], a median of 6.3 months after their stroke diagnosis (interquartile range 5.8 to 7.3 months)[37]. This person-centred interview lasts between 30 and 60 minutes and is designed to identify any unmet or ongoing needs for both the patient and their carer(s). It encompasses a variety of signposting, health and wellbeing support as well as risk factor monitoring and outcome measurement. Rehabilitation may continue beyond this point.



	Hospital setting	Community setting
Time-Frame	Discreet from days to weeks	Variable up to six-months and beyond
Interventions	Routine / diagnostic to facilitate discharge	Specific to patient's ongoing rehabilitation goals
Model of care	Organised stroke unit	Dispersed and varied
Setting	Hospital ward	Patient's home / community environment

Figure 1-2: Simplified overview of Stroke Care Pathway in England

1.2.3 Changes in the stroke pathway

Having provided an overview of the current pathway, it is important to acknowledge the changes that have taken place over the last 15 years and their influence on the development of current community services. During this time, numbers of hospital admissions resulting from stroke have risen in England, Wales, and Northern Ireland[37,49]. The most recent annual figures report over 91,000 patients were admitted to hospital with stroke, and over two thirds required ongoing rehabilitation on discharge[36]. Lengths of hospital admission following stroke have fallen from a mean of 34 days in 2001, to 17 days in 2023[37,49]. Aside from improvements in efficiency, this reduction in time spent in hospital has been influenced by two key factors. Firstly, a shift in policy over the last decade towards the development of community-based health care services, as prioritised in the NHS Long-Term Plan[43]. Secondly, a growing evidence base for the effectiveness of community stroke rehabilitation which has informed evidence-based national guidance.

A number of Cochrane reviews have been undertaken exploring the relative effectiveness of Early Supported Discharge (ESD) services in stroke rehabilitation. ESD services are stroke specific rehabilitation teams, based in the community. Their aim is to provide a seamless transition between hospital and home, providing stroke survivors with MDT rehabilitation in their home environment. The first review, published in 2001 by Langhorne et al. found that for a selected group of stroke patients, ESD may reduce the length of their hospital stay. However, the associated risks and benefits at that point remained unclear[50]. The latest review published in 2017, again by Langhorne et al. concluded that for selected individuals, appropriately resourced ESD services with coordinated MDT input may reduce hospital stay, long-term dependency and admission to institutional care. In addition, ESD was reported to be cost-effective[51].

In 2011, contributors to the original review published a consensus document to support commissioners and service providers in implementing ESD services[52]. Subsequent research explored the challenges, facilitators, and impact of providing ESD[53]. Building on these findings a large-scale observational study explored the effectiveness of ESD. Core evidence-based components were identified as contributing to this outcome and realist methods were employed to understand the influence of context[54]. This evidence now underpins current policy in England and is reflected in guidelines such as National Clinical Guidelines for stroke 2023[38] and the National Institute for Health and Care Excellence (NICE) stroke guidance[39]. In 2022, NHS England published the Integrated Community Stroke Service (ICSS) model. This proposed the incorporation of existing service configurations, such as Early Supported Discharge (ESD) and community stroke rehabilitation, into a single integrated service [42].

Over the last 15 years, community stroke services have evolved from a variety of existing services, using the available skills to meet the needs of stroke survivors after discharge from hospital. These include extensions of hospital-based stroke units, outpatient rehabilitation and generic community rehabilitation. Therefore services may have a variety of historical commissioning and governance arrangements and often sit within a variety of organisations[55]. Services may differ in terms of the patients they treat, their staffing arrangements, models of service and interventions offered[47]. The most recent organisational audit for England, Wales and Northern Ireland in 2021 identified 664 separate teams in the community. These were staffed by a workforce of 6,710 whole time equivalent staff with a combined annual caseload of over 112,000 stroke patients. This was an increase of 23,289 on the number of stroke patients going through these services since 2015, illustrating the expanding and evolving nature of these services[47].

As community services have evolved to meet growing demand recruitment has commonly prioritised clinical staff. This has resulted in a shortage of administrative support[56]. In addition, when compared with acute hospital trusts community services commonly have less well developed IT systems, weaker infrastructure and less capacity for IT support[57]. Consequently, community services often lack the organisational capacity to flex in order to meet both IT and administrative support needs, compared to the larger and more established acute sector.

1.3 Audit in stroke

In 1995, a panel convened by the World Health Organisation proposed the routine collection of specified indicators including time to assessment, mortality, patient satisfaction and frequency of secondary complications[58]. Research priorities were identified as the development of a single index outcome, the definition of a minimum data set and the development of appropriate instruments for the measurement of outcomes. Today there are a number of established national quality registries and audit programmes internationally within stroke. Examples include the Swedish Riksstroke registry[59], the Scottish Stroke Care Audit[60] and the Australian Stroke Clinical Registry[61]. Differences exist between these, for example whether they are mandated and what data they collect[62].

For the last ten years, the Sentinel Stroke National Audit Programme (SSNAP) has collected data for stroke patients in England, Wales and Northern Ireland. SSNAP assesses the quality of the organisation and delivery of multidisciplinary stroke care[63].This audit has been informed by the development of evidence-based national clinical guidelines for stroke[64]. It began operation in 1998 as the National Sentinel Stroke Audit (NSSA), a retrospective case note review. In 2010, this evolved into the Stroke Improvement National Audit Programme (SINAP), which focused on the quality of care during the first 72 hours of an acute stroke admission[65].

In 2013, SSNAP produced its first pilot report, with Wales joining the following year. SSNAP is one of the 28 NCAs commissioned by HQIP on behalf of NHS England. The audit is therefore externally initiated and mandated by the conditions of the NHS Standard Contract[66]. Today, SSNAP prospectively collects structure, process and outcome data for over 90% of hospital-admitted stroke patients in England, Wales and Northern Ireland. This equates to more than 91,000 patients per year[36]. The acute component of the audit collects data from inpatient settings (hyperacute and acute / stroke unit) whilst the post-acute component predominantly collects data from community settings and includes the six-month review. In addition, there are biennial acute organisational audits that provide a snapshot of the structure and organisation of acute stroke services. These have also been completed for post-acute services in 2015 and 2021.

Audit feedback reports are an established method of providing summative information regarding clinical performance and are a common feature of quality improvement approaches within healthcare[30]. The SSNAP audit feedback report (referred to from this point on as the feedback report) consists of a results portfolio (Excel spreadsheet) and a graphical representation of key performance indicators (PowerPoint slides) for the teams that submit data. For acute services these are reported quarterly, whilst post-acute results are reported twice a year due to the lower numbers of patients involved. These are made available on the SSNAP website (https://www.strokeaudit.org/), searchable by individual team or region. An annual public report is also generated which includes contextualising clinical commentary from a national perspective.

The size of the SSNAP database has offered opportunities to gain insights into the quality of services delivered and its predictors, such as the influence of staffing patterns and temporal variations in quality across the week[18,67,68]. Data from this audit has been used to inform a range of policy initiatives within the NHS over the last two decades. Examples include the National Stroke Strategy and the introduction of financial incentives linked to performance[18]. Evidence suggests that the stroke national audit has been successful in driving improvements in hospital-based stroke care by highlighting where clinical practice or service delivery varies between NHS trusts, and by comparison with both national averages and accepted national clinical guidelines[64].

Reflecting on Rudd et al.'s review of stroke audit research in the hospital setting[64], SSNAP would appear to have leveraged improvements much greater than the 4% reported by the Cochrane review[19] discussed in section 1.1.4. This could suggest audit is only one component of a more far-reaching quality improvement approach, facilitated by SSNAP. In this scenario, although audit data may drive quality improvement, it could be dependent on a number of factors such as the populations served, existing networks and resource availability. Comparisons with potentially similar audits such as the neighbouring Scottish Stroke Care Audit (SSCA) may point to the influence of such factors. Established in 2002, SSCA is embedded in a national stroke improvement programme facilitated by established managed clinical networks[69]. However, there are distinctions between the contexts in which SSNAP and SSCA operate and the populations they serve.

Influenced by its diverse geography, Scotland has a higher proportion of its population residing in rural or less densely populated areas[70]. These factors may influence access to time critical stroke treatments such as thrombolysis and challenge the ability of SSCA to drive quality improvement in these areas. Differences also exist in the characteristics of the populations served by the audits. For example Scotland has greater health inequalities when compared with other parts of the UK[71]. These differences highlight the importance of contextualising audit findings if they are to inform quality improvement.

Like many of national audit programmes, SSNAP has historically focused on acute and hospital-based care[72]. However, in line with the policy shift to develop community-based healthcare, SSNAP expanded to include the post-acute activity up to six-months post stroke[43]. Although fewer measures are collected in the post-acute component compared with the acute, the format remains similar. This began in 2013, reporting data for 4,667 community patients and has steadily increased to 34,114 patients in 2023[37]. A number of international registries contact patients via questionnaire or telephone, between three and six-months after discharge. The data collected at this point varies, including mortality, health-related quality of life, patient reported experience of hospital care, social care requirements and unmet needs[62].

1.4 What is quality and how do you measure this in stroke?

In 2021 the World Health Organisation defined quality of care as:

> “*The degree to which health services for individuals and populations increase the likelihood of desired health outcomes*.”[73]

This is encompassed and expanded upon in the six dimensions of quality, proposed by the Health Foundation[74] summarised in Table 1-2.

Table 1-2: Six Dimensions of Quality

For service-users	**Safe** Avoiding harm to people from care that is intended to help them.
	Effective Providing services based on evidence that produce a clear benefit.
	Experience • Caring. Staff involve and treat people with compassion, dignity and respect. • Responsive and person-centred. Services respond to people’s needs and choices and enable them to be equal partners in their own care.
For service providers	**Well-led** They are open and collaborate internally and externally and are committed to learning and improvement.
	Sustainable They use their resources responsibly and efficiently, providing fair access to all, and according to need of their populations.
	Equitable They provide care that does not vary in quality because of a person’s characteristics.

For the purpose of this study, quality improvement will encompass any activity intended to contribute to these quality dimensions. These may include improvements in:

- Experiences or outcomes of patients, carers or staff.
- Efficiency of services.
- Efficacy of interventions.
- Adherence to clinical guidelines, professional standards or participation in audit[75].

Donabedian proposed that quality of healthcare be evaluated using a combination of three facets of the system: the structure, process and outcome of care[76]. These are discussed in the context of stroke care and examples offered in the following paragraphs.

Structural measures of care involve factors such as staffing establishment, skill-mix and access to specific interventions. Examples of these structural measures collected within stroke by SSNAP include access to specialist nursing, seven-day therapy provision and access to specialised imaging[46]. Walsh et al. report that the relationship between measures of patient outcomes and individual structures of care to be inconclusive[77]. However, there is evidence that in combination structural measures may influence outcomes. One such example is the introduction of stroke units. These specialised units have multiple components such as specific staffing models and access to specialist interventions. Their introduction has been instrumental in delivering significant improvements to patient outcomes within stroke care[78].

Process measures reflect the quality of the wider service or pathway, therefore should encompass the multiple disciplines involved[38]. A balance is required between standardised process measures that are applicable to all, and multiple measures tailored to individuals that more accurately reflect their care[77]. In stroke, a variety of granular process measures are collected by SSNAP, capturing a spectrum of multidisciplinary activity. Many of these measures are time-focussed, for example, the time taken to scan a patient, the length of admission or number of minutes of physiotherapy received[37]. Consequently they can be generated easily from existing data, do not require additional resources to produce and provide continuous quantitative data that is amenable to a broad range of statistical analysis.

Outcomes of care indicate changes in the health or quality of life of a patient. These are measurable at a variety of levels for example impairments such as muscle power, functional activities of daily life or dependence. A plethora of rehabilitation outcome measures exist but there is variability in their use in clinical practice which limits their comparability[79]. Before being implemented in clinical practice, the validity, reliability and responsiveness of an outcome measure must be estalished[77]. Over the last ten years, multiple international consensus recommendations have been published regarding the choice of post-stroke outcome measurement for both research and clinical practice. Table 1-3 summarises these recommendations and highlights some overlap, despite a large degree of variation.

There is growing interest in the use of patient reported outcome measures (PROMs) across research and clinical care over recent years. Typically, these instruments reflect a patient's perception of functional status, well-being, and health-related quality of life[80]. Studies have suggested they offer greater sensitivity to change than clinician reported measures such as the modified Rankin Scale (mRS) and may be a more accurate reflection of meaningful outcomes experienced by an individual[81]. However, due to their heterogeneous and complex nature, there is much debate around the implementation of PROMs. Commentators call for a stronger evidence-base and a better understanding of their psychometric properties as well as the factors that may influence these outcomes, before strategic implementation[82]. Ultimately any measure chosen must be done so with due consideration for its purpose, acknowledging its limitations and most importantly based on the best available evidence.

Table 1-3: International consensus recommendations

Lead author (year)	Focus	Measures
Rymer et al. (2014)[83]	Global (Clinical practice)	Discharge disposition Ambulatory status Communication status Modified Rankin Scale (mRS) Quality of life
Kwakkel et al. (2017)[84]	Sensorimotor (Research)	National Institutes of Health Stroke Scale (NIHSS) Fugl-Meyer Motor Assessment (FMA) Action Research Arm Test (ARAT) 10-meter walk test (10MWT) EQ5D Modified Rankin Scale (mRS)
Wallace et al. (2018)[85]	Aphasia (Research)	The Western Aphasia Battery Revised (WAB-R) General Health Questionnaire (GHQ)-12 Stroke and Aphasia Quality of Life Scale (SAQOL-39)
Pohl et al. (2020)[79]	Motor activity (Clinical practice)	Fugl–Meyer Motor Assessment (FMA) Action Research Arm Test (ARAT) 10-meter walk test (10MWT) Timed-up-and-go (TUG) Berg Balance Scale (BBS) National Institutes of Health Stroke Scale (NIHSS) Barthel Index (BI) Functional Independence Measure (FIM) Stroke Impact Scale (SIS)
Duncan-Millar et al. (2021)[86]	Upper limb (Research)	Visual Analogue Scale (VAS) for pain Dynamometry Action Research Arm Test (ARAT) Wolf Motor Function Test (WMFT) Barthel Index (BI) Motricity Index (MI) Fugl-Meyer Motor Assessment (FMA) Box and Block Test Motor Activity Log Nine Hole Peg Test Functional Independence Measure (FIM) EQ5D Modified Rankin Scale (mRS)
English et al. (2024)[87]	Post-stroke fatigue (Research)	The Fatigue Severity Scale 7 (FSS-7) Visual analogue scale (VAS)
Criekinge et al. (2024)[88]	Balance and mobility (Research)	Fugl-Meyer Motor Assessment (FMA) Trunk Impairment Scale (TIS) Mini-Balance Evaluation Systems Test (Mini-BEST) Berg Balance Scale (BBS) 10-meter walk test (10MWT) Dynamic Gait Index (DGI) Functional Ambulation Categories (FAC)

Data collected by SSNAP are predominantly process measures. In comparison with outcome measures, process measures offer advantages such as ease of measurement, extraction from existing hospital systems and interpretation[89]. In routine clinical practice, there are challenges to the consistent collection of any measure across a variety of clinical settings[90]. Before clinical teams are tasked with any additional burden of data collection, there must be sufficient understanding of its limitations and interpretation for it to be of clinical use. Table 1-3 details a number of measures assessing a variety of domains. No single measure can describe clinical outcome following stroke[90], however the inclusion of numerous measures by SSNAP would be unfeasible with regards to the resources required. Instead, it is more practical to select a few, well validated measures that capture more global outcomes of disability, survival and quality of life. Those included by SSNAP are listed below.

The modified Rankin Scale (mRS). The mRS is a clinician-reported measure of global disability and uses a six-point scale to indicate the severity of an individual's disability. The measure goes from zero (no symptoms) to five (severe disability and confined to bed), a score of six can be used to indicate if a patient has deceased[91]. The mRS is commonly used in the evaluation of outcomes for stroke patients both clinically and in research[92]. There is debate regarding the interrater reliability of this measure and its sensitivity to change, however the majority of studies have been completed in acute, single-site settings[91,93]. For the purposes of SSNAP, an estimation made regarding mRS prior to admission is made, informed by healthcare records, patient and carer interviews. In addition, the mRS is collected on discharge from inpatient rehabilitation, on discharge from community rehabilitation and at six-months post stroke. Although this variety in clinical setting may impact reliability it is suggested to be acceptable for the purposes of national registries or clinical audit[94]. There are advantages that make the mRS a convenient choice for both clinical practice and collection by SSNAP. Any member of the MDT is able to rapidly appraise a patient using the explicit scale descriptors or a structured interview[95], to establish a global measure of their disability, which is easy to interpret and communicate.

Mortality at 30-days[96] provides stroke patient survival rates in this given period through national data linkage to the statutory registers of death in England and Wales (Office of National Statistics).

EQ5D-5L is collected as part of the six-months post stroke review. This is a standardised measure of health-related quality of life developed by the international EuroQol Group designed for clinical and economic evaluation across a spectrum of clinical conditions[97]. The EQ5D-5L assesses health across five dimensions, each with five levels of severity. The five dimensions are: Mobility, Self-Care, Usual Activities, Pain and Anxiety. In addition, the measure contains a virtual analogue scale (EQ-VAS) on which the stroke survivor indicates their perceived health[97].

1.5 Rationale for further study

SSNAP is an established clinical audit programme with a proven track record for driving quality improvement in hospital-based stroke care[64]. SSNAP is unique in that is currently the only national stroke audit or registry that collects data detailing stroke care beyond hospital discharge. Despite this, its role in driving quality improvement in this setting is as yet, unexplored.

Although the audit has been expanded to include post-acute services, the impact of collecting these measures in the community setting is unclear. This chapter has highlighted a number of factors that may influence the ability of an audit to drive quality improvement in this setting.

- Dispersed delivery of services
- Varied models of service delivery (skill mix and disciplines within teams)
- Less well-established organisational infrastructure (IT and administrative)

Therefore, the role of clinical audit in driving quality improvement specifically in community stroke care warrants further exploration. The aim of this study is as follows:

To understand the role of national clinical audit in driving quality improvement in community stroke care.

1.6 Chapter summary

This chapter has described the development of clinical audit and the influence of national policies on the use of audit in the UK. The national clinical audit programme has been introduced and a summary of the evidence regarding the effectiveness of clinical audit presented. Changes in the organisation and delivery of stroke care in the UK have been detailed and distinctions made between the hospital and community settings. The role of research in shaping both the provision of clinical services and the use of clinical audit have been highlighted.

The development of national clinical stroke audits has been detailed, with a specific focus on SSNAP in England, Wales and Northern Ireland. Finally, quality and its measurement in stroke care has been discussed. This chapter has provided a background to, and rationale for further study. A broad aim has been proposed and a number of key points for consideration have been identified. The following chapter details the philosophical underpinning of previous audit research. Subsequently, a rationale is presented for the methodology chosen for this study and key terms are defined. Finally, an overview of the thesis structure is provided.

2 Methodology

2.1 Introduction

The previous chapter has introduced the role of audit within healthcare, focusing on the Sentinel Stroke National Audit Programme. An argument has been made that although audit has proved to be an effective tool for quality improvement within hospital-based care, its role in the community has yet to be explored and warrants further investigation.

Prior to undertaking research, consideration must be given to methodological coherence; the congruency of the philosophical standpoint, research question and methods used[98]. Therefore, this chapter provides firstly an explanation of the philosophical underpinning of previous audit research. Secondly, a rationale is presented for the methodology chosen for this study and key terms are defined. Finally, an overview of the thesis structure is provided.

2.2 Research paradigms: A brief overview

A research paradigm is an overarching philosophical stance encompassing models of shared ideas, beliefs and assumptions about how '*knowledge*' is produced [99]. These models contain distinct frameworks of ontology, epistemology and methodology, providing agreed perspectives on what constitutes '*reality*' and how this should be investigated[100]. Historically, the two most prominent research paradigms within health and social sciences have been positivism and interpretivism.

Positivism relies specifically on scientific '*evidence*', such as experiments, to reveal a '*true nature*' of society[100]. In positivism, objects have an existence that is independent to, and therefore discoverable by an individual[101]. Historically, this paradigm dominated research in health and social sciences, occupying a prime position in the agreed hierarchy of evidence-based medicine at the turn of the last century[102].

Interpretivism emerged from a critique of positivism in the social sciences. Proponents argue that knowledge of the social world is constructed though human interaction and communicated socially; therefore can only be understood from the perspective of the individual engaged within it[100].

There has been much debate regarding the relative merits of these distinct paradigms in informing research practice[103]. In the 1970's a third paradigm began to gain prominence, that of realism. Realism assumes that reality exists and is knowable, regardless of whether it is perceived or not[104]. It also acknowledges that observations are influenced by personal, social and cultural frames. In doing so, realism offers an opportunity to explore both structure and agency[105]. This is seen by many as bridging the positivist and interpretivist paradigms, leveraging elements of both to provide an alternative approach to developing knowledge[106].

In contrast to the successionist view of causation central to the positivist paradigm, realism uses a generative model of causality[107]. Where successionist causation claims intervention A results in effect B, a generative causation proposes a more complex model. In this model, context influences and interacts with a generative mechanism, contributing to a discoverable outcome[108].

There are a number of branches within realism, the two most significant being critical realism and scientific realism. Bhaskar is largely credited with popularising the theory of critical realism in the 1970's[109]. His original theory was developed further in the following decades, with contributions from Archer and Sayer[110,111]. More recently, scientific realism as proposed by Pawson and Tilley has become prominent within healthcare research[112]. This work has been developed by a number of contributors. Many of whom have collaborated in the RAMESES project, providing explicit and standardised recommendations for the design, conduct and reporting of scientific realist research[113].

There are a number of commonalities between these two branches of realism. These include an understanding of the existence of the unseen and generative causality, a catholic approach to multiple methodologies and the importance of theory driven science[114]. However they have differing beliefs regarding the importance of, and ability to create a "closed system" in social sciences, such as those in controlled experiments in the natural sciences. For critical realists, this degree of experimental control is deemed unachievable in social research due to human agency. Instead, they propose acknowledging the use of a moral lens and deductive reasoning to explore human action[115]. In contrast scientific realists recognise the contingent nature of knowledge and suggest a closed system to be impossible and therefore unnecessary. Instead they propose the focus should be on a transparent explication of the various influences on a system[116]. Table 2-1 compares the key features of the three paradigms discussed[100,101,108].

Table 2-1: Key features of interpretivism, realism and positivism

	Interpretivism	Realism	Positivism
Ontology	Reality is not objective; it can only be understood from the perspective of the individual engaged within it.	Reality is stratified: that which can be experienced (empirical), events that happen but may not be experienced (actual) and real. Reality is independent of both actors and observers.	Reality exists and is discoverable by an objective observer.
Epistemology	Knowledge of the social world is constructed though human interaction and communicated socially.	Theories are generated using relationships between the contextual environment and components of the social and physical structure. These are tested and refined to generate contingent understanding.	Knowledge is testable by observation or experience.
Methodology and associated methods	Qualitative methods, such as interview, ethnography and focus group. Commonly inductive. Seeks rich data.	Mixed-methods, using a variety of data types and sources to assess the influence of context and explanatory power of mechanisms. Inductive and deductive theory building / refining and testing.	Quantitative methods such as controlled experiments. Deductive theory validation. Seeks statistical power.
Analysis	Findings are exploratory rather than explanatory. Interpretation is heavily contextualised, therefore potentially transferable but not generalisable.	Findings explore and explain ‘what works, for whom, and why’. Contextualisation enables transferability of findings to similar contexts.	Findings are causal. Validity, reliability, and replicability enhance generalisability.

2.3 Paradigms in which clinical audit has been evaluated

Audit is described as a complex intervention[16], having several interacting components and features that are sensitive to the local context[31]. The new MRC framework for developing and evaluating complex intervention proposes five features that constitute a complex intervention[31]. These are listed in the table below alongside examples of these features evident in SSNAP.

Table 2-2: Features indicating an intervention is complex

Feature	Example from the Sentinel Stroke National Audit Programme
Number of interacting components within the intervention.	Continuous cycle of measuring performance, providing feedback, implementing change and sustaining improvement.
Number and difficulty of behaviours required by those delivering or receiving the intervention.	Behaviours vary depending on individual roles within the audit process e.g. data collection, delivering clinical intervention that is being audited or using feedback to inform change
Number of organisational levels targeted by the intervention.	Feedback intended to inform individual and team level behaviours as well as service level organisation and provision of services.
Number and variability of outcomes.	Improvement in the: - Outcomes of patients - Efficiency of services - Efficacy of interventions Outcomes vary between teams.
Degree of flexibility of the intervention permitted.	Standardised dataset. However, data collection and use of feedback varies greatly between teams.

Traditionally, research into clinical audit has been firmly pitched within the positivist paradigm[19]. However despite a growing body of trials exploring the effectiveness of audit and feedback, in the years between the first and most recent Cochrane reviews, little progress in the field was reported[117]. Commentators suggested study heterogeneity including the clinical setting, professionals involved and purpose, resulted in a lack of generalisable learning. This has prompted a call for the use of conceptual frameworks to describe common features of settings, behaviours and interventions[25].

Foy and colleagues have pointed to the unrealised potential of audit, highlighting the discrepancy between what it *could* provide and what it *actually* delivers, in terms of quality improvement[118]. Qualitative research may offer a means of understanding factors that contribute to this discrepancy, by exploring how and why clinical audit does (or does not) lead to quality improvement. For example, Clarke et al. used a mixed-methods case-study to understand why audit recommendations regarding stroke rehabilitation were not being met in England[119]. Findings revealed few staff understood the evidence underpinning the audit recommendations, which impacted both their clinical practice and engagement with the audit. This information would not have been evident from the quantitative component of the study alone.

Similarly, Taylor et al. used an ethnographic approach to explore how auditing therapy intensity influenced inpatient stroke rehabilitation in the UK[13]. This study highlighted inconsistencies in audit practice and stakeholder perceptions of the audit which influenced clinical practice and confidence in the audit. Authors suggested their integration of existing theory enabled a deeper understanding and broader applicability of findings to other settings.

More recently, two studies within the scientific realist paradigm have provided in-depth theorising on the causal mechanisms that influence the effectiveness of audit and their interaction with context. Alvarado et al. explored variation in the use of feedback from national clinical audits[34], whilst Hut-Mossel et al. sought to understand how and why audit works in quality improvement[16]. This use of theory informed qualitative, or mixed-methods approach may provide an opportunity to explore complex interventions such as audit. Understanding *how* and *why* audit contributes to quality improvement may enable practitioners to move closer to realising its potential as a tool for quality improvement.

Scientific realism has been acknowledged as an appropriate approach in the evaluation of complex interventions where context is influential[120]. This approach offers two distinct methods of investigation, firstly a realist synthesis and secondly a realist evaluation (RE). Realist syntheses offer a mixed methods and theory driven alternative to conventional Cochrane-style literature reviews. By explaining the outcomes, success or failure of complex interventions they have the potential to inform real world policy and practice[113]. RE is described in more detail in the following section. In brief, RE uses a variety of mixed methods to generate, test and refine programme theories in order to evaluate complex interventions. Both realist synthesis and evaluation aim to understand what works, for who, under what circumstances and how.[108]

2.4 Choosing a paradigm in which to situate this PhD

Scientific realism has been proposed as an appropriate methodology for this PhD for a number of reasons. Firstly the influence of context is central to the focus of enquiry; the implementation of an established quality improvement tool (SSNAP) in a novel context (community). Secondly as stated already, realist methodology is acknowledged as an appropriate tool by which to evaluate complex interventions, such as a national clinical audit[120]. Realist methods use a theory driven approach. They are able to exploit a variety of research methods to scrutinise *how* and *why* the complexities of audit as highlighted in table 1-2, contribute to quality improvement. Finally, RE has been proposed as a robust tool by which to influence change at the level of national policy[113] and this study has been ambitious in its aims to inform both national policy and practice.

The field of realist inquiry is acknowledged as a catholic and evolving church. Pawson and Manzano emphasise realism as a broad research strategy, rather than *“a strict technical procedure*”[121]. However, this can be challenging for the novice researcher, sometimes faced with conflicting methodological interpretations and definitions. For clarity, the following section provides working definitions of the key components of RE in the context of this thesis.

2.5 Realist Evaluation

The focus of RE is understanding what works, for whom, under what circumstances and how[108]. A number of components specific to realism contribute to this understanding, and these are detailed below.

2.5.1 Context

Context describes the conditions in which an intervention occurs and determines the degree to which a mechanism may be triggered, if at all. Context may have a number of constituent features, which potentially enable or disable a mechanism[122]. Pawson proposes four levels at which contextual features may be identified[123]:

- The individual, those involved in the intervention as well as wider stakeholders e.g. administrators uploading audit data or managers receiving audit feedback.
- The interpersonal relationships underpinning the intervention
  e.g. management and administrative support.
- The institution or setting in which the intervention is implemented
  e.g. organisational culture and leadership engagement.
- The wider infrastructure such e.g. resource availability.

2.5.2 Mechanism

Mechanisms can be defined as "*underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest*."[124] They are a combination of the resources offered by an intervention, and the subsequent response that is generated[108].

Resources may have a variety of manifestations such as financial e.g. equipment, or behavioural e.g. role modelling. Responses are often less obvious to a casual observer and commonly require a significant amount of digging to unearth. Responses may include emotions such as fear, goal-directed behaviours such as motivation or perceptions such as empowerment.

Mechanisms are often activated along a continuum, in response to an evolving context. This results in a "*dimmer switch*" response of varying intensity, as opposed to a binary effect whereby the outcome is simply either present or absent[115].

2.5.3 Outcome

Outcomes of an intervention result from the activation of mechanisms within a context and may be intended or unintended. The outcome of interest for this study is quality improvement and has been defined in Chapter 1. There may be various patterns of outcomes for different groups of stakeholders. For example improvements in the experiences of patients at an individual level, improvements in efficiency at a services level or improved reputation at an organisational level[125].

2.5.4 Theory

Davidoff et al. argue that theory should be used purposefully and explicitly when developing and evaluating interventions. They suggest this not only reduces the time taken to develop improvement interventions, but optimises learning and enables the transfer of knowledge from one project to the next[126]. Theories may be categorised as Programme theory, Middle-range theory or Grand theory.

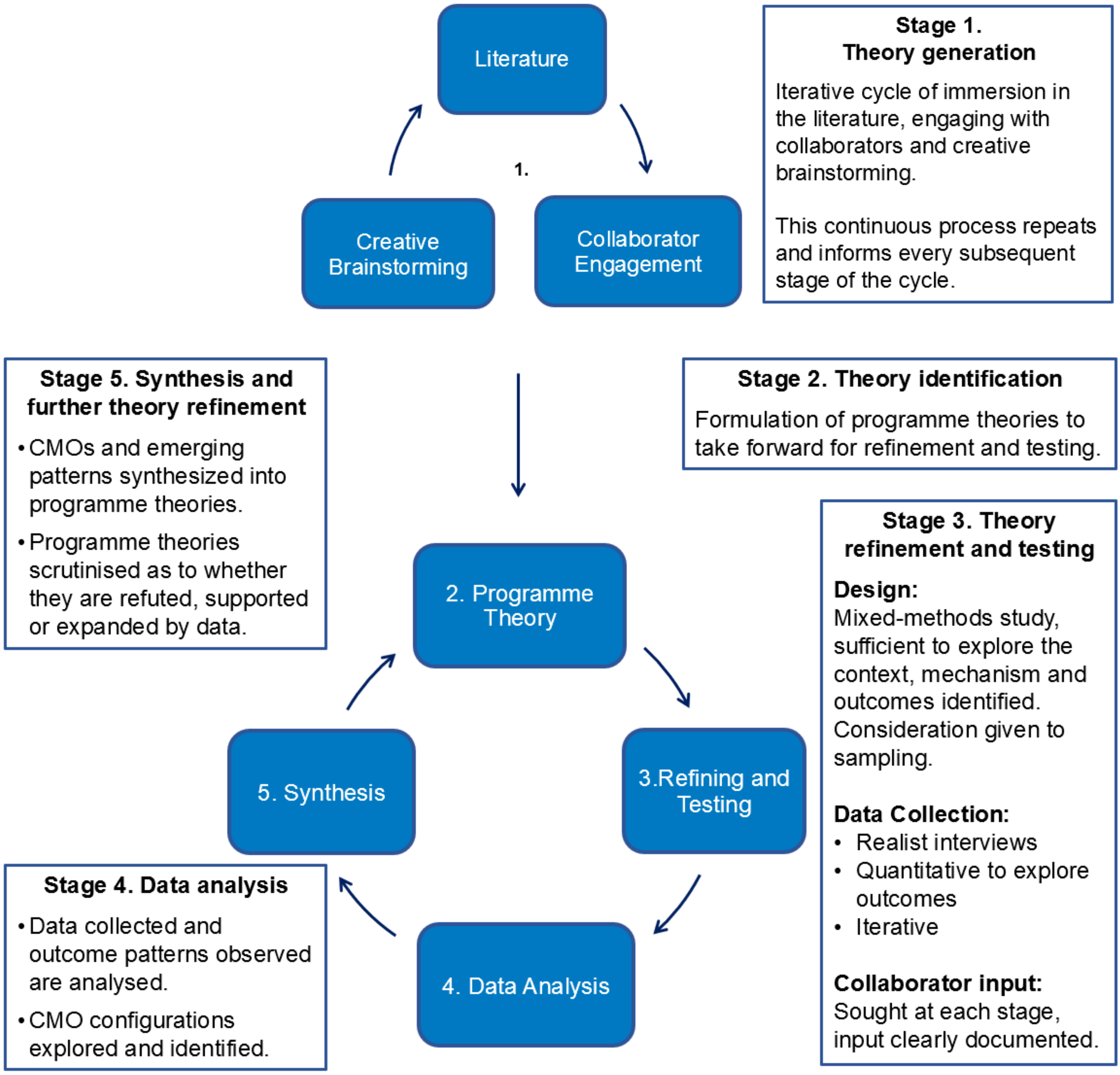
Programme theories are the foundation of RE, providing a granular account of how and why a specific intervention contributes to an outcome[127]. REs generate, refine and test programme theory in an iterative cycle[108]. Although not prescriptive, Figure 2-1 describes the research and design process underpinning RE. This cycle is adapted from work done by Gilmore et al[128], based on the original proposition by Pawson and Tilley[108].

Middle-range theories are achieved through multiple RE cycles of testing and refinement across a variety of contexts, but not all RE's will result in the level of abstraction required for a Middle-range theory[108,129]. These theories sit above the granular detail of an individual intervention and therefore may be applicable across a range of similar programmes[129]. Grand theories are typically sociological, generalisable across many different domains as they are abstract in their formulation[126].

Stage 1: Theory generation

Jagosh proposes three key steps that underpin theory generation, the first of which is immersion in the literature[130]. Theories may be informed by a broad scope of evidence, not limited by methodological approach. This is followed by collaborator engagement and finally "creative brainstorming". Where possible, this cycle should be iterative and involve a number of collaborators with diverse perspectives[130]. Figure 2-1 illustrates the RE cycle (adapted from Gilmore et al.[128]).

The Realist Evaluation Cycle



Stage 1. Theory generation

Iterative cycle of immersion in the literature, engaging with collaborators and creative brainstorming.

This continuous process repeats and informs every subsequent stage of the cycle.

Stage 2. Theory identification

Formulation of programme theories to take forward for refinement and testing.

Stage 3. Theory refinement and testing

Design:
Mixed-methods study, sufficient to explore the context, mechanism and outcomes identified. Consideration given to sampling.

Data Collection:

- Realist interviews
- Quantitative to explore outcomes
- Iterative

Collaborator input:
Sought at each stage, input clearly documented.

Stage 4. Data analysis

- Data collected and outcome patterns observed are analysed.
- CMO configurations explored and identified.

Stage 5. Synthesis and further theory refinement

- CMOs and emerging patterns synthesized into programme theories.
- Programme theories scrutinised as to whether they are refuted, supported or expanded by data.

Figure 2-1: The Realist Evaluation Cycle

Stage 2: Theory Identification

Preliminary theories that are under development are termed, candidate programme theories (CPTs). If there are multiple theories, it may be necessary to prioritise which theories are taken forwards for exploration. This may be informed by the research question, the available resources and collaborator input. Following early refinements these become initial programme theories (IPTs), ready for iterative cycles of testing and refinement, before being presented as refined programme theories (PTs).

Programme theories can be articulated using the heuristic CMO, describing the proposed **C**ontext, underlying **M**echanism and subsequent **O**utcome of the intervention. A single programme theory may have a number of CMOs that contribute to it. Developed as an analytical tool by Pawson and Tilley, CMOs are used to explore mechanisms of change and the conditions in which outcomes are more or less likely to be successful[112]. These patterns of interactions are used in RE to understand generative causation[128].

Stage 3: Theory refinement and testing

Guidance from the RAMESES II project advocates collecting a broad range of data in terms of both sources and methods to increase an evaluation's robustness[131]. This has the potential to strengthen causal claims regarding underlying programme theory through data triangulation[132]. Data should be collected that adequately describes the context, mechanism and outcomes of an intervention, as well as the interactions between context and mechanisms that generate outcomes (including unintended outcomes)[133]. These multiple sources and data formats require bespoke and clear articulation of the steps taken, individuals involved, and tools used e.g. computer software. The methods used in this study are detailed in later chapters.

Consideration must be given to seeking out a diverse sample of stakeholders. A variety of perspectives are required to reflect the many facets of an intervention, and the different levels at which context and mechanisms may interact and outcomes manifest[133]. Emmel advocates theoretical sampling where possible. In this scenario respondents are specifically selected based on their ability to offer insight into aspects of the programme theory under scrutiny[134].

Participants involved in this study were stakeholders from across the audit process. This included anyone working in, leading, managing or commissioning community stroke rehabilitation in England. Stakeholders included both clinicians, and non-clinical roles such as administrative support or commissioning. Details regarding recruitment, sampling and stakeholder characteristics are included in the appropriate study chapter.

Stage 4: Data analysis

RE does not prescribe a single method of data analysis. Most realist studies use CMOs as their main analytical tool by which to interrogate programme theory. However, the methods employed to identify CMOs vary between studies, as do the approaches taken to their use in theory refinement[128]. Examples include realist thematic analysis[135], analytical induction[136] and “realist qualitative analysis”[137]. Despite the publication of guidelines stipulating the transparent reporting of analysis[138], many studies lack details of the process used[128,139]. The approach taken to analysis and synthesis in this study is informed primarily by the training received from the Centre for Advancement in Realist Evaluation and Synthesis and is outlined in the following paragraphs.

Following immersion in the data, CMO configurations are identified, coded and any inter-relationships highlighted. A configuration describes the relative association between context, mechanism and outcome. Any patterns, or demi-regularities of context, mechanism and outcomes in the data are explored[140]. The process of collating and scrutinising these configurations varies depending on the research method(s) used[132]. Therefore, greater detail is included in the following chapters.

At this point in the analysis, it may be possible to consolidate a number of similar or overlapping CMOs. Conversely it may become evident that several contextual features interact with potentially different underlying mechanisms and the researcher needs to return to the data to understand if there are multiple CMOs contained therein. This cyclical process of scrutinising CMOs, exploring their roots in the data and linkages between sources continues throughout the analysis and synthesis phases[128].

Stage 5: Synthesis and further theory refinement

Programme theories are refined when there are CMOs in the data that either support (confirm), expand (add greater detail to) or refute a theory. In other words, patterns of generative causation are required if theory is to be refined. This process uses abduction and retroduction and may incorporate existing theory to understand patterns identified within data[133].

Abduction describes reasoning whereby inferences are based on "*educated guesswork*". This process typically begins with an incomplete account, for which the most likely explanation is sought[141]. Critics of abductive reasoning point to concerns over drawing conclusions from unsubstantiated "*guesswork*"[142]. However within a RE, these are not haphazard assumptions. These "*hunches*" are informed by an immersion in literature and extensive engagement with a variety of collaborators regarding potential causal relationships. The process of retroduction tests these "*hunches",* by iteratively returning to the data to provide the best possible explanation[133].

Theories are held up to the light, compared and contrasted. Areas of overlap, tension and potential inter-relationships between theories are examined with collaborators and stakeholders (where methods allow)[143]. As with analysis, synthesis may vary greatly depending on the data and methods used, however *how* data is used in refining theory must be clearly described and justified[131]. Data analysis and synthesis specific to this study are detailed in later chapters.

2.5.5 Collaborator engagement

Collaborator engagement is fundamental to realist methodology. It is recommended that researchers gather a group of "experts" to sense check and inform the focus of enquiry at every stage of the cycle[144]. These individuals are commonly described as stakeholders in the literature. However to avoid confusion with the stakeholders who acted as participants in this study, the term collaborators has been used within this thesis instead. Pawson et al. suggest these individuals are essential in "validating" emerging findings and dissemination activities[123]. Below is an overview of collaborators and communities engaged at various points throughout this study. Their contributions are detailed in the appropriate chapters, and their influence on the study design and subsequent findings are described.

Collaborator expertise has been categorised to provide context for their contribution and highlight the perspective from which it was offered.

Clinical	Team Lead Physiotherapist – KB
	Integrated Stroke Delivery Network Clinical Lead – CL
	Clinical Specialist in Stroke – RS
Audit	Quality Improvement Research Fellow – MS
	Post-doctoral Research Fellow – ED
	Sentinel Stroke National Audit Programme - MJ
	Sentinel Stroke National Audit Programme – RF
Policy	Stroke Programme NHSE – RF
Methodological	Senior Research Fellow with realist expertise – NC
	Post-doctoral Research Fellow with realist expertise – JH
	Professor in Medical Statistics – SL
	Realist expertise – JJ
EQ5D	EuroQol Research Fellow – JY

The following communities have provided opportunities to refine the conceptualisation of aspects of this study. They have shared expertise and connected the student with both collaborators and participants.

- International Audit and Feedback Meta lab https://www.ohri.ca/auditfeedback/
- Centre for Advancement in Realist Evaluation and Synthesis (CARES) https://realistmethodology-cares.org/
- NottsRealism @NottsRealism
- Sentinel Stroke National Audit Programme team https://www.strokeaudit.org/
- EuroQol PhD Network https://euroqol.org/euroqol/
- RAMESES online forum https://www.jiscmail.ac.uk/cgi-bin/webadmin?A0=RAMESES

2.6 Personal reflection

As well as understanding the paradigm in which this study is situated, it is important to acknowledge the position of the researcher. As a female Physiotherapist in stroke, I have experience of working in both acute hospital-based and community rehabilitation. As a clinician and Team Lead, I have engaged with SSNAP at a variety of levels. This includes data collection and upload, using feedback for quality assurance, quality improvement, commissioning services and more recently using data for research external to this PhD.

It would be impossible to put these experiences aside, indeed they have offered valuable insights, enabled extensive clinical collaboration and for many individuals provided credibility as someone who has "*walked the walk*" as one participant noted. However, I have gone to great lengths to avoid discussing personal experiences with participants or collaborators, other than to acknowledge that I have them. Care has been taken to avoid assumptions regarding tacit knowledge or shared understandings regarding SSNAP or clinical practice with participants or collaborators.

This candour at the outset demonstrates an insight into the potential risk of partiality these experiences pose. However, it also illustrates the rigour and transparency demonstrated throughout. Commensurate with RE collaborators have been instrumental in regularly sense-checking findings and supervisors have acted as a second reviewer, independently analysing sections of data to enhance trustworthiness. This declaration is made to instil confidence for the reader in the integrity of both the researcher and the research presented. Additional reflections are made in the closing chapter as to how I and others involved in this study may have shaped the study and its findings.

2.7 Thesis structure

This thesis comprises seven chapters including four phases of research. Each phase of research is detailed in a separate chapter (3-6), building on findings from the previous and contributing to the overall aim as stated below:

To understand the role of national clinical audit in driving quality improvement in community stroke care.

To aid the reader each phase is presented as a stand-alone study detailing the rationale, relevant methods, analysis and findings etc. The following section provides a brief overview of thesis chapters.

2.7.1 Chapter 1: Background and introduction

This chapter introduces the role of audit within healthcare, focusing on the Sentinel Stroke National Audit Programme. The stroke pathway is described, and distinctions are made between the contexts of hospital-based and community stroke care. A rationale is proposed that although audit has proved to be an effective tool for quality improvement within hospital-based care, its role in the community has yet to be explored. Assumptions have been made that the audit will contribute to quality improvement in the community as it has done in the hospital. Chapter 1 highlights a number of contextual features specific to community stroke care that may challenge these assumptions. These warrant further investigation.

2.7.2 Chapter 2: Methodology

This chapter explores the philosophical underpinnings of audit research and provides a rationale for undertaking a RE of SSNAP in the community setting. For clarity and to provide a shared understanding, key terms and concepts of RE are detailed. The thesis structure and study configuration are both outlined.

2.7.3 Chapter 3: Exploring the audit literature

What contextual features influence the contribution of externally initiated, MDT clinical audits to quality improvement in high income countries?

A scoping review of the literature is used to identify contextual features that influence the contribution of clinical audits to quality improvement. Although the intention was to focus specifically on the community setting, there was insufficient literature. The scope was therefore expanded to include all healthcare settings. In order to generate transferable findings, the focus on externally initiated, MDT audits in high income countries was maintained. Findings are used to generate CPTs, for development in subsequent chapters.

Objectives:

1. To identify relevant evidence, key themes and gaps within the literature.
2. To generate CPTs, for development in later chapters.
3. To inform the development of a survey exploring audit in community stroke care.

2.7.4 Chapter 4: Exploring stakeholder experiences of SSNAP

CPTs generated from the literature are used as a framework to explore stakeholder experiences via an online mixed-method survey.

What are stakeholder's experiences of using SSNAP in the community setting?

This chapter explores the experiences of community stakeholders across the audit cycle. Findings are used to refine the CPTs generated from the scoping review.

Objectives:

1. To investigate stakeholder experiences of engagement with SSNAP.
2. To investigate stakeholder experiences of participating in SSNAP.
3. To investigate stakeholder experiences of using SSNAP feedback for quality improvement.
4. To use findings to refine CPTs and develop IPTs for testing in later chapters.

2.7.5 Chapter 5: Exploring the influences on SSNAP in the community setting

This chapter investigates the contextual features and associated mechanisms by which the IPTs generated in Chapter 4 propose SSNAP feedback contributes to quality improvement. These theories are used as a framework to explore the following question:

What influences the ability of SSNAP to contribute to quality improvement in the community setting?

Realist interviews are used as an opportunity to collaborate with stakeholders in scrutinising, refining and testing these theories.

Objectives:

1. To investigate how audit engagement is influenced by stakeholder perceptions.
2. To investigate the influence of dedicated time for audit within a team.
3. To investigate the influence of the online platform on data submission.
4. To investigate perceptions of data accuracy and the influence this has on whether data is used for quality improvement.
5. To refine and test IPTs.

2.7.6 Chapter 6: Exploring EQ5D-5L in the context of community stroke care

Findings from earlier chapters proposed the collection of the EQ5D-5L on commencement of community rehabilitation may influence the likelihood of stakeholders using SSNAP feedback for quality improvement. The EQ5D-5L is a patient reported outcome measure that reports health-related quality of life. This chapter details an exploration of the EQ5D-5L in the context of community stroke rehabilitation. Statistical analysis of SSNAP data was used to explore the following question:

What influences EQ5D-5L variability in community dwelling stroke survivors?

Objectives:

1. Summarise the evidence-base for the use of EQ5D-5L in stroke rehabilitation.
2. To explore associations between predictors and EQ5D-5L at six-months post stroke.
3. To explore associations between predictors and change over time in EQ5D-5L.
4. To explore the interpretation of EQ5D-5L in this population.

2.7.7 Chapter 7: Discussion

Chapter 7 provides an overview of the findings from all four study phases and situates these within contemporary research literature. The strengths and limitations of this thesis are discussed, and reflections made on the challenges encountered.

The thesis concludes by highlighting the original contribution made by this study. Implications for policy, practice and research are summarised and recommendations made for each of these going forwards.

2.8 Chapter summary

This chapter has set the methodological scene for the thesis, providing a rationale for the chosen methodology and defining key terms. The positionality of the researcher and its potential to influence this study have been acknowledged and steps taken to enhance rigour and trustworthiness outlined.

Finally, an overview of the thesis structure is provided. Objectives are described for each chapter that contribute to the overall aim of the study:

To understand the role of national clinical audit in driving quality improvement in community stroke care.

3 Exploring the audit literature

Using a scoping review to generate Candidate Programme Theories (CPTs).

3.1 Introduction

The previous chapters have provided a rationale for this study and described the underpinning methodology. The overall aim of the study is:

To understand the role of national clinical audit in driving quality improvement in community stroke care.

As a realist evaluation (RE), the first stage of investigation is theory generation. This requires an iterative cycle of immersion in the literature, collaborator engagement and creative brainstorming[130] and is illustrated in Figure 3-1.

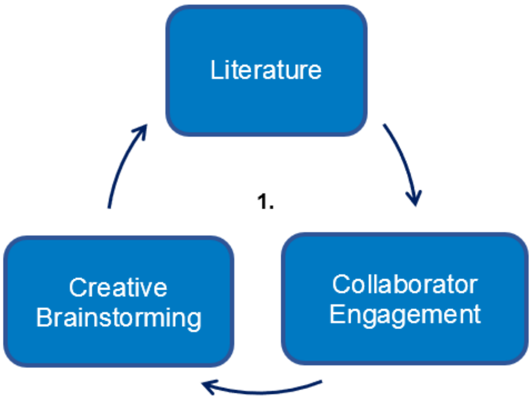


Figure 3-1: The Realist Evaluation Cycle - Stage One

This chapter outlines stage one of the RE cycle. Firstly, a rationale for the focus and type of literature review is provided, followed by the review itself. Secondly, findings from the review are used to generate CPTs. The process by which these theories are developed including the role played by collaborators is detailed. Finally, CPTs are presented, ready for further refinement in the following chapter.

3.2 Rationale

SSNAP is an established quality improvement tool for hospital-based stroke care[64]. However, there are differences between hospital-based and community stroke care, which may affect how SSNAP contributes to quality improvement in the community. Exploration is required to understand how the context of community stroke care influences the ability of SSNAP to contribute to quality improvement.

3.2.1 Focus of review

Previous literature reviews regarding clinical audit have been broad, unbound by country, healthcare system or clinical setting[16,19,145]. These have included audits of non-patient facing activities such as medical education, health waste management and resource use. Audits may have been initiated internally or externally, and predominantly focused on activities undertaken by a single discipline.

A preliminary appraisal of the literature identified few publications regarding audits undertaken in the community, therefore it was decided not to limit the review to this setting alone. Instead, in order to generate findings potentially transferable to the context of community SSNAP, this review focuses on audits with other comparable contextual features.

These include audits that are:

- Undertaken by a multidisciplinary team.
- Externally initiated.
- Undertaken in High Income Countries[146] (HIC).
- Concerning patient-facing care.

3.2.2 The choice of scoping review with “realist lens”

Scoping reviews are often chosen when evidence is scant or emergent and methodologies divergent[147,148]. In contrast to systematic literature reviews with narrowly focussed research questions, scoping reviews are not restricted to specific study designs and may take a broader view of the topic[149]. This enables scoping reviews to be used to synthesise and summarise an array of evidence to identify gaps in the evidence and inform decision making[148]. Similar to a systematic review, the scope of exploration can be articulated using the PICO (Patient, Intervention, Comparison and Outcome) framework[149]. This framework aids the transferability of findings to comparable interventions or settings[147]. Arksey and O’Malley outlined their methodological framework for scoping reviews in 2005, which has subsequently been developed and revised[148,150]. The following scoping review follows guidance from the latest iteration, the PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews)[151]. A checklist is included in Appendix 3-2.

On reflection, a realist synthesis may have been more appropriate for this study. However, this phase of work was commenced prior to any formal training in realist methods, therefore counsel was sought from the realist community. Following conversations with Professor Andrew Booth and Dr Justin Jagosh via the online RAMESE network (Appendix 3-1) and doctoral students with experience of undertaking a realist synthesis, a decision to undertake a scoping review using a realist lens was deemed most appropriate. This was a pragmatic approach taken in light of the available resources (time, finances and skills) against a desire for rigorous research. The intended purpose of a “realist lens” in this review was to explore nature of the architecture of MDT audits and to sensitise the reviewer to potential causal insights in the literature (including complete theories).

Due to the iterative nature of refining and rewriting a doctoral thesis, and the learning journey of a PhD student immersed in realist methods, the scoping review presented in this chapter may be perceived as closer to a realist synthesis than initially intended. However, from the outset this review was planned as a scoping review, using recommended structure, reporting conventions and checklists outlined in the following pages.

3.3 Scoping review

3.3.1 Aim

The aim of this chapter was to explore the following question:

What contextual features influence the contribution of externally initiated, MDT clinical audits to quality improvement in high income countries?

As described in Chapter 2, context may be evident at different levels. Examples of contextual features within audit may include:

- Individual attitudes, behaviours, knowledge or beliefs.
- Interpersonal relationships and communication within teams.
- Institutional setting, such as organisational structure and leadership.
- The wider infrastructure and resource availability.

3.3.2 Objectives

1. To identify and map relevant evidence, key concepts and themes (including existing programme theories) and define gaps within the evidence base.
2. To use findings, collaborator engagement and creative brainstorming to generate realist CPTs, specific to the context of community stroke care.
3. To inform the development of a survey exploring community stakeholders experiences and perceptions of SSNAP in the next chapter.

3.4 Methods

The following section summarises the methods that underpin this scoping review.

3.4.1 Eligibility criteria

The review was conceptualised using the PICO framework[149] to define the exclusion and inclusion criteria. Sources of information were not restricted to peer reviewed journals or by methodology, so as not to exclude potential insights. Where literature reviews or meta-syntheses were identified with similar criteria to this scoping review, these reference lists were hand searched for eligible studies.

Table 3-1 summarises the exclusion criteria. Commonly discernible from a documents title and abstract, these criteria were used to screen documents for exclusion. Documents published before 1990 were excluded as this corresponds with significant changes in policy regarding clinical audit. Only articles available in English language were included as no funds were available for translation. The setting was limited to high income countries[146], to reflect healthcare contexts comparable with the UK where SSNAP is implemented.

Table 3-1: Exclusion criteria

Domain	Exclusion Criteria
Population	Not involving healthcare workers Non HIC[146]
Intervention	Non-clinical audits e.g. waste management / education Internally initiated audits Involving a single discipline or healthcare profession
Other	Published before 1990 Not available in English language

Those documents not excluded on the basis of these criteria went on to be assessed for eligibility against the more detailed inclusion criteria in Table 3-2. Documents that satisfied each of the inclusion criteria were eligible for inclusion.

Table 3-2: Inclusion criteria

Domain	Inclusion Criteria
Population	**Healthcare workers** • Healthcare employee, including non-registered, clinical, administrative or managerial roles • Any healthcare setting including acute hospital / primary care / community • Countries defined as a HIC[146]
Intervention	**Externally initiated audits of MDTs** • Clinically focussed audits i.e. of patient facing activities • Initiated outside of the clinical team providing care • Involving more than a single discipline of healthcare profession
Outcome	**Quality improvement** Qualitative or quantitative reports of any of the following: • Patient / carer experiences or outcomes • Efficiency in clinical service • Efficacy of clinical intervention • Adherence to clinical guidelines • Meeting professional standards or clinical targets • Staff experiences
Other	**Contextual feature** Details of any contextual features such as: • Individual attitudes, behaviours, knowledge or beliefs • Interpersonal relationships and communication within teams • Institutional setting, such as organisational structure and leadership • The wider infrastructure and resource availability

3.4.2 Information sources

To identify potentially relevant documents, the following bibliographic databases were searched: Medline, AMED, Web of Science, Embase, PsychInfo, Wiley and Cochrane Libraries. The electronic database search was supplemented by searches of unpublished grey literature using both Google Scholar and hand searching relevant sources including researchers, forums or organisations active in the area of clinical audit.

3.4.3 Search Strategy

The search strategy was formulated through exploration of keywords and reference lists from the initial preliminary scoping exercise. In addition, terms were informed by a previous literature review exploring how audits improve the quality of hospital care[16]. Search terms were adapted for controlled vocabulary, MeSH headings and database functionality as appropriate. This was further refined with support from an experienced medical librarian.

There were challenges in focussing some search terms. For example, attempts to search for “externally initiated” audits specifically returned low numbers of results and failed to capture known sources of evidence. Therefore, a decision was taken to combine three broader strategies describing the population setting (healthcare), intervention (audit) and outcome (quality improvement). It was acknowledged that this broader search would generate a large number of documents for screening but reduced the risk of excluding potential insights.

The following is an example of the search strategy used in Medline (via OVID) on 14th July 2021.

Table 3-3: Example Search Strategy

1	Hospitals/ or (hospital* or ((health* or clinical) and (organi?ation* or centre* or center*)) or (health sector* or healthcare sector* or health care sector) or (primary and (health or care)) or community or domiciliary).ab,ti.
2	Clinical Audit/ or Medical Audit/ or ((extern* or medical or clinical) and (registry or registries or audit*)).ab,ti.
3	Efficiency/ or Efficiency, Organizational/ or (Quality Improvement/ or Quality Assurance, Health Care/) or (efficien* or effectiveness* or performance* or improve*).hw,kf,ti.
4	1 and 2 and 3
5	limit 4 to (English language and yr="1990 -Current")

?=Wildcard, *=Truncation, ab.=Abstract, ti.=Title,
hw.=Subject Heading Word, kf.=Keyword Heading Word

3.4.4 Selection of sources of evidence

In order to enhance the rigour of the scoping review, a second reviewer (RK) was involved at each stage of data selection (in addition to the student LR). The following paragraphs describe the selection of sources of evidence and the role of the second reviewer (RK), as illustrated in Figure 3-2.

Identification

Following preliminary scoping activities, discussions were held with collaborators (MJ, SL, RF, NC and RS) and subsequently a second reviewer (RK) to develop an understanding of the potential shape of the literature: its scope, size and any gaps already identified. Discussions were had regarding the impact of refining searches further e.g. limiting to externally mandated audit. A decision was made to maintain a broad initial search, to prevent losing relevant insights. Searches were then undertaken as outlined in Table 3-3.

Screening

Following removal of duplicates, the search yielded 7,322 documents. The first 50 documents were screened (title and abstract only) by both reviewers independently using the exclusion criteria detailed in Table 3-1. No disagreements were identified. LR completed the remaining screening resulting in 292 documents.

Eligibility

Both reviewers assessed the first 64 of the remaining 292 documents independently (full text). Documents were retained if they met the full inclusion criteria in Table 3-2. There were no disagreements. LR assessed the remaining documents for inclusion. Both reviewers committed time to exploring grey literature and reference lists independently, yielding a further 2 documents, resulting in a final total of 40 documents.

Studies were not excluded on the basis of methodological rigour. Excluding methodologically weaker studies poses the risk of excluding what Ray Pawson terms "*nuggets of wisdom*"[152]. Instead, two publications informed the appraisal of evidence on the basis of relevance, richness and rigour. These were the RAMESES quality standards for realist synthesis[153] and Dada et al.'s realist appraisal guidance[154]. Although subjective, this appraisal provides the reader with an understanding of the contribution made by individual sources of evidence. Details were added to the data extraction chart (Appendix 3-3).

Relevance

Evidence was appraised with regards to its relevance to the research question and therefore its potential to contribute to theory generation. Relevance was deemed to be high, medium or low. A high rating indicated the evidence was directly relevant and contained substantial detail. A medium rating indicated some detail, but focussed on only part of the question, and a low rating indicated little relevance to the question.

Richness

The degree of theoretical detail that described how audit was expected to work was appraised. This was deemed to be either conceptually rich, thick or thin. Conceptually rich described evidence with well detailed concepts and theories. Conceptually thick evidence had detailed descriptions of the audit but without reference to any underpinning theory. Conceptually thin evidence had limited descriptions of the audit without any theoretical propositions.

Rigour

No formal scoring of rigour was undertaken as RAMESES does not advocate for the use of a formal checklist. Instead, any methods used to generate the findings were appraised with regards to how credible, appropriate and trustworthy they were. Any concerns or reservations were noted in the data extraction chart, and this was left blank if none were identified.

3.4.5 Data charting process

A data extraction form was developed, informed by previous systematic reviews of audit[16] and the specific focus of this review. The following information was extracted by LR in the final form (Appendix 3-3): Source (author, year and country), title, study design, aim of the study, setting, study participants and focus of the audit. Notes were made regarding relevance, richness and rigour as discussed earlier. Key extracts regarding any contextual features reported as influencing the ability of the audit to contribute to quality improvement were included in the final column.

3.4.6 Organisation of findings

Findings from this scoping review were organised into two main categories:

1. Existing theories regarding the role of audit in quality improvement.

2. Contextual features identified by the review as influencing the ability of audit to lead to quality improvement.

Existing theories are listed and summarised in the first section. Contextual features are organised thematically in the following section. Any parallels between existing theories and the contextual features identified are highlighted in the subsequent discussion section.

3.5 Results

3.5.1 Selection of sources of information

Figure 3-2 illustrates the process by which documents were sourced and considered for inclusion[151]. The role played by the second reviewer at each stage is indicated in yellow on left hand side.

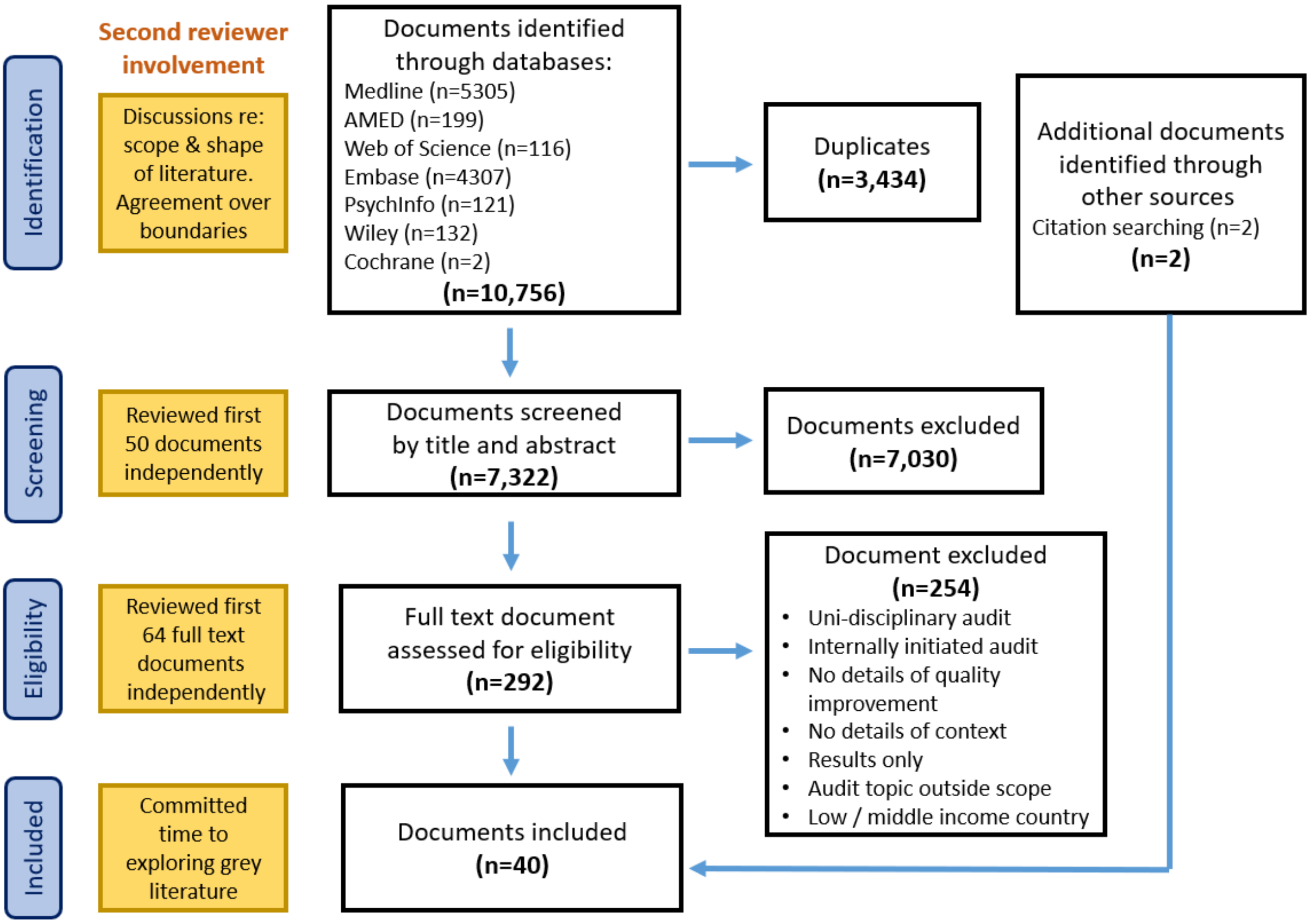


Figure 3-2 PRISMA Flow diagram

3.5.2 Characteristics of sources of evidence included

Studies predominantly originated from the UK (n=18)[13,17,23,33,34,155-167] and elsewhere in Europe (n=14)[168-181], with smaller numbers from Canada (n=4)[182-185], Australia (n=2)[186,187], America (n=1)[188], New Zealand (n=1)[189]. A detailed breakdown of country of origin is illustrated in Figure 3-3.

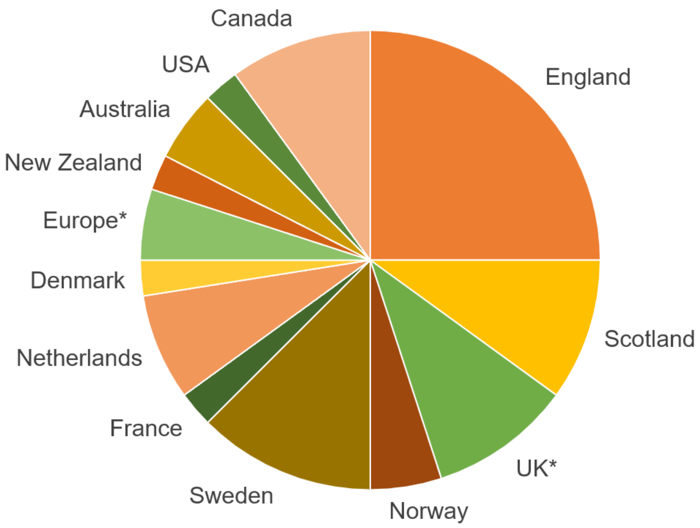


*Figure 3-3: Origin of studies (*indicates multiple countries)*

The majority of studies (n=35) used qualitative or mixed methods. These included methods such as focus group and interviews as part of methodological approaches such as RE and case study design. Of the five studies that used quantitative methods alone, four used quantitative surveys [158,171,172,174] and one used medical record review[156].

Eight studies reported the outcomes of specific audits [155,156,171,179,185,187-189]. The focus of which ranged from guideline compliance such as hand hygiene[188,189] falls[187] and prescribing[155,156], to clinical interventions such as urinary catheters[185] and whole clinical pathways such as thoracic cancer surgery[179]. The remaining studies explored audit more broadly e.g. the barriers to compliance, or implementation of feedback. Only five studies included audit activity outside of the hospital setting[166,168,180,183,184]. These were all audits of clinic-based activities. Therefore no studies focussed specifically on audit activity in a community setting.

3.5.3 Results of individual sources of evidence

Due to the considerable number of studies, this table is included in Appendix 3-3.

3.6 Summary of evidence: Existing theories

Only one study included in this review proposed theories relevant to the scope of enquiry. Alvarado et al.[34] used data from 54 interviews with audit staff, Doctors and Nurses from five healthcare providers in England to identify circumstances that supported or constrained audits from resulting in quality improvement.

They proposed a number of mechanisms that explain why different groups within healthcare organisations interact with national clinical audit feedback. These were categorised as reputation, professionalism, competition, incentives and professional development.

The resultant programme theories were articulated as context, mechanism and outcome configurations and are summarised in Table 3-4. For ease of reference, these have been numbered 1-5.

Table 3-4: Overview of proposed theories from Alvarado et al.

Context		**Mechanism**		**Outcome**
In what circumstances	**For whom**	**Audit resource**	**Organisation response**	
NHS Trusts operate in a context of competition, choice and funding initiatives designed to stimulate quality improvement.	**1.** Trust Boards and their subcommittees that have oversight of clinical services across their organisation.	Trust Boards are notified if a service is to appear as an outlier in the publicly available annual report.	**Reputation:** Trust Board acts to preserve reputation.	Data interrogation to establish cause of outlier status, may lead to more frequent monitoring of the service for assurance.
	2. Clinicians who trust feedback is accurate as they upload data to the NCA supplier directly, but do not monitor routinely due to constraints on their time.	The public report produced by NCA suppliers offers national benchmarks against which to compare service performance.	**Professionalism:** Clinicians incorporate the NCA report into the service's clinical governance processes, to assess service performance and where improvements can be made.	Supplier feedback highlights if service is an outlier in comparison to peers. The clinical service makes changes to improve their performance if resources allow.
Professional groups within Trusts have different improvement priorities, and power to support service changes.	**3.** Tertiary centres that compete with other organisations for patient referrals from district hospitals.	The public report enables services to benchmark their performance against peer organisations in target-based measures.	**Competition:** The clinical service uses feedback to evidence competitive performance to feeder services.	Feeder services may refer more patients. Clinical teams may act to improve performance to attract patient referrals.
	4. Clinical services resourced to collect accurate and timely data and to maintain local databases.	Audit support staff customise feedback using local data i.e. without national comparators.	Measures considered important for **professionalism** or to obtain **incentives** are integrated into monitoring processes.	Clinical staff can quickly identify trends, introduce change to improve performance and monitor where resources allow.
	5. Junior doctors and nurses are expected to complete projects as part of their placement within the clinical service.	NCAs (via supplier or local databases) offer data that can be used to address trainees' research questions.	**Professional development:** Trainees extract data for projects which provide learning about how it could potentially be improved.	Knowledge/lessons from research projects might be used to inform service delivery.

3.7 Summary of evidence: Contextual features

Contextual features that influence the ability of audit to contribute to quality improvement

Findings were grouped around two distinct points on the audit cycle. These are illustrated below in an adapted cycle (Figure 3-4). The green wedge represents features that influence how individuals engage with and participate in audit process. The purple wedge represents features that influence the use of feedback to inform quality improvement.

Figure 3-4: Adapted audit cycle

Findings are presented in a narrative form. Key extracts and study details are contained in Appendix 3-3.

3.7.1 Engagement

Although those who are engaged are more likely to participate, engagement and participation are not synonymous. Individuals who are engaged may encounter barriers to participation and those who do participate, may be disengaged from the process (lacking interest). This review found three features that influenced an individual's engagement with the audit process. Evidence of engagement included individuals being open to involvement in audit, being interested in audit activities or being motivated towards participation in audit. The three features were:

i. Individual beliefs regarding the audit and its purpose
ii. Perceptions of the credibility of the audit
iii. Organisational culture

Individual beliefs regarding the audit and its purpose

A number of studies reported engagement in audit to be influenced by a belief that audit offered the prospect of improving patient care[34,166,173]. Stevenson et al. found teams that regarded audit as a *"mechanism to help identify what needed to be changed*" were more likely to engage with audit[166]. Engagement was reportedly motivated by potential outcomes such as *"incentives, financial or accreditation*" that may enhance patient care[34]. In contrast, Taylor et al. reported stroke clinicians who believed audit to be linked primarily with commissioning of services were apprehensive towards engagement[13]. When therapists perceived the audit purpose to be *"monitoring of therapy time*" this led to fears regarding data being used for commissioning of services[13].

Two studies reported a specific group of individuals engaged with audit for the purpose of career progression. Dunne et al. highlighted that clinical audit was a mandatory component of UK foundation medical training, therefore doctors were motivated to engage[161]. This was echoed by Bowie et al. who reported doctors were commonly engaged in audit, which was perceived to be for the purpose of career progression[17].

Perceptions of the credibility of the audit

Engagement with an audit was described as being influenced by its perceived credibility. This review identified two features that reportedly underpinned this perception. Firstly, the choice of indicators against which performance was measured and secondly an association with a reputable professional body.

There was lack of agreement between studies regarding the types of measures that should be included in an audit. Wagner et al. reported teams were motivated to engage when measures were perceived as *"meaningful to their practice and captured the full scope of their care*"[183]. Clinical measures, for example reflecting an individual's mood or physical ability were prioritised by healthcare professionals over non-clinical process measures such as waiting times. Sparring reported the inclusion of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) as facilitators for organisational engagement with audit. They described a "*Paradigm shift towards value-based health care, which fits perfectly with the introduction of PROMs and PREMs."* [181]

In contrast, Manion et al. reported clinical staff to have preference for process measures as they were perceived as "*more reliable … and easier to measure*"[163]. Whereas Arvidsson suggested that audits focussing on predominantly these non-clinical measures "*may reduce professionals' interest in audit*"[168]. Despite this debate, there was agreement that for an audit to be credible, the standards against which it was measured should be informed by the best available evidence[164,181].

Endorsement by professional bodies was reported as a motivating factor for engagement with national clinical audit[158,159]. Taylor et al. proposed that an association with professional bodies conferred a perception of authority. This was reported as being "*due to the credibility of the established professional societies and authoritative bodies associated with the reports"*[23].

Organisational culture

The culture of an organisation with regards to audit was described as a strong influence on individual engagement. Three features were identified as contributing to this culture. Firstly, the organisational support provided from management and those in leadership positions. Secondly, a shared understanding regarding the audit process amongst those involved. Finally, an individual embedded within the team with an interest in the audit.

Management support for audit was frequently reported as resulting in greater audit engagement within teams[169,173,175,180,182,186]. Sinuff et al. proposed that in addition to providing support, senior managers must also acknowledge audit feedback and recognise achievements if clinicians are to be engaged with audit[182]. In addition to support from management, the engagement of leaders at a variety of levels and across disciplines e.g. Nurses, Physicians and Administrators was described as a strong influence on the success of an audit[182,185]. Dixon-Woods et al. highlighted strategies used by leaders, such as promoting "*collective responsibility*" in order to engage teams with audit[160]. They described the legitimacy "*breathed into*" audit by effective leadership as critical to an organisation culture of audit engagement. This perceived legitimacy of audit within an organisation was identified by McVey et al. as motivating the engagement of healthcare professionals in audit[33].

A lack of clarity regarding the audit process within an organisation, was identified as negatively influencing engagement[162,172,182]. Egholm et al. highlighted that when "*roles and responsibilities for acting on data are unclear*" this presented challenges to engagement[172]. Sinuff et al. reported that participants perceived the audit process to lack transparency and as a consequence clinicians felt disconnected from the process. This resulted in reports of staff being disenfranchised when their "*opinions about the process were not sought nor were they informed of the process"*[182]*.*

The presence of an individual embedded within the team with an interest in the audit was highlighted as influencing their engagement. [173,181]. These individuals were sometimes referred to as "*audit champions*". Gude et al. defined champions as "*one or two people responsible for implementing the intervention locally*"[177]. Taylor et al. used the term "*local clinical leader*" to describe "*someone influential who clinicians respect due to their clinical experience*"[13]. However, challenges were highlighted in lone individuals being responsible for audits. For example, Dunne et al. found the most frequent reason for incomplete audits was the driver being an individual who "*either completed their objective (presentation / publication) or moved hospital trusts*"[161].

3.7.2 Participation

The predominant contextual feature described in the literature as influencing participation was resource availability. These fell into three broad categories:

i. Time
ii. Information technology
iii. Expertise

Time

A lack of dedicated time for audit was reported as the main barrier to participation in a number of studies[33,169,175,178], especially in the context of competing demands [17,162,168,173,177]. However, Bowie et al. suggested time pressures were often used as a "*smokescreen….to hide a multitude of other reasons*" for non-participation such as apathy, disinterest or challenging team dynamics[17]. This suggestion was not echoed in other studies in this review. Eldh et al. stated that the amount of time required to register data was a significant limitation of the Riksstroke registry. As a consequent they reported that "*merely 65% of the Riksstroke respondents*" considered the benefits of participation worth the resources required to do so[174]. In contrast, Langston et al. highlighted the simplicity and speed in which an audit could be completed in their study as a key reason for its success[188].

Dixon-Woods et al. highlighted that audit activities such as data entry were "*rarely built into job specifications….and rarely an activity directly funded or resourced by organisations"*[160]. A lack of dedicated time to participate in audit was reported to "*constrain its use as a tool for stimulating quality improvement*"[34]. This was reported as a specific problem when attempting to implement change, where studies described a lack of capacity to act on feedback and bring about quality improvement[17,157,159]. A "*failure to support and resource change"* by an organisation was described as decreasing motivation for individual participation[17,168]. In situations where managers consistently failed to act on feedback, McVey et al. described clinicians as "*questioning the value of audit participation*"[33].

Inequalities were highlighted in the "*varying opportunities to partake in audit*" available to different staff groups[17]. The mandatory participation of junior doctors in audit as part of their training, was reported to underpin this inequality[161]. Bowie et al. highlighted the discrepancy between Doctors who "*often have dedicated contractual time*" for audit participation and nursing staff who reported "*managerial pressure to focus solely on clinical work*"[17].

Information Technology (IT)

Examples of IT challenges for audit participation were reported as duplicate administration due to the technical constraints of "*incompatible IT systems*" [181] and "*challenges accessing supplier-held data*"[34]. Dixon-Woods et al. suggested that "*these mundane obstacles have a powerful impact on clinicians' ability and willingness to complete data entry*" and participate in clinical audit[160].

Expertise

Studies described a lack of available expertise within organisations around both IT and data analysis. Consequently, a "*lack of IT support*" was reported as impacting the ability of individuals to participate in audit[158,176,178]. Specific activities that were described as being limited were the ability of individuals to submit data[158] and to interpret audit feedback[176,178].

3.7.3 Using audit data to inform quality improvement

A number of features were identified as influencing the ability of audit data to inform quality improvement. These include:

i. The perceived accuracy of the data submitted to the audit
ii. The accessibility of feedback provided by the audit
iii. The perceived utility of feedback provided by the audit

The perceived accuracy of the data submitted to the audit

Doubts regarding the accuracy of data submitted were reported to "*hamper the feedback's credibility*" and inhibit acceptance of feedback by clinical teams[177]. A number of studies highlighted concerns regarding the perceived trustworthiness of data. Sources of mistrust included "*inconsistent or inaccurate coding*"[165], a lack of "*methodological consistency between practices*" [13,184] and "*low data quality*"[181]. Dixon-Woods et al. suggested teams' were at risk of being "*misrepresented by poor quality data*" if audit tasks were consistently delegated to non-clinical staff, who may lack the expertise to aggregate complex clinical information[160].

Taylor et al. found variation in the *"interpretation of audit requirements*" and a lack of uniformity in the reporting practices of inpatient stroke units in the UK. These inconsistencies were described as resulting in "*rivalry and mistrust*" between teams as well as in the audit tool itself[13]. Clinicians were mistrustful of feedback containing national data, suggesting other teams were "*playing the numbers game*" to enhance their performance in the report[13]. Participants in the study also questioned whether improvements reported by the audit reflected "*real life improvements*" or apparent improvements following changes to audit processes and systems.

Feedback was perceived as less accurate if there was a significant delay in reporting[182]. A number of studies reported the timeliness of audit feedback influenced its ability to contribute to quality improvement[34,163,165,182-184]. For example, feedback was described as "*unhelpful*" when building business cases that required evidencing with recent information[33]. Similarly, Fredriksson et al. cited a "*lagging data access*" as a barrier to quality improvement for those commissioning services[176]. There was a lack of agreement between studies regarding the optimum frequency for audit cycles. Jolliffe et al. proposed fortnightly cycles of audit and feedback[186]. In contrast, Wagner et al. suggested six-month feedback cycles to be excessive and describing reports of "*feedback fatigue*" from clinicians[184].

The accessibility of feedback provided by the audit

For national clinical audits to result in quality improvement Phekoo et al. suggested findings must be accessible. This requires them to be "*disseminated widely, not merely [in] annual reports*"[164]. However, Egholm et al. reported that feedback commonly failed to reach frontline staff due to what they described as "*complex delivery networks*"[172]. Gould et al. proposed this failure to reach the individuals whose activities were being audited resulted in feedback being unable to effect change and contribute to quality improvement[162].

As well as being accessible to those delivering the activities being audited, it is important that those commissioning and providing services should access audit feedback. Botje et al. proposed that "*quality*" including audit data should feature as a regular item on all healthcare board meetings. They reported this action to be associated with the successful implementation of quality improvement initiatives as well as signalling the value placed on the audit[170]. McVey et al. suggested that hospital boards were more likely to engage in audits that were "*mandated by NHS England"* and for whom results were publicly available[33]. The publicly accessible nature of these results was described as motivating boards to engage with feedback in order to minimise risk to their reputation and avoid appearing as "*negative outliers*" in reports[33].

This review found the prospect of publicly accessible audit feedback to have a mixed reception, with reservations expressed by a number of authors. Dixon-Woods et al. raised concerns regarding the potential for professionals to "*weaponise data as a means of blaming and shaming*"[160]. Whereas Taylor et al. described healthcare professionals as "*motivated to improve, driven by a competitive spirit*" when able to access national comparative data[23]. Competition between providers has been used as a strategy within the NHS to offer increased choice to patients. In this context, Alvarado et al. highlighted the role of publicly accessible feedback *"to attract patient referrals*" for financial benefit[34]. Despite the initial "*negative media attention*" attracted by poor audit performance, Freeman et al. described how the public reporting of results garnered greater senior management support and ultimately "*helped drive considerable improvement*"[189].

Eldh et al. argued that making feedback available is ineffective if individuals are unable to interpret and operationalise it for quality improvement[175]. Clinicians were described by some as struggling to understand and interpret large volumes of data[182,184]. In contrast, Alvarado reported audit feedback to lack the level of detail that would enable clinicians to "*pick out subtler changes*" that could inform quality improvement[34]. These difficulties were not limited to clinical staff. Asprang et al. reported "*professionals and senior managers struggled to understand the content*" of reports[169].

The format in which feedback was provided was described as influencing accessibility. For example, Wagner et al. described participants struggling to navigate data on an online platform, impairing their ability to access or share audit findings[184]. A lack of technical ability was reported to limit the accessibility and utility of data for both clinicians and senior managers[176]. However, Asprang et al. argued that responsibility lies with the audit provider to generate feedback that is understandable for its intended audience. They suggested that the use of "*words and concepts that professionals are able to understand could facilitate understanding and organizational change*."[169] There was agreement within the studies that feedback reports from an audit should be easy to access, visualise and interpret if they are to contribute to quality improvement[168,177,182,184].

The perceived utility of feedback provided by the audit

Cornish et al. suggested that clinical teams are motivated to participate in audits if they perceive feedback as useful[158]. However, Bodansky et al. advised caution in assuming that feedback automatically leads to quality improvement. The provision of feedback alone was proposed as insufficient to change clinical practice. Instead, they proposed that feedback offered with "*consideration of the principles of behaviour change*" may enhance quality outcomes[156].

Studies in this review identified a variety of ways in which audit data was used to inform quality improvement. These included comparison with national averages, exploring "*trends over time*"[158] and benchmarking against other services[157,179]. Mannion reported that the inclusion of process measures in feedback was preferable to outcome measures. Process measures were described as supporting the identification of "*specific actions needed to improve the quality of care*" and therefore perceived as more actionable[163].

Taylor et al. proposed comparison against evidence-based standards stimulated quality improvement by enabling "*teams to identify areas for improvement*"[23]. However, some suggested comparison had the potential to lead "*hospitals to become complacent*" if they discovered other services were performing equally poorly[155,167]. Sykes et al. described participants questioning the value of using audit for benchmarking, other than drawing the attention of the hospital board[167]. "*If you're somewhere near the bottom then they want something done about it, it's a useful lever"*

A number of strategic uses for audit data were identified. These included providing "*evidence for service planning and for making business cases*" or "*leverage or ammunition*" in making a case to management for additional resources[23,33,157,163,167].

3.8 Discussion

This scoping review explored the contextual features influencing the contribution of externally initiated, MDT clinical audits to quality improvement. Findings are consistent with previous reviews that explored the use of clinical audit more broadly, that audit *generally* contributes to quality improvement but is dependent on specific contextual features[19,145,190,191]. This review identified a number of contextual features that are particularly influential for audits that are both MDT and externally initiated. These focus on the challenges of engaging multiple disciplines and the utility of the data generated.

An individual's beliefs regarding the purpose of audit are acknowledged as influencing their engagement[145]. However this can be challenging for MDT audits, due to their reliance on contributions from multiple professionals with diverse priorities and beliefs regarding the purpose of the audit[17,161]. Consequently, a shared understanding of audit is essential, including clear roles and responsibilities regarding the process[172]. For MDT audits, this can be difficult due to the size of teams and range of disciplines involved. This may explain the crucial role played by champions in using MDT audits for quality improvement[173,177,181]. The importance of champions in wider quality improvement is well established[16,192]. This role varies depending on the intervention being "*championed*", examples include knowledge brokers, role models or organisational boundary spanners[193].

The availability of resources has been identified by this review as a key feature influencing participation in MDT audit. Resources predominantly included time but also analytical expertise. Without dedicated audit staff, clinicians were often tasked with data collection[175]. Dowding et al. have argued that this burden of data collection in national clinical audits must be addressed if healthcare professionals are to be released to provide frontline care[194]. In the UK, the NHS has faced criticism for a lack of analytical expertise leading to limited capacity for analysis and monitoring of data quality[195]. The influences of these features on participation are well documented in the broader audit literature and are not unique to externally initiated MDT audits[24,196,197].

This review is in agreement with the wider literature, in that data must be accurate if it is to be perceived as trustworthy[196]. Two contextual features were identified that were specifically pertinent to data from externally initiated MDT audits. These are the measures collected by the audit, and the way in which findings are reported.

Debate was evident in the studies included in this review regarding the choice of measures that should be included in clinical audit[163,168,181,183]. By their nature, MDT audits may collect an array of metrics, detailing the contribution and outcomes of a variety of healthcare disciplines[198]. Consequently, there is the potential to generate large volumes of feedback. This can obscure key findings and reduce the effectiveness of audit in contributing to quality improvement[199]. Hysong et al. call for a taming of the "*proliferation*" of clinical measures, warning that there is a risk of "*spending more time documenting care than providing it*"[200]. Instead they propose clinicians should be engaged in using a "*small, meaningful and motivating set of indicators*" appropriate to the situation[200]. MDT audits therefore need to identify what these small, meaningful and evidence-based measures should be.

This may be an opportunity for MDT audits to consider PROMs as a patient centred measure of MDT interventions. There is increasing interest in using PROMs clinically within healthcare[201]. In the UK, HQIP have recommended the inclusion of PROMs in any national clinical audits commissioned or recommissioned after 2022[199]. However, Devlin and Appleby caution that the development of PROMs requires robust evaluation to ensure measures reflect factors associated with the intervention under scrutiny[202]. Regardless of the choice of measure used in quality improvement, metrics must be perceived as credible by participants whilst not being "*too irksome or burdensome to collect*"[203]. This review has highlighted that striking this balance may be challenging for MDT audits.

Meyer et al. argue that ultimately measures must be selected to meet the needs of the end-user[203]. However this review suggests pinpointing these individuals may be complex for MDT audits. Findings highlight externally initiated, MDT audits are used for quality improvement at a variety of levels such as individual, team and organisation. Alvarado proposed five theories including a range of stakeholder groups all of whom could be perceived as "*end-users*", from trust boards to a variety of clinical staff[34]. Therefore "*end-users*" may vary depending on the context in which the audit is completed, and this should inform the choice of measures used.

Findings from externally initiated audits are commonly reported publicly via the professional body or organisation commissioned to provide them. The perceived authority offered by these organisations was described as galvanising MDTs around a shared goal[159]. Alvarado et al.[34] proposed that the making of audit feedback publicly available may trigger quality improvement via two routes (see Table 3-4). Firstly, a desire to maintain an organisation's reputation (Theory 1). This concurs with the wider literature where the public reporting of results has been described as stimulating leadership interest in audit for the purposes of managing reputation[196,204,205]. The second route proposed by Alvarado et al. suggested performance was enhanced in the face of competition (Theory 3). This suggestion is contested in the literature, with critics describing competition as wasteful and a "*diversion of energies*" that has the potential to widen the gap in care inequality[206]. In contrast, proponents argue that in the hospital setting, increased competition leads to improved healthcare performance in terms of quality, staff satisfaction and productivity[207].

This review has highlighted specific contextual features of externally initiated MDT audits that may influence their ability to contribute to quality improvement. These findings will be used in the following section (3.8) to generate CPTs as per the RE evaluation cycle illustrated in Figure 3-1.

3.8.1 Strengths and limitations

This scoping review was conducted systematically using a recognised methodology[151]. As part of an examined PhD study undertaken primarily by a single individual, attempts to increase rigour by the involvement of a second reviewer are described in Section 3.4.4. Support was sought from an information specialist in the form of a medical librarian in the formulation of a search strategy. However, it is important to acknowledge potential weaknesses in the search strategy. For example excluding single-discipline audits that otherwise met the inclusion criteria, may have disregarded potentially useful insights. In addition, resource limitations may have resulted in the omission of significant non-English publications.

Interestingly, despite the Institute for Healthcare improvement being based in the USA, relatively few studies included in this review originated from America. One reason for this may be their lack of universal healthcare provision, which necessitates individuals to purchase healthcare interventions via private insurance or directly “out-of-pocket”. This may reduce the prevalence of multidisciplinary models of service delivery, as care must be accountable for example, a specific number of physiotherapy sessions. In contrast, universal healthcare which is available in the majority of developed countries outside the USA, enables the upfront investment in more complex and less prescriptive systems such as multidisciplinary teams that can flex in response to patient need.

As with all studies, the potential influence of the researcher must be considered. There was a risk that the conceptualisation of audit may differ between individuals. Steps taken to minimise this risk include the clear articulation of definitions, discussion with collaborators and the involvement of a medical librarian and a second reviewer.

3.8.2 Conclusion

Clinical audits are a recognised tool for quality improvement in health care. This review identified a number of contextual features that influence the ability of externally initiated MDT audits to contribute to quality improvement. In addition, a gap in the evidence regarding MDT audit in the community setting has been identified. The following section describes the first step in exploring how these findings translate into the community setting. Section 3.9 details how the findings of this scoping review have been used to develop CPTs with which to investigate the role of SSNAP in driving quality improvement in community stroke care.

3.9 Generating candidate programme theories

Realist guidance proposes the starting point for an evaluation is to develop initial rough programme theories or CPTs[133]. These theories are described by Geoff Wong as an "*educated guess*"[208]. They can be informed by both immersion in the literature and engagement with experts in the field[133]. In this study, findings from the scoping review were used to generate CPTs in three overlapping phases.

i. Discussion with clinical collaborators
ii. Creative brainstorming
iii. Sense-checking and refinement

3.9.1 Discussion with clinical collaborators

Findings of the scoping review were presented and discussed with clinical collaborators (KB, CL and RS). Although contextual features were the focus of the review, where associated mechanisms or outcomes were proposed or alluded to within the literature, these were also discussed. The purpose of this phase was to:

- Highlight features perceived as relevant to stroke care in the community and contextualise to this setting.
- Focus the study and prioritise findings to take forwards.
- Use findings to tentatively explore potential context, mechanism and outcome configurations relevant to stroke care in the community.

Collaborators were asked to prioritise findings to take forwards based on their:

- Perceived relevance to stroke care in the community.
- Perceived value to their services of further exploration.
- Congruence with collaborators clinical experiences of SSNAP in the community.

The following tables contain summaries of the contextual features, potential mechanisms and outcomes from the literature, that collaborators prioritised to take forwards for further exploration. Table 3-5 includes features related to engagement and participation in clinical audit, whereas Table 3-6 includes those related to using audit feedback for quality improvement. A summary of collaborator discussions and personal reflections on these discussions are included in both tables.

Table 3-5: Contextual features, potential mechanism and outcomes (Engage)

A. Engagement and participation			
	Potential contextual features	**Potential mechanisms**	**Potential Outcomes**
Components from literature	A culture that suggests audit is a worthwhile activity – based on perceived benefits such as improved patient care [33,34,160,166,173] and past experiences [17,33,168] Management support[169,173,175,180,182,186] A perception that audit is a legitimate activity [33,160] Information available about the audit[162,182] Clarity regarding individual roles in the audit[162,172,182] Resource availability: time [17,33,158,160,162,168,169,173-175,177,178], IT[158,178] and data analyst[158,176,178]	Understand audit purpose and process[162,172] Insightful regarding role within audit[162,172] Perceive relative benefit of audit [184]	Engagement including attitudes and interest[17,33,34,160,166,173,186] Participation in audit activities including data collection [17,33,158,160,162,168,169,172,174,175,177,178,182]
Collaborator discussion	What is a culture? Is everyone talking about the same thing? Who decides what is "*sufficient time*"? Perceptions may vary. Accessing analytical expertise is unlikely in community setting. Resources in community: laptops can be a significant challenge. Despite champions being a strong theme within findings, it was felt to be a "*known-known*" and common sense. Therefore further exploration was deemed to lack value. Credibility: both the measures used, and the provider reputation were felt to influence trust in feedback rather than engagement. Therefore included in following table. Competition not perceived as relevant to community stroke at the current time.	Information may be available and individuals aware, but still choose not to engage or participate. **Suggestions:** Confidence in completing audit activities varies. Is audit perceived as legitimate activity? Sitting at a computer can be seen as not contributing to rehabilitation. Are there competing demands? How is audit prioritised against other activities? Is audit perceived as important?	There is definitely something underneath participation at the level of engagement, some people just don't "*get on board*" despite huge amounts of effort and available resources. Collaborators clearly frustrated by this and feel there is value in understanding the underlying causes. Completing tasks or having complete data sets was felt to be a concrete and observable outcome for participation.

Personal reflection	Culture was difficult for collaborators to conceptualise, quite broad and manifests at different levels. Culture may need describing with a proxy e.g. positive role models / talked about in a positive manner perceptible to an individual. There won’t be a standard answer for sufficient time or training, it may be individual perception rather than an absolute. A perception from some that there is enough time and resources, but this isn’t sufficient to tip the balance. Is there another contextual feature that prevents / or is required, or is a combination required?	Collaborators clearly felt that despite a conducive context and sufficient resources, some individuals choose not to engage or participate in audit. There appears to be a tipping point in terms of competing demands, that audit is de-prioritised.	How to measure engagement? It definitely warrants separate exploration to participation as it influences part of causal chain.

Table 3-6: Contextual features, potential mechanisms and outcomes (Data)

B. Use of audit data			
	Potential contextual feature	**Potential mechanism**	**Potential outcome**
Components from literature	Perceived accuracy of data submitted[13,160,165,177,181,183] Meaningful measures[168,181,183] Reputation of audit provider[23,33,158,159] Timeliness of feedback[33,34,163,165,176,182-184] Capacity to act on feedback[17,157,159]	Perceptions of the audit report as trustworthy[13,158] Using audit feedback reports to make comparisons between services[13,23,33,34,157,158,165,166,179,184,189] Using audit feedback reports to support in planning service development[23,33,34,157,163,167]	Audit feedback informs quality improvement[13,23,33,34,158,165,166,179,184,189]
Collaborator discussion	What does accurate look like? Is it about patients or services? Concerns about different interpretations of "*rules*" as community teams were perceived to vary greatly. No one confident in the mRS as a meaningful measure, therefore difficult to motivate teams to collect. SSNAP was perceived as reputable and credible. Six-monthly reporting in community gives a perception of it being less informative as it's less timely. Capacity to act on feedback limited by lack of dedicated time for quality improvement in the community. Post-acute SSNAP reports perceived as easy to "*get hold of*" but differing opinions regarding how easy they are to interpret.	Suggestions for what prompts or inhibits use of data for quality improvement: Trustworthiness was discussed at length, gaming by "*other teams*" a common theme. Trust in feedback strongly associated with doubts over the accuracy of their own data and other teams. Motivated by the message contained in the data (only if they are confident its accurate).	How do you distinguish between successful and unsuccessful attempts to use data for quality improvement that are unrelated to the audit e.g. lack of finance within an organisation?
Personal reflection	A variety of reasons contribute to a perception of data being perceived as inaccurate: measures used, lack of timeliness, methodological differences between teams in data collection.	Perceptions of data accuracy influence both confidence and motivation to act on or use data.	How to identify unsuccessful attempts at quality improvement and identify causes?

3.9.2 Creative brainstorming

Creative brainstorming describes the process by which insights from the literature, engagement with collaborators and personal reflections are synthesised in order to generate tentative CPTs. Despite engagement in realist communities such as the Nottingham Realists and immersion in the realist literature, the need for additional training to support this process was identified. This was undertaken via the Centre for Advancement in Realist Evaluation and Synthesis (CARES). The four-day interactive workshop titled “Constructing Excellent Initial Programme Theories” was completed under the tutelage of Justin Jagosh[209-212]. Tables 3-5 and 3-6 were used as a starting point from which to explore potential CPTs. The following paragraphs detail the considerations made as part of this iterative process of refinement, examples are provided. Each consideration systematically adds an additional layer of refinement to the articulation of the programme theory.

Intrinsic dimensions

Causation

As described in Chapter 2, realist research is underpinned by generative causal theory. This can be expressed as an “*if….then*” statement proposing how a specific context may trigger an associated mechanism[210]. Clinical collaborators (KB, CL and RS) made suggestions as to how the potential contextual features presented in table 3-5 and 3-6 could be adapted to be more applicable to the setting of community stroke care. In addition, they provided feedback regarding the potential associations between these contextual features and the potential mechanisms. Mechanisms were less well described in the literature. Collaborators discussed any mechanisms identified, as well as proposing alternative suggestions for exploration. For example, in the literature a perception of trustworthiness was proposed to increase the likelihood of audit reports being used for quality improvement. However, collaborators felt that trustworthiness was dependent on several features of the report that may motivate its use. This generated a number of preliminary “*if …then*” statements describing a variety of proposed mechanisms.

Granulation

Theories must be sufficiently detailed to enable the researcher to attribute causality to specific components[210]. In the example given above, collaborators felt "*trustworthiness*" could be influenced by a number of contextual features such as the measures used in the audit, or the perceived accuracy of data submitted. These were therefore proposed as separate "*if…then*" statements, providing a more granular and detailed account for exploration.

Articulation

Theories must be articulated explicitly to avoid ambiguity over causal claims and allow for robust testing of theories[210]. For example when discussing how resource availability influenced participation, laptops were identified as a resource specific to the community setting. Therefore rather than "*access to IT*" as proposed in the literature, laptops were specifically named as a resource. The articulation of *"if …then"* statements were discussed with a variety of collaborators, not just clinical, to ensure clarity.

Clustering

During collaborator discussions it was tempting to add additional elements into "*if…then*" statements, specifically contextual features. For example when describing feedback reports, collaborators proposed a variety of contextual features that may stimulate their use such as their presentation, timeliness and perceived accuracy. This resulted in clusters of features describing a number of aspects of the context. In reality, these may have distinct mechanisms by which they contribute to the outcome. Therefore, these "clusters" required teasing out into single strands of "*if…then*" statements to identify a single facet of causation for exploration[210].

Extrinsic dimensions

Rivalry and opposition

Rivalry describes two theories with similar contexts and outcomes but different mechanisms. Rivalry can expose which elements of a context are important and is therefore a useful process for early programme theory development[211]. For example:

"If stakeholders can access information about the audit (purpose and process) and their roles are clearly articulated, then they will ***be empowered*** *to use this information to participate in the audit and audit tasks will be completed".*

Rival:

"If stakeholders can access information about the audit (purpose and process) and their roles are clearly articulated, then they ***feel they have no choice and they are obliged*** *to participate in the audit and audit tasks will be completed".*

Oppositional theories are those where the presence or absence of a mechanism leads to different outcomes[211]. For example:

"If individuals perceive audit to be a worthwhile activity and have busy caseloads, then they ***choose to prioritise*** *audit activity against the competing demands on their time and audit activities are completed".*

Opposing theory:

"If individuals perceive audit to be a worthwhile activity and have busy caseloads, then they ***choose not to prioritise*** *audit activity against the competing demands on their time and audit activities aren't completed".*

Both rivalry and opposition allow the side-by-side comparison of theories. This exposes a deeper reality and increases objectivity by minimising attachment to singular theories[211]. Both approaches were used in this study to generate CPTs. This exercise increased the number of "*if…then*" statements but enabled the consideration of broader perspectives of causality.

Organisation

To support conceptualisation and enhance the clarity of causality, theories can be organised in different ways such as around an appropriate middle range theory or implementation chain[212]. CPTs in this study were organised using the adapted framework for audit illustrated in Figure 3-4.

Consolidation

Due to the large number of theories, on closer scrutiny many had overlapping claims or were stating the same claim. Those theories that overlapped or alluded to similar causal claims were consolidated, i.e. combined where possible to reduce the number of *"if…then*" statements. Care was taken not to remove important or unique articulations of causal claims[209].

Prioritisation

This process generated a large number of potential CPTs in the form of *"if…then*" statements, with varying articulations, level of granulation and degrees of clustering. Examples of these statements are included in Appendix 3-4. Two collaborators (RS and CL) were involved in discussions regarding the final prioritisation of five CPTs to take forwards. Decisions were made based on the perceived value to community stroke care, of further exploration.

It was challenging not to take more CPTs forwards at this point, as there were several that warranted further exploration. However, the decision-making process has been clearly detailed. Jagosh suggests this process develops "*theoretical sensitivity*" for the researcher, that may be useful in the later stages of the RE cycle[209].

3.9.3 Sense-checking and refinement

Five CPTs were presented to PhD supervisors and collaborators with expertise in audit and realist methodology (MJ, NC, SL, RF, ED and JH), for feedback and sense checking (see Appendix 3-5).

Although positive, feedback highlighted concerns that five theories may be too many to explore in depth within a PhD. The merits of attempting to include all five theories, in comparison to more detailed investigation of fewer were debated. Theories one to four were felt to be strongly interrelated as part of an explanatory causal chain. Minor changes were made to simplify the wording of theories. The fifth theory proposed that if stakeholders had the skills to scrutinise data, they would be more confident using it for quality improvement. It was agreed that as this had some potential crossover with other theories it should be omitted at this stage.

There was much discussion regarding the value in proposing theories that could be perceived as “*common sense*”. However, there are two important reasons for exploring these “*known-knowns*”. Firstly in an era of evidence-based medicine, if understanding remains tacit and is not published in peer-reviewed literature, it fails to provide leverage for clinical or strategic change[213]. Secondly in realist research, CPTs are not required to be comprehensive[208]. Neither should they be so tightly focussed that they are unable to benefit from further scrutiny. Instead, they are a starting point for exploration, a “cross on the ground” through which to dig deeper. The Realist researcher must be open to exploring what lies beneath. Excavation may point to different configurations of context, mechanism and outcome as well as revealing more granular details at different contextual levels such as individual, team or organisational. This process resulted in four CPTs articulated as “*if…then*” statements detailed in Table 3-7.

Table 3-7: Four CPTs, articulated as "If…then" statements

Context	Mechanism	Outcome
1. Individual perception of audit influences motivation to engage		
If individuals perceive audit to be a worthwhile activity	Then they are motivated by the potential benefits	Individuals will engage with the audit and access resources
2. If information regarding the audit is available, individuals are empowered to participate		
If the purpose and process of audit is explained and roles articulated	Then individuals have insight into what is expected of them and are empowered to participate	Individuals will complete the audit tasks appropriate for their role
3. If stakeholders have resources to support participation, data will be inputted completely		
If resources such as laptops are available to complete audit activities	Then individuals are enabled by the resources and motivated by the perceived value placed on the audit by their organisation	Data inputted will be complete
4. If data is perceived as accurate then it will be used to inform quality improvement		
If data contained in feedback report is perceived as accurate	Then the report will be perceived as trustworthy, and individuals will have the confidence to act upon it	Audit feedback is used to inform quality improvement

3.10 Chapter summary

This chapter has outlined stage one of the RE cycle. A scoping review exploring contextual features that influence the contribution of externally initiated, MDT clinical audits to quality improvement has been detailed and findings presented. Using findings from this review, clinical collaborators contributed to the development, contextualisation and prioritisation of broad CPTs to the setting of community stroke care. With the support of collaborators with expertise in audit and realist methods these were further refined, and four theories selected to take forwards. These theories seek to explore contribution of SSNAP to quality improvement in community stroke care.

The CPTs generated in this chapter are explored and refined using an online survey, detailed in the following chapter.

4 Investigating stakeholder experiences of SSNAP

Using a mixed-method online survey to develop Initial Programme Theories (IPTs).

4.1 Introduction

The role and impact of national audit on quality improvement in the community setting have yet to be established. The previous chapter has highlighted a gap in the literature regarding MDT audits conducted in the community. However, a number of contextual features were identified that influenced the ability of externally initiated MDT audits, such as SSNAP, to contribute to quality improvement in other healthcare settings. These included the perceived benefits of participating in an audit, the availability of information and resources to support participation and confidence in the accuracy of the data submitted to the audit. The influence of these features on the ability of SSNAP to contribute to quality improvement in the community setting warrant further exploration.

The four CPTs generated and described in Chapter 3 were used as a framework with which to explore the influences of these contextual features on stakeholder experiences of SSNAP in the community.

4.1.1 Aim

The aim of this chapter was to gain an understanding of the following question:

What are stakeholders' experiences of using SSNAP in the community setting?

4.1.2 Objectives

1. To investigate stakeholder experiences of engagement with SSNAP.

2. To investigate stakeholder experiences of participating in SSNAP.

3. To investigate stakeholder experiences of using SSNAP feedback for quality improvement.

4. To use findings to refine CPTs and develop IPTs for testing in the next chapter.

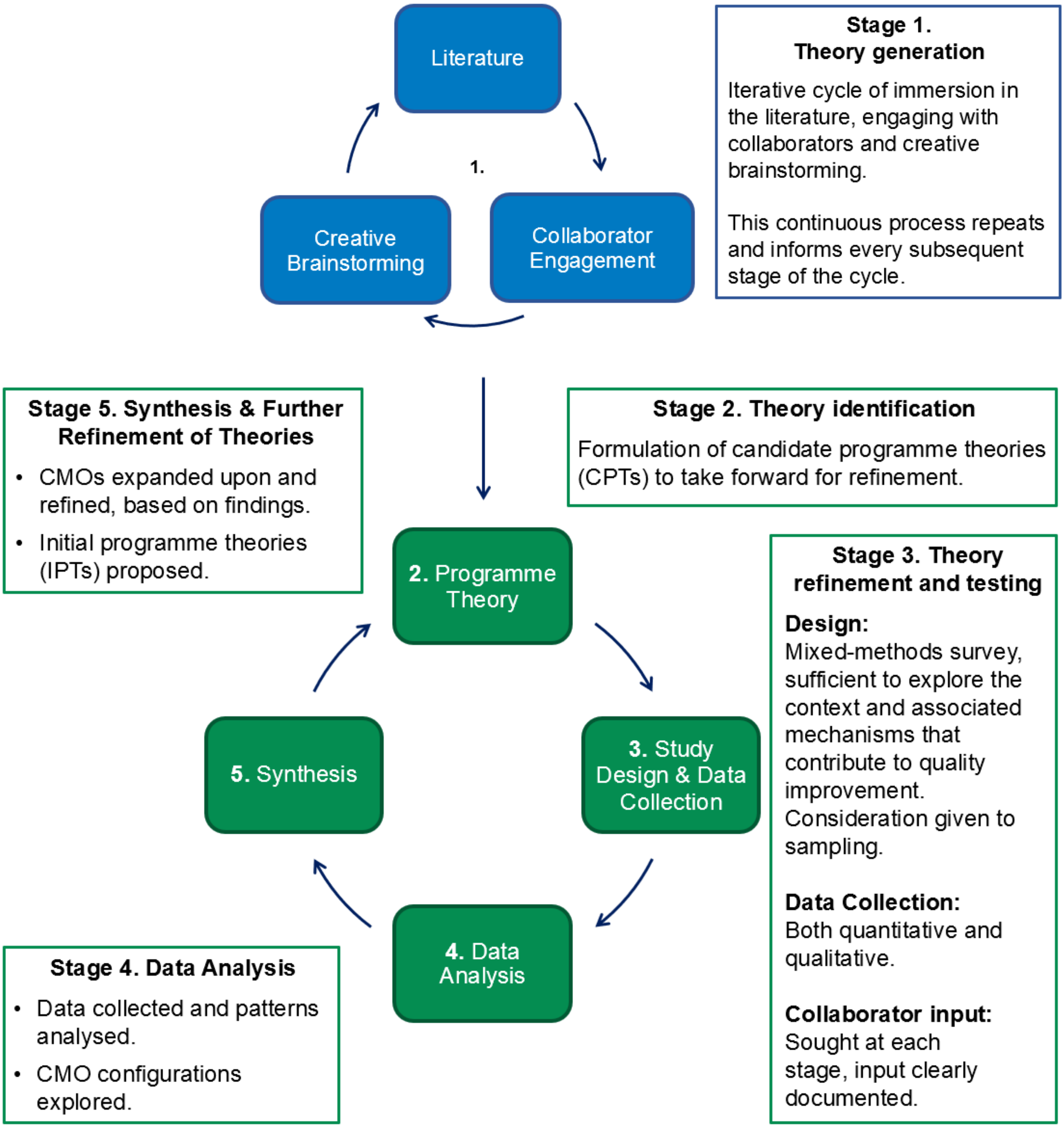
For the purpose of this study, stakeholders were defined as anyone working in, leading or commissioning a community stroke rehabilitation service that contributed to SSNAP. The activities undertaken by stakeholders may vary based on their role, for example Administrators and Rehabilitation Support Workers are more likely to be involved in data collection, whereas Managers and Commissioners are more likely to use audit feedback to inform service planning. This may vary between teams.

4.2 Methods

4.2.1 Methodological framework

This study adopted a realist approach, appropriate for the evaluation of complex interventions such as audit [16,120] and was informed by established quality criteria[138]. RE seeks to develop, refine and test programme theories that explain "*what works, for whom, under what circumstances and how*?"[138]. Programme theories consist of context, mechanism and outcome (CMO) configurations. These form a hypothesis regarding how a specific contextual feature, or combinations of features may influence the outcomes of interest, via an underlying mechanism[120]. Definitions are provided in Chapter 2. In this study the contextual features and mechanisms that influenced stakeholder experiences of using SSNAP in the community setting were explored. This included factors that shaped their engagement, participation and use of audit feedback for quality improvement.

CPTs were informed by a scoping review of the literature described in Chapter 3, these are detailed in Table 3-7. Although studies identified by the review were predominantly hospital or clinic based, findings provided a platform from which to explore the community context. These were prioritised and nuanced to the setting of community stroke rehabilitation through collaborator discussions. This process formed stage one of the realist evaluation cycle, as illustrated in blue in Figure 4-1.



Stage 1.
Theory generation

Iterative cycle of immersion in the literature, engaging with collaborators and creative brainstorming.

This continuous process repeats and informs every subsequent stage of the cycle.

Stage 2. Theory identification

Formulation of candidate programme theories (CPTs) to take forward for refinement.

Stage 3. Theory refinement and testing

Design: Mixed-methods survey, sufficient to explore the context and associated mechanisms that contribute to quality improvement. Consideration given to sampling.

Data Collection: Both quantitative and qualitative.

Collaborator input: Sought at each stage, input clearly documented.

Stage 4. Data Analysis

- Data collected and patterns analysed.
- CMO configurations explored.

Stage 5. Synthesis & Further Refinement of Theories

- CMOs expanded upon and refined, based on findings.
- Initial programme theories (IPTs) proposed.

Figure 4-1: The Realist Evaluation Cycle

This chapter describes the use of a mixed-methods online survey for the first cycle of stages 2-5 of the realist evaluation cycle as illustrated in green in Figure 4-1. Consistent with realist approaches, this phase of study used a mixed-method, explanatory design to explore theories in greater depth[214]. An online survey was chosen to access a national sample of stakeholders. This captured the perspectives of a broad range of individuals in different roles, regarding their experiences of the audit. The anonymous nature of online surveys provided opportunities for candid feedback, uninhibited by the presence of a researcher.

Prior to 2017 the use of surveys in RE was relatively unheard of. A mapping review by Renmans and Pleguezuelo published in 2023 identified a number of more recent studies where surveys had been used as part of RE.[132] In the majority of studies, surveys took the form of validated tools for the purpose of categorising contextual features[215], identifying outcomes[216] or describing beliefs that may point to underlying mechanisms[217] . Studies collected predominantly quantitative data which was analysed statistically. Debate exists regarding the manner by, and extent to which, surveys may inform the development of programme theory[218]. However, Renmans and Pleguezuelo propose that innovative methods are required for RE, including the development of realist surveys in order to strengthen RE practice and outcomes[132].

This survey collected both quantitative data regarding context and outcomes as well as qualitative free text opportunities for elucidation or expansion. The Good Reporting of a Mixed Methods Study (GRAMMS) Framework was adhered to[219]. Firstly, the entire quantitative results and qualitative findings are detailed separately. Narrative integration occurred subsequently at the interpretation and reporting level. For each CPT in turn, the relevant quantitative results are presented, followed by the qualitative findings that expand or illuminate further[220]. The intention of this mixed methods approach was to generate a more complete understanding than would be possible from quantitative or qualitative findings alone[221].

As described in Chapter 2, collaborator engagement is fundamental to RE[123,144]. Collaborator meetings were completed virtually, either individually or in groups of two or three, their contributions are detailed at the relevant point in the chapter. Ethical approval for this study was granted by the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS 387-1021) (see Appendix 4-1). All data were collected, and all methods carried out in accordance with relevant guidelines and regulations. Informed consent was obtained from all participants prior to completing the survey.

4.2.2 Survey design

The survey was developed in three stages, firstly the content of items, secondly the logic of the tool and finally piloting and refinement. This resulted in 18 survey items which are summarised in Table 4-2. The survey was designed and reported in line with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES)[222] (see Appendix 4-2).

1. Content development

Attempts were made to articulate components of the proposed context, mechanism and outcome for each CPT as survey items. In survey research, it is recommended that measurements and questions be informed by those whose social world is the subject of investigation[223]. Therefore, feedback from collaborators (RS, CL, KB and JH) informed the choice of language, format and underpinning conceptualisation of each item. Through discussion with collaborators it was agreed that not all components of programme theory could be explored fully using survey methodology. Mechanisms were more challenging to articulate, as they often explore behaviours which are difficult to quantify. This is where free text options were used, for example asking for details regarding participation or barriers to participation. An example is included in the Table 4-1 below. This resulted in 18 survey items (see Table 4-2).

Table 4-1: Example of context, mechanism and outcome articulation

CMO Configuration	Articulated as survey item
Context The purpose and process of audit is explained, and roles / expectations articulated	- I understand the purpose of the audit - I understand what my role is in the audit - I understand the activities I need to complete - I understand how to complete the required activities (5-point Likert response options)
Mechanism Individuals are empowered to participate by having an understanding of audit and insight into what is expected	If you are unable to fully complete the audit tasks required for your role, please explain why (*Free text response)
Outcome Stakeholders will complete audit tasks appropriate for their role	Indicate from list which audit activities you undertake (Options include “other”) Are you able to fully complete audit activities required for your role? (Yes or no response options)

Where possible, existing literature such as research findings or guideline documents provided a structure from which to develop survey items. For example, Item-4 explores individual understanding of the audit process. This specific item comprises ten statements, proposed by HQIP to conceptualise the four stages of the audit process[15]. Item-6 explores the audit activities undertaken as part of a participant's role. Based on the activities identified in the ten HQIP statements, these were adapted to the context of post-acute stroke care and expanded by collaborator feedback.

Work by Taylor et al. used surveys to explore how outputs from national clinical audits are utilised and findings from this study were used to inform several items[23]. For example, the study identified a lack of resources as a barrier to participation. With feedback from collaborators, "resource" was sub-divided into three distinct components for exploration in Item-7: training, equipment and time. Taylor et al. also highlighted a number of purposes that audit findings were used for[23]. These were supplemented with additional purposes identified in the wider literature before being adapted to the context of post-acute stroke care and divided into what collaborators perceived to be *passive* and *active* uses. Item-15 explores what the collaborators described as *passive* uses, namely comparison and benchmarking, and Item-16 explores the *active* use of data in planning service development.

2. Logic and format development

Following discussion with collaborators (MJ, NC, SL and RF), all items in the survey were mandated, meaning that participants would be unable to progress to the next item without providing a response. It was agreed that the risk of a lower response rate was outweighed by the benefits of complete datasets. In addition, consideration was given to the advantages and disadvantages of using survey items specific to respondent's role. Although possible using internal survey logic, this would potentially result in a fragmented dataset, with some items having few responses. Instead, consideration was given to the wording of each item, in order for it to applicable and understandable by all stakeholders. A combination of categorical, free text, yes / no and five-point Likert scale response formats were utilised. Choices were informed by both the existing literature as detailed and conversations with collaborators.

Categorical items were used to provide context, such as the ISDN a participant worked in. Categories were also used to establish the roles of participants, the audit activities undertaken by them and how feedback reports were shared and utilised within their organisation. Free text options were specifically included for participants to expand upon yes / no answers, provide greater detail and offer examples if appropriate. Free text boxes were triggered in response to participants selecting "other" from a list of categories. For example, Item-10 prompts participants to select resources that they use to support audit activity, if they select "other" then they are prompted to offer details. Likert scales were utilised to explore participant perceptions of the audit, establishing their agreement with a number of statements. Five categories of "*agree completely, agree partially, neither agree or disagree, disagree partially* and *disagree completely*" were used. The use of named categories such as these has been found to provide acceptable levels of reliability and be user-friendly[224].

3. Piloting and refinement

The survey was piloted, using different audiences for specific purposes. Family and friends provided feedback regarding the logic, coherence and functional utility of the tool. Clinical colleagues and collaborators with audit experience (RF, MJ, NC, JH and RS) provided feedback on the clarity and technical content.

Initially there were thirty-seven items in the survey and most of the early feedback related to the length and perceived repetition of items. Therefore, consideration was given to the organisation, clustering and amalgamation of items to aid clarity. Much of this was achieved by grouping associated items together and increasing the use of Likert scales. This also satisfied clinical colleagues who felt items required a greater number of responses options than yes or no alone. Other changes made in response to feedback included the wording of items and the use of examples to aid clarity. The National Institute for Health and Care Research (NIHR) proposes that public involvement underpins research excellence[225]. Therefore, the engagement of the Nottingham Stroke Research Partnership Group (NSRPG) was sought from the outset. Feedback from early engagement informed the wording of a number of survey items, reducing the perceived use of jargon.

*Table 4-2: Summary of survey items (*free text opportunity)*

Item	Topic	Response option
2	Role	Categorical (Single response option)
3	ISDN (region)	Categorical (Single response option)
4	Understanding of audit process (10 sub-items)	5-point Likert scales
5	Understanding of role (4 sub-items)	5-point Likert scales
6*	Activities undertaken as part of role	Categorical (Potential multiple responses)
7*	Resource availability (3 sub-items)	5-point Likert scales
8*	Participant able to fully complete activities	Yes / No
9	Perceived benefit of participation (4 sub-items)	5-point Likert scale
10*	Resources used to support participation	Categorical (Potential multiple responses)
11*	Perceptions of data collected (3 sub-items)	5-point Likert scale
12*	Should SSNAP collect additional metrics	Yes / No
13	Is information from audit feedback report shared?	Yes / No / Don’t know
13a*	In what situations? (select)	Categorical (Potential multiple responses)
14	Does respondent receive feedback?	Yes / No
14a*	Main source of feedback	Categorical (Single response option)
14b	Confidence in interpreting the report	5-point Likert scale
14c*	Feedback frequency	Categorical (Single response option)
14cii	Is frequency appropriate? (Y /N too often /N not often)	Categorical (Single response option)
14d	Audit feedback report accuracy (4 sub-items)	5-point Likert scale
15	Is SSNAP used for comparison purposes?	Yes / No / Don’t know
15a*	Purpose of comparison	Categorical (Potential multiple responses)
16	Is SSNAP used for service development?	Yes / No / Don’t know
16a*	Purpose of service development	Categorical (Potential multiple responses)
17*	Any additional quality improvement use	Yes / No
18*	Any additional comments	Free text only

4.2.3 Sampling and recruitment

Between 01.12.2021 and 01.04.2022, an advert was circulated via social media and professional networks (see Appendix 4-3). Individuals who worked in, managed or commissioned a community stroke rehabilitation team collecting SSNAP data were invited to participate. Online surveys require basic digital literacy and access to a device such as a computer or android telephone[226] which was deemed achievable for potential participants. A participant information sheet and contact details were available on the first page of the survey (see Appendix 4-4), followed by participant consent which was mandatory for participation. Consistent with RE, representation was sought from diverse stakeholders in terms of role and geographical region. The survey was open for four months, during which time it was possible to see the response rates by both region and role, which enabled focused targeting of adverts and prompts via social media and established clinical networks.

Participant numbers were expected to vary between categories reflecting the number of individuals in these roles e.g. there are more clinicians employed within community stroke than commissioners. This is commensurate with RE as the purpose of sampling is to illuminate different facets of the intervention[133] rather than seek statistical significance. Participants accessed the survey via a secure link in the advert. The online platform (Jisc Online surveys™) stored participant responses. Once the survey had closed, quantitative data were exported to a Microsoft Excel™ file and qualitative data were exported to NVivo™ software for organisation and to assist in data management.

4.2.4 Data analysis

This study used a sample of convenience, as described previously and the response rate, as a proportion of the potential workforce was therefore expected to be low. As the study was informed by realist methodology, the aim was to gain causal insights from diverse stakeholders rather than make statistical inferences. An aspiration target was set for 150 participants, with representation from each of the categories of roles across the post-acute audit pathway and at least 50% of the ISDNs in England.

For quantitative data, descriptive statistics were used to illustrate participant responses. For the purpose of the narrative reporting, agreement was defined as an aggregation of "*agree completely" and "agree partially"* responses. For transparency, all responses (including neutral) were illustrated. Following this, analysis of qualitative data from free text responses followed an iterative process of realist theory refinement as proposed by Dalkin et al.[227]. Although undertaken primarily by a single researcher (LR) to enhance rigour, excerpts of raw data, early coding, integration and theory refinement were discussed with collaborators (RS, JH, MJ, RF, NC and SL). Both quantitative and qualitative data were exported into NVivo™ software to support the following process:

Theory development

A single node was created for each CPT generated by the preliminary scoping review. These were given summative titles, for example "Perceptions of audit influences engagement". A linked memo was created for each node, containing a more detailed description of the CPT. This memo was used to document any changes or refinements made to the CPT. No text was deleted from memos, instead the strikethrough font was used to ensure changes could be tracked and there was transparency in decisions made. Where causal insights were identified that did not fit into existing nodes, additional nodes were created.

Coding

Quantitative data was coded to relevant categories. In order to become familiar with qualitative data, prior to coding all free text responses were read and re-read, resisting the urge to begin analysis until fully immersed in the data[140]. Survey items were constructed to explore components of the CPTs and free text answers in surveys were generally brief, extending to a couple of sentences at most. Consequently the presence of whole context, mechanism and outcome interactions were unlikely. Instead, a process of "configuring" was used to assemble aspects of these interactions from one or more participants, to form a causal picture[228]. Export coding was predominantly used due to the succinct and often blunt responses provided, extracting direct sections or single words from the text[229]. Consistent with realist methodology, both an inductive and deductive approach to analysis was taken[138]. The deductive framework was provided by the programme theories whilst analysis was open to new inductive insights from the data.

Theory refinement

Refinement occurred in the presence of sufficient data to challenge or expand upon theories and was tracked using linked memos as described. Where insufficient data existed to support or challenge components of a theory, this was identified as "unsubstantiated"[227]. The resulting theories were collated and further refined in light of any similarities or overlaps identified[128]. Gilmore et al. propose this process of "tidying up" ensures that only those theories with greatest explanatory power are taken forward, resulting in greater clarity[128]. Final refinements were made with input from collaborators who offered critical reflection on the articulation, clarity and logic of theories (RS, JH, MJ, RF, NC and SL).

The intent of using a mixed methods, explanatory design was to allow the opportunity to explore constructs in more depth[214]. Integration involved analysis of quantitative findings prior to qualitative with the intention of generating a more complete understanding than would be possible from quantitative or qualitative findings alone[221].

The following section has three components. Firstly, quantitative results are presented using descriptive statistics to provide a narrative. Secondly, qualitative findings are detailed separately, these are presented thematically. For each CPT in turn, the relevant quantitative results are presented, followed by the qualitative findings that expand or illuminate further. The process of CPT refinement is detailed.

4.3 Results

4.3.1 Quantitative results

The following section summarises the quantitative survey findings. Between 01.12.2021 and 01.04.2022 there were 206 responses to the online survey.

Participants

Individuals responded from across the post-acute audit pathway from administrative support through to commissioning. The majority of respondents were either members of the MDT Band five and above, or Team Leaders with a clinical role. Figure 4-2 illustrates distribution of participant role.

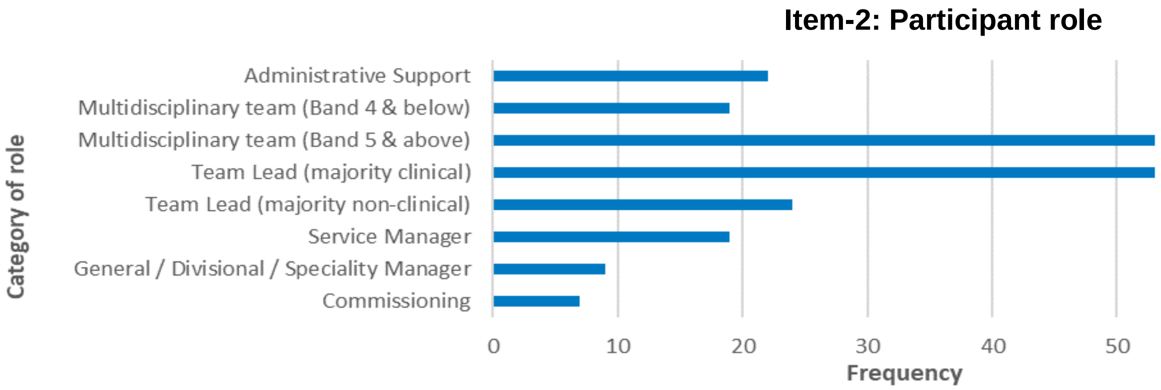


Figure 4-2: Graph illustrating distribution of participants by category of role

Representation was achieved from all 20 ISDNs in England (Figure 4-3). Two ISDN regions had higher numbers of responses, the East Midlands and London, with the remaining ISDN regions having between 2% and 7% of responses each.

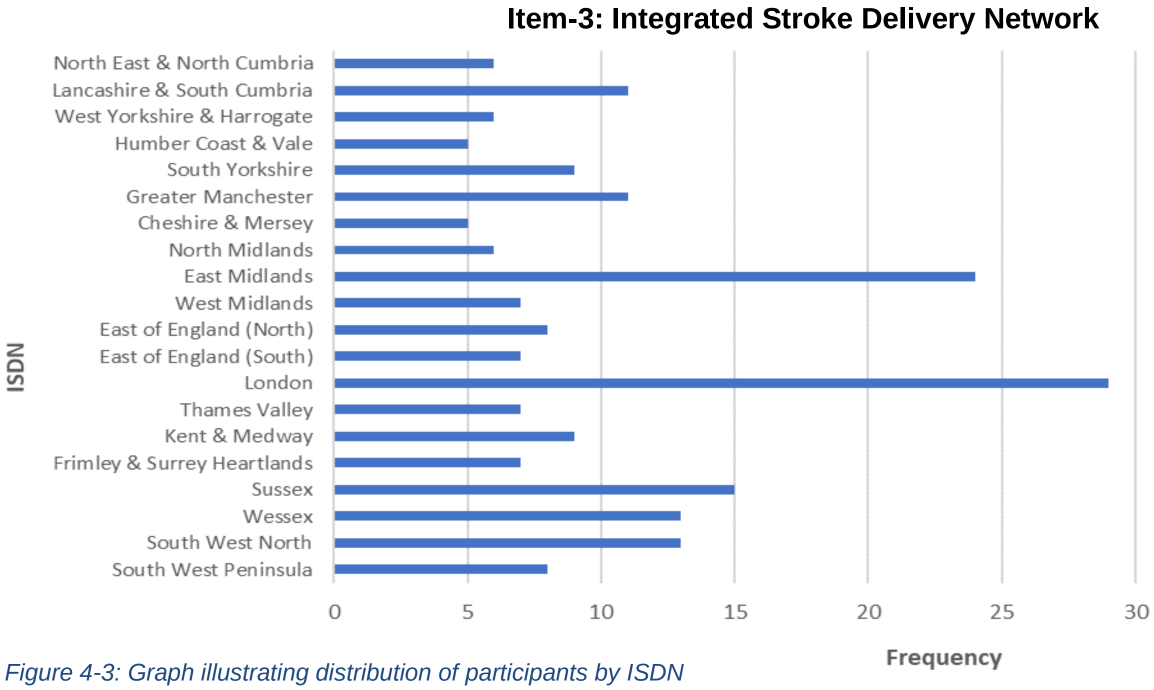


Figure 4-3: Graph illustrating distribution of participants by ISDN

Participation

Participants were asked to indicate from a list, the audit activities they undertook as part of their role. The most frequently indicated response was “Data collection” and the least frequent was “Sharing SSNAP data outside my organisation”. Those who selected “Other” gave examples of compiling reports for distribution within their organisation. Participants could select more than one response. The distribution of responses is illustrated in Figure 4-4.

Item-6: What audit activities do you undertake as part of your role?

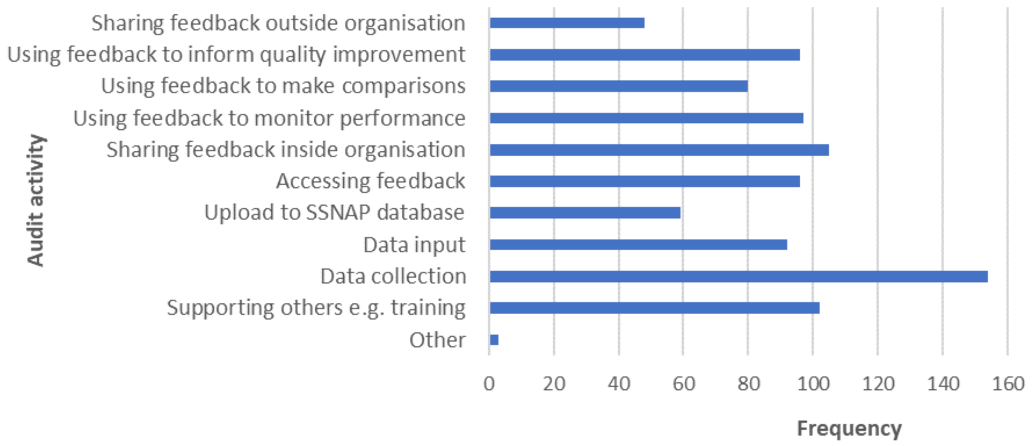


Figure 4-4: Graph illustrating reported audit activities

Participants were asked to indicate from a list, the resources they used to support their participation in the audit; they could choose more than one response. The most frequent was “Local knowledge within my team” and the least utilised resource was reported as “SSNAP YouTube”. The distribution of responses is illustrated in Figure 4-5.

Item-10: Do you use any of these resources to support your audit activity?

Figure 4-5: Graph illustrating reported resources used

Five-point Likert scales were used to establish agreement with a number of statements. Response options were consistent for all items and are listed below each graph for reference. For the purposes of narrative descriptions, those indicating complete or partial agreement are aggregated and reported as agreement with the statement.

Participants were asked to indicate their agreement with three statements regarding the sufficiency of equipment, time and training resources available to support their participation in SSNAP. Responses are illustrated in Figure 4-6. The majority of participants (91%) felt they had the equipment needed to support their participation in the audit. However, whilst 56% agreed they had sufficient training for their role, only 32% agreed they had enough time in their working day to complete the audit activities required in their role. As part of Item-7, participants were asked about their ability to prioritise audit activities, 48% agreed they were able to when needed.

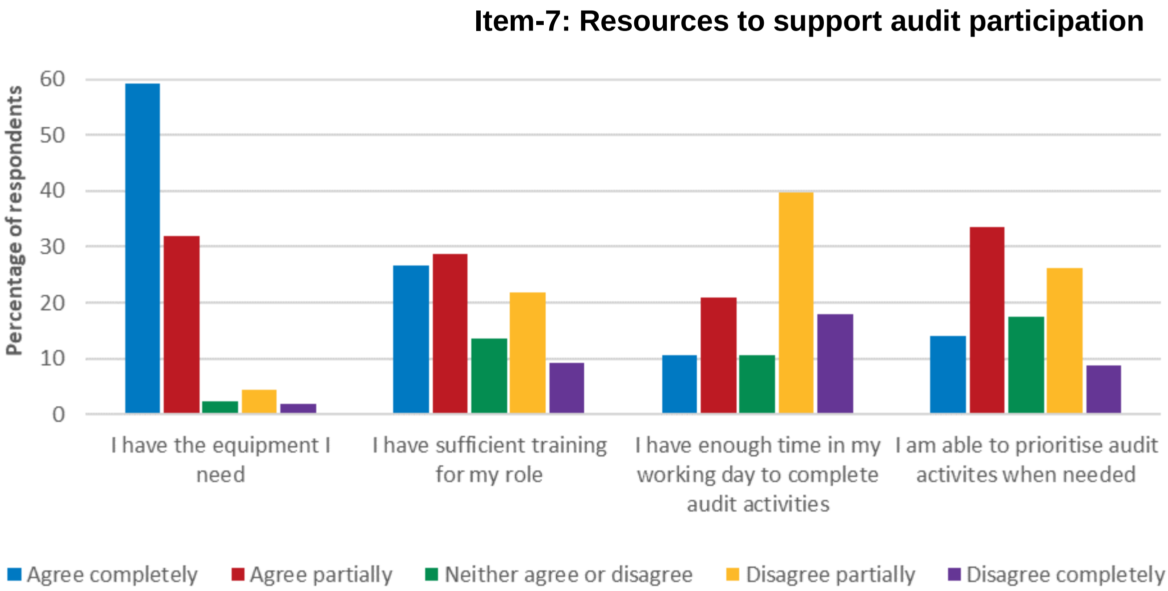


Figure 4-6: Graph illustrating agreement with statements (resources)

Regardless of resource availability, when participants were asked in Item-8 “Are you able to fully complete the audit activities for your role?” 69% confirmed they were (not illustrated).

In Item-9, 60% of participants agreed that SSNAP was a worthwhile use of their time, illustrated in Figure 4-7. In an attempt to understand the level at which the benefits were perceived, participants were asked specifically whether it benefitted their service, their patients and themselves. 57% agreed it benefitted their service, 54% agreed it benefitted their patients but only 33% felt it benefitted them personally or professionally.

Item-9: Perceived benefits of participation

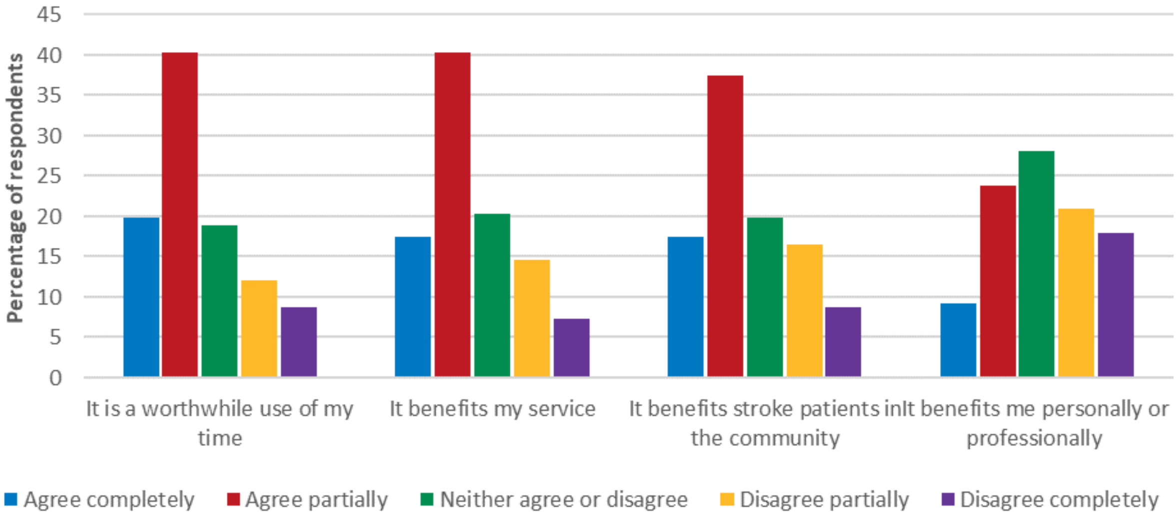


Figure 4-7: Graph illustrating agreement with statements (perceived benefit)

Understanding of the audit process

Item-4 explored individual understanding of the audit process. This item comprised ten statements, proposed by HQIP to conceptualise the four stages of the audit. Figure 4-8 illustrates reported agreement with the first five statements regarding the data collection components of the audit process. The majority of participants agreed they understood the purpose of audit, the evidence against which performance is measured, the data collected and how this is done.

Item-4a: Understanding of audit purpose and processes (Data collection)

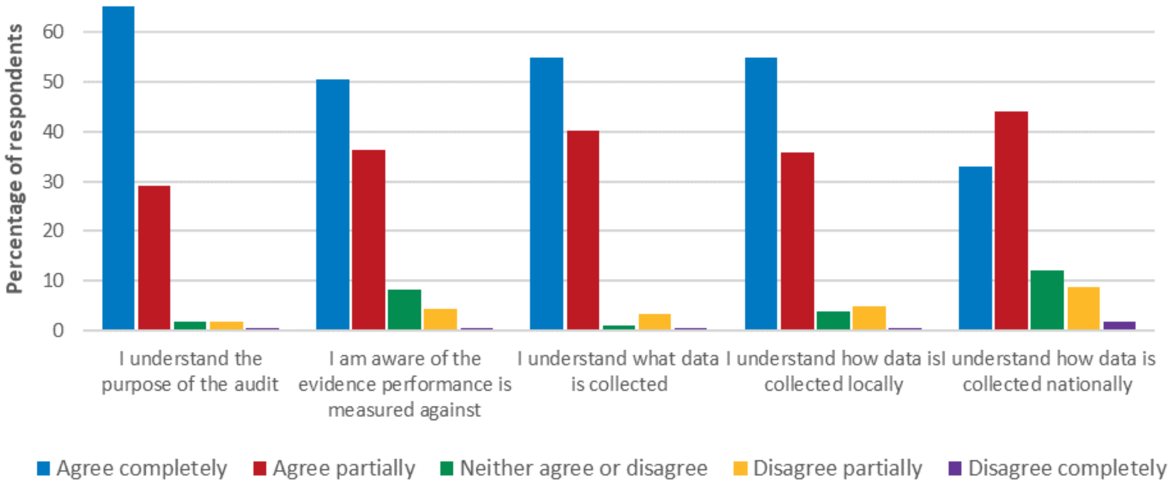


Figure 4-8: Graph illustrating agreement with statements (data collection)

However, participants reported less confidence when accessing, interpreting and using audit reports (as illustrated in Figure 4-9). When asked, 63% agreed they understood how to access reports, but fewer (55%) agreed they understood how to interpret reports. In addition, 57% agreed that they understood both how to use the report to inform service delivery, and how to share learning from the audit. Finally, 61% agreed that they understood how to embed audit into routine practice.

Item-4b: Understanding audit processes (Access and utility)

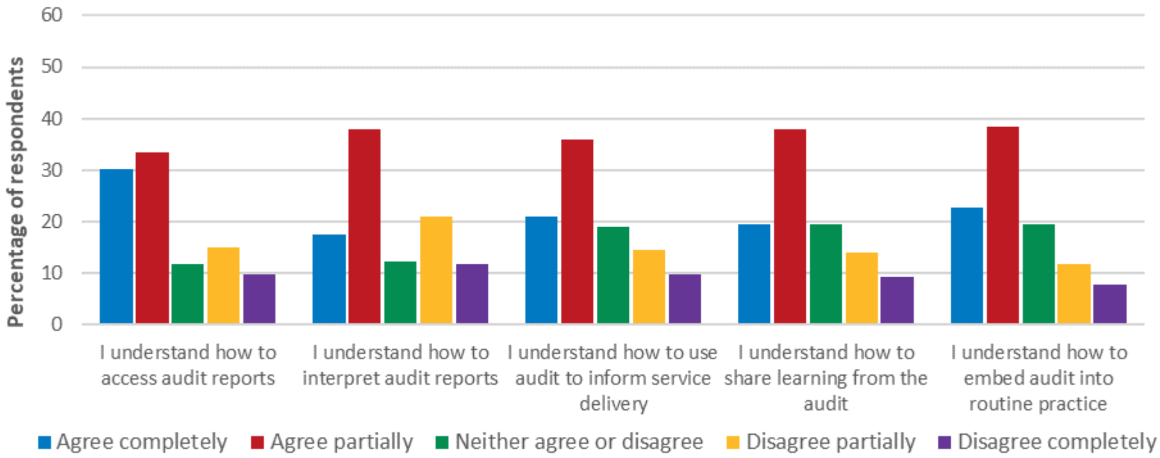


Figure 4-9: Graph illustrating agreement with statements (access and utility)

Figure 4-10 illustrates participants reported understanding of their individual role within the audit. The majority agreed that they understood their role (91%), the activities required of them (91%), how to complete these activities (88%) and where to seek support if needed (87%).

Item-5: Understanding of individual role in audit process

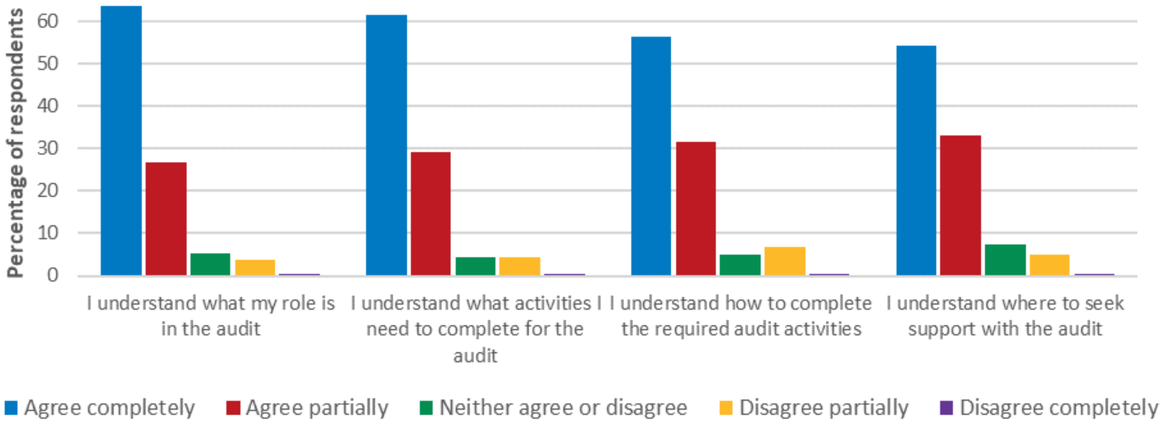


Figure 4-10: Graph illustrating agreement with statements (role)

Perceptions of data submitted to SSNAP

This section describes participant perceptions of the data inputted into SSNAP by their teams. When asked, just over half (55%) of participants agreed that data was complete for all stroke patients seen by their service. However, only 26% perceived the data submitted accurately reflected the rehabilitation delivered by their service. These are illustrated in Figure 4-11 below.

Item-11: Stakeholder perception of completeness and accuracy of data submitted

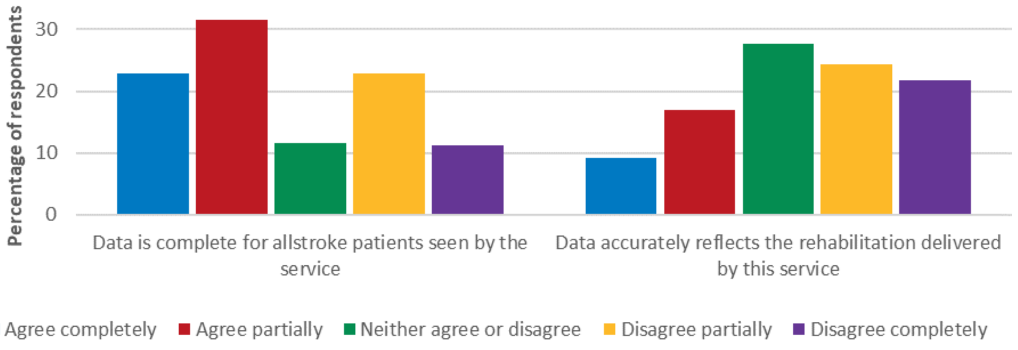


Figure 4-11: Graph illustrating agreement with statements (data submitted)

When asked in Item-12: "*Is there additional information you feel SSNAP should be collecting*?" 44% of participants stated yes (not illustrated). The free text responses are detailed in the qualitative findings.

Perceptions of SSNAP feedback report

The following section describes how the SSNAP report is perceived by participants. When asked, 71% of participants described having access to the report. Only 28% of these participants agreed the report accurately reflected changes made by their patients. Whilst 35% of these participants believed the report accurately reflects the rehabilitation delivered by their service, fewer (18%) believed it accurately reflects the rehabilitation provided by other services. These are illustrated in Figure 4-12.

Item-14d: Respondent perception of SSNAP report

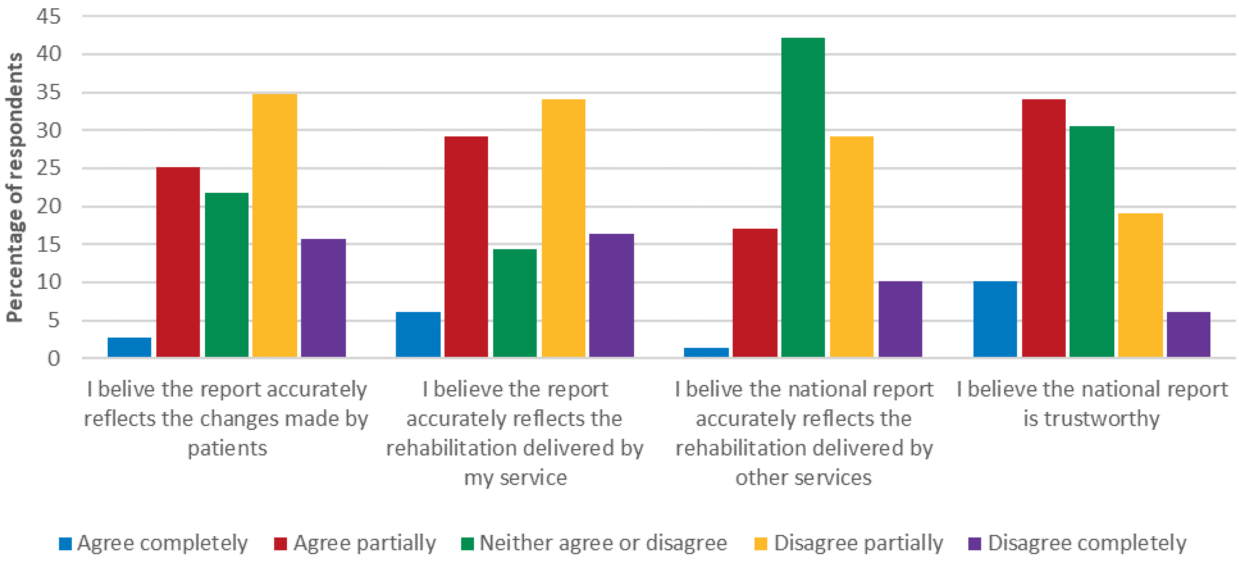


Figure 4-12: Graph illustrating agreement with statements (SSNAP report)

Despite the low number of participants agreeing they perceived the reports to accurately reflect the services delivered or patients served, 44% agreed they believed the report to be trustworthy. The largest proportion of neutral responses in the survey was reported for the perceived ability of the national report to reflect rehabilitation services offered by other services, as illustrated in figure 4-12.

Dissemination of SSNAP feedback report

This section reports the responses of the 71% of participants who stated they had the opportunity to access or receive information from the feedback reports. It describes their main source of information, where in their organisation this information is shared as well as their perceptions regarding the frequency of feedback and their confidence in interpreting it. Potential sources of clinical audit feedback were identified from the literature and participants were asked to identify which single source applied to them. The distribution of responses is illustrated in Figure 4-13.

Item-14a: What is your main source of information from the audit?

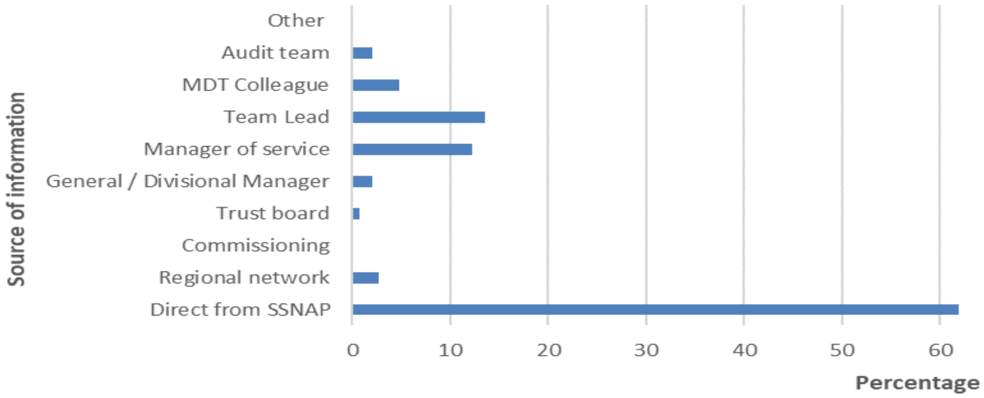


Figure 4-13: Graph illustrating distribution of sources of information

Participants were asked if they were aware of information from the audit feedback report being shared within their organisation, and if so in what situations this occurred. A variety of situations in which audit feedback is shared within healthcare organisations were identified from the literature. Participants could select more than one. Over half of participants (57%) were aware of information being shared within their organisation. The distribution of situations in which audit feedback was reported as shared or discussed is illustrated in Figure 4-14.

Item-13a: In what situation(s) is information from the SSNAP report shared?

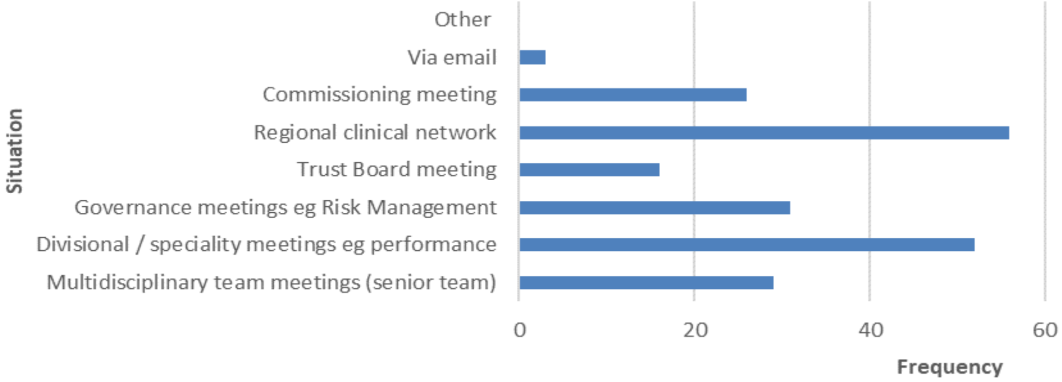


Figure 4-14: Graph illustrating situations where SSNAP report is shared

When asked in Item-14b, 56% of participants who had access to the report felt they had the skills to interpret it, as illustrated in Figure 4-15. Item-14c asked participants with access to the report to state whether its frequency was sufficient, too frequent or too infrequent. Just over half (55%) felt it to be too infrequent, 43% reported it to be sufficient and 3% reported it was too frequent (not illustrated).

Item-14b: Interpreting the report

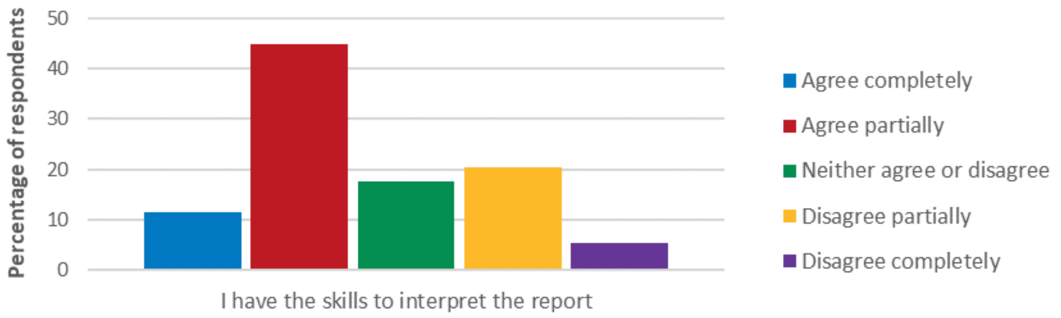


Figure 4-15: Graph illustrating agreement with statement (interpretation)

Use of SSNAP feedback report

This section describes the purposes participants reported using the report for within their organisation. When asked, 57% of participants reported that someone in their organisation used the feedback reports to make comparisons between services. Respondents were prompted to indicate the purpose of the comparison from a list, informed by the literature. More than one response could be selected. The distribution of responses is illustrated by Figure 4-16.

Item-15a: What was the purpose of comparison?

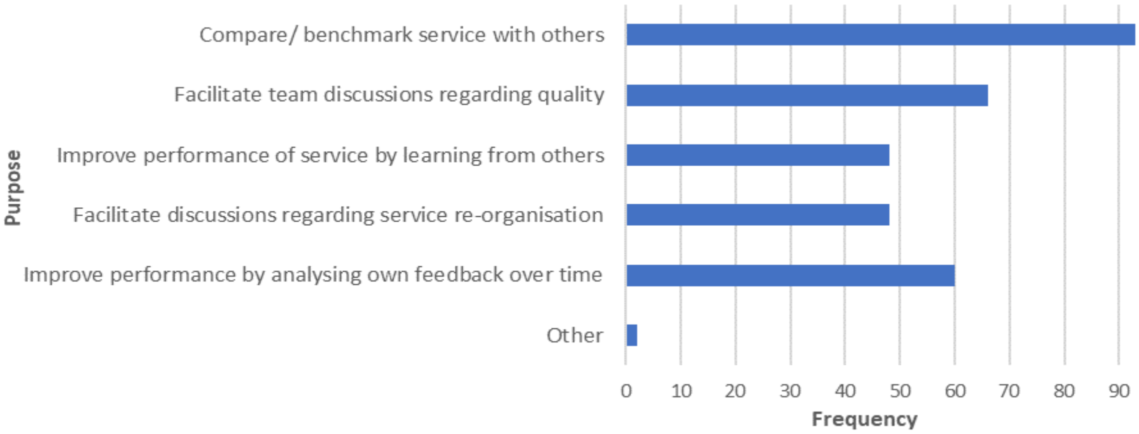


Figure 4-16: Graph illustrating purposes of comparison

Two participants indicated “other” and offered further details. In both of these instances the purpose of the comparison was to generate data regarding trends in their own service.

Participants were asked if they were aware of the feedback report being used to plan service development or improvement within their organisation, which 39% reported being aware of. Participants were asked to indicate the aims of these plans from a list informed by the literature; more than one could be selected. Figure 4-17 illustrates the results. For those indicating "other", reports were used for a combination of setting service improvement goals and generating reports for local dissemination.

Item-16: SSNAP feedback used in the planning of quality improvement

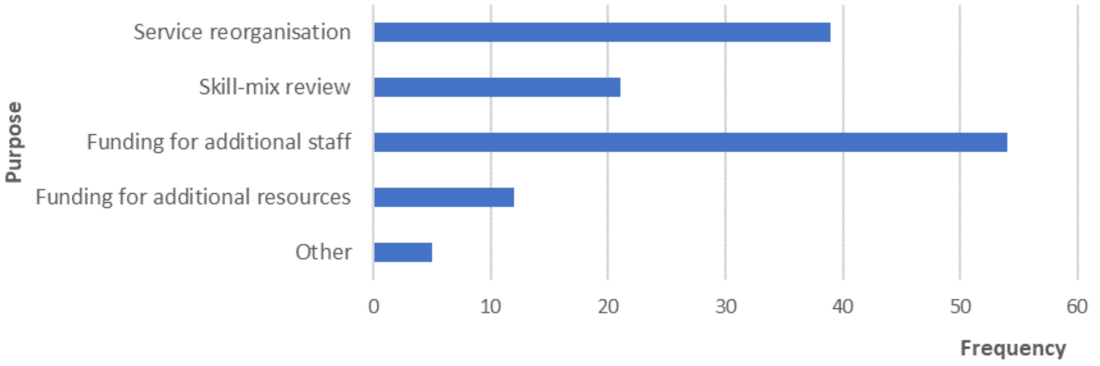


Figure 4-17: Graph illustrating purpose for which SSNAP used

Participants who reported using the audit feedback report for quality improvement, were asked to indicate whether they perceived this had been successful (yes or no options only). Figure 4-18 illustrates the proportion of respondents who perceived the resultant quality improvement plans to have been successfully actioned (green) or not (red).

Item-16a: Perceived success of quality improvements informed by SSNAP feedback

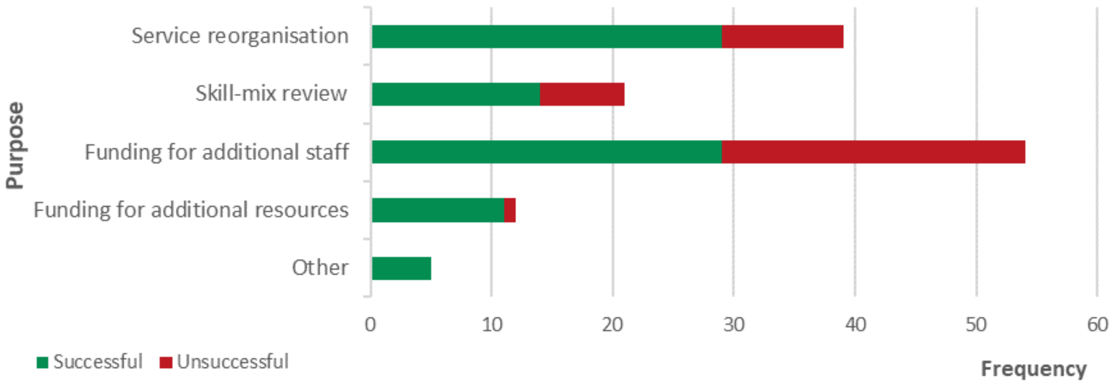


Figure 4-18: Graph illustrating perceived success of quality improvements

4.3.2 Qualitative findings

The following sections summarise the qualitative findings from free text responses. Findings fall into two broad categories, firstly the perceived barriers to engagement and participation in audit, and secondly perceptions of the audit feedback report. Participant roles are provided to offer context to quotes, using the following convention: **[Participant number: Role]**. Roles are listed in Table 4-3.

Table 4-3: Participant roles and abbreviations

Category of role	Role Abbreviation
Administrative Support	Admin
Multidisciplinary team (Band 4 & below)	MDT<5
Multidisciplinary team (Band 5 & above)	MDT5+
Team Lead (majority clinical)	Team Lead-C
Team Lead (majority non-clinical)	Team Lead-NC
Service Manager	Manager-S
General / Divisional / Speciality Manager	Manager-G
Commissioning	Commissioner

Perceived barriers to engagement and participation

Those participants who indicated they were unable to complete SSNAP activities were prompted to offer further explanation and identify the perceived barriers. Barriers described included negative past experiences of audit, a lack of dedicated time for the audit and challenges with the online platform. The following section provides a summary of these perceived barriers to engagement and participation in SSNAP.

a. Previous experience of audit

Previous experiences of audit were reported as influencing engagement with the audit process. Participants described the importance of experiencing change as a result of audit, particularly for clinical staff *“Clinicians need to see positive change …it’s no point collecting data and not taking it forward for service improvement. Otherwise, you do not get buy in”* **[P3:Team Lead-C]**. Participants who reported a “*lack of trust support*” for service improvement **[P29:MDT5+]**, described this a challenge when attempting to engage the wider teams in audit. *“It’s difficult to get motivated or motivate the team if we know there is no funding to make changes.”* **[P178:Team Lead-C]**. A perception of a “*lack of leadership support*” and “*organisational priorities lying elsewhere*” **[P153:MDT5+]** were also identified as challenges to engagement.

Experiences included how audit feedback was used within organisations, for example, who reviewed data and for what purpose. Where participants reported feedback as being jointly reviewed and with commissioners, there was a perception of services being “*more successful in getting change*”, therefore participants were motivated to engage by these potential benefits **[P3:Team Lead-C]**. In contrast, where participants had negative experiences of the manner in which feedback was used, this was reported as a barrier to future engagement. *“It can feel like the data and report is a stick to beat us by not an enabler for conversations and improvement”* **[P26:Team Lead-NC].**

b. Lack of dedicated time for audit

Participants reported an *“admin burden on teams*” **[P9:Manager-S]** created by the audit. This was commonly described as an additional, rather than core activity of the team. “*We do not have time to do our job let alone this”* **[P145:Team Lead-C].** As a result, clinical pressures were often reported as taking priority. *“When I’m busy patient discharge takes priority, and I can’t get as much audit done as I’d like*” **[P180:MDT<5].** However, these issues were not isolated to clinical participants; senior managers and commissioners also reported struggling to engage with audit when juggling responsibilities for a number of clinical areas. *“This is one of many areas I am responsible for I can't always ring fence time*” **[P196:Commissioner].** Managerial participants reported they were unable to commit time to familiarising themselves with audit feedback or the online platform. This was reported by one manager as resulting in them “*being unable to navigate the database effectively*” **[P72:Manager-S].**

Concerns were raised regarding the inappropriate use of resources where teams without administrative support were using clinical staff to input data. Data input was reported to fall to more senior clinicians who may be experienced in using the audit tool and accessing the platform, compared to junior or rotational staff. *"I am a high-level clinician inputting data as we do not have funding for admin support"* **[P123:Team Lead-C].** Participants described it being "*difficult to find time"* **[P195:MDT5+]** when teams are already working at capacity and "*patient discharge takes priority*" **[P53:Team Lead-C]**. One participant described SSNAP as "*an 'extra' job to do in a team that is already stretched*" **[P17:MDT5+]**.

c. Challenges with the online platform

Frustrations were expressed with *"incompatible IT systems*" **[P59:Admin].** Participants described inputting the same data multiple times, for local reporting systems as well as the SSNAP database. Questions were raised as to why platforms, such as Rio™ and SystmOne™ could not cross-populate with SSNAP to prevent what one participant described as *"wasted effort in duplicating tasks*" **[P109:Manager-S]**.

The perceived inflexibility of the SSNAP online platform was reported as generating additional work for those uploading records. Issues such as a reliance on the acute team to complete activities, limited response options and having to restart episodes if errors were made. Participants reported their frustration at being *"at the end of chain"* in terms of their *"dependence on the acute team to have completed their part"* **[P38:MDT<5]**. The act of *"chasing the acute teams to input their data"* was described as both frustrating and time consuming **[P204:Admin]**. There was particular dissatisfaction with a question regarding cognitive screening, where many participants highlighted the insufficiency of yes or no response options. "[The audit is] *so rigid in its requirements that it will not allow some questions to have 'not known' drop down choice*" **[P163:Team Lead-NC]**.

Frustrations were reported with regards to a perceived lack of agency surrounding the data participants input and records they contribute to. *"At the moment if you make an error, like the wrong date, you have to revoke it and do it from scratch again. It is time consuming. If you are allowed to submit you should be allowed to amend it"* **[P15:Admin]**.

Participants' perceptions of the audit feedback report

The following section describes participants' perceptions of the audit feedback report. This includes the completeness of data from which the report is generated, the metrics used to capture data, variations in audit practice and report utility.

a. Data completeness

Data submitted by teams was commonly described as incomplete, qualitative data highlighted a number of factors perceived to contribute to this. These included the challenges associated with the online platform *Unlocking and transferring records is such an arduous task…some patients just never get done"* **[P54:Admin]**.

Participants reported not having sufficient time or resources to "*complete as fully as we would like, so our reports are incomplete*" **[P72:Manager-S]**. The dependence on acute colleagues to transfer records was also reported to undermine data completeness resulting in *"the figures not* [being] *an accurate representation of the service"* **[P32:Team Lead-NC]**.

Discrepancies were highlighted between caseloads recorded on SSNAP and those receiving rehabilitation. For example, "*SSNAP does not acknowledge stroke where diagnosis was not recorded as first condition"* therefore this activity is not recorded **[P163:Team Lead-NC]**. Similarly, "*direct community referrals are not able to be added* [which] *does not enable us to accurately reflect what our team does*" **[P117:Team Lead-C]**.

The process of inputting six-month review data requires the ongoing rehabilitation episode to be completed and locked, despite many patients reportedly continuing with rehabilitation after this point. A number of participants expressed frustration at patients being "*artificially ended in SSNAP in order to complete the six-month"* **[P48:Team Lead-NC]**. As a consequence, participants reported the data "*fails to capture the entirety of a service"* **[P13:Team Lead-C]**.

b. Metrics

Alongside patient characteristics (age, sex comorbidities etc) the SSNAP post-acute audit collects information on therapy and nursing input (measured in minutes), discharge destination and the modified Rankin Scale (mRS) score. The mRS is a clinician assessed measure of functional independence. These metrics were described as failing "*to capture the full scope of a service provided to stroke patients*" **[P63:Team Lead-C]**. Several factors were reported to contribute such as the inability to record the full spectrum of professionals involved or interventions, which was perceived to generate a *“limited perspective of the team’s work”* **[P187:Team Lead-C].**

Participants described the report as failing *“to reflect the myriad of community commissioning models*” resulting in an inability to capture activity outside traditional models of rehabilitation **[P112:Manager-S]**. Concerns were highlighted that non-face to face activities were not recorded. *“It does not gather family support or non-patient facing tasks which are a significant amount of stroke rehab… does not reflect realities of service delivery”* **[P64:Manager-S]***.*

Participants reported a tension between a need to be patient focussed and a desire to be compliant with the audit. *“Patients are not always ready to set goals within the first visit ... If we delay and are patient directed with goals, it looks like we are not setting goals* **[P102:Team Lead-C]***.*

A perception that the “*main focus* [of SSNAP] *is a medical model and priority is acute services*” was described **[P112:Manager-S]**. This was reportedly underpinned by the relatively small number of metrics collected for the post-acute compared to the acute section of the audit as well as the relevance of some of the questions included.

“Community questions [are] *very much ‘tagged’ on e.g., ‘where was patient discharged to?’, is relevant when discharged from hospital, not when input has been in patient’s house!”* **[P1:Team Lead-NC]**

Participants reported the clinical measures used were *“not sensitive to this patient group, complexity or needs”* **[P85:Commissioner]**. The inclusion of the mRS was questioned; participants described it as *“not sensitive enough to measure specific functional gains for patients”* **[P148:Team Lead-C]** *or “show the real changes that teams make”* **[P170:MDT5+]**. Concerns were also raised regarding the inter-rater reliability of the mRS, specifically between the acute and community settings *as it “can be interpreted differently, so acute and community teams will have different views of ability”* **[P38:MDT<5]***.*

A variety of suggestions were made with regards to the additional data SSNAP should collect in the post-acute setting. These have been categorised as team activity, patient reported measures, patient need, vocational rehabilitation and carer support. See Table 4-4 for summary.

Table 4-4 Suggestions of metrics to be included in the audit

Team activity ‘*Non patient facing activities’* **[P169:MDT5+]** ‘*Video and telephone contact’* **[P64:Manager-S]** *‘Collaboration with ‘roles outside the traditionally therapy model’* **[P64:Manager-S]** ‘*Detailed reasons why mood and cog screens are not completed … clinical reasons rather than organisational’* **[P48:Team Lead-NC]** *‘Post 6-month intervention’ or as a minimum ‘record that the data has been artificially ended and acknowledge this’* **[P48:Team Lead-NC]**
Patient reported ‘*Patient-centred qualitative feedback’* **[P154:MDT5+]** ‘*PROMs / PREMs’* [Patient reported outcome measures/ Patient reported experience measures] **[P200:Commissioner]** *‘EQ5D would be a more holistic representation’* **[P194:Commissioner]** ‘*EQ5D at different points of journey to show change’* **[P206:Manager-S]**
Patient need ‘*Something that reflects the dependency or needs of these patients’* **[P203:Manager-S]** ‘*Carer input status should be on all section of discharge through the pathway’* **[P99:Team Lead-C]** *‘Self-management, proper self-management takes investment, we need to capture it’* **[P170:MDT5+]** *‘Unmet needs’* **[P130:Team Lead-C]** ‘*Rehab profile information- complexity/ levels of dependency’***[P21:Team Lead-C]**
Vocational rehabilitation ‘*Whether someone is working and what job they did’* **[P83:Manager-S]** ‘*Further information regarding higher lever patients return to pre-stroke leisure, vocational and social*’ **[P3:Team Lead-C]**
Carer support ‘*Specific metrics relating to carer support or burden’* **[P84:MDT5+]**

There was agreement that there should be a focus on “*quality-based outcomes rather than process-driven* [measures]” **[P161:Team Lead-C]**. In addition, proposals were made that comparisons should be made “*from community admission to discharge to truly reflect the outcomes of the patients rather than comparing discharge from acute and discharge from community*” **[P48:Team Lead-NC]**. It was proposed that “*more meaningful outcome measures should be adopted*” **[P157:Manager-S]**, but other than the EQ5D, specific measures were not detailed. A number of participants proposed that these measures “*should not be additional, but rather more relevant*” to patients in the post-acute setting **[P102:Team Lead-C]**.

c. Variation in audit practice

Concerns were raised by a number of participants regarding the impact of variations in audit practices on the perceived accuracy and subsequent utility of data inputted. The underlying cause of this perceived inaccuracy was depicted as being either unintentional or intentional.

Unintended variation was described as resulting from differences in how teams interpret aspects of the audit. Concerns were highlighted such as "*huge discrepancies between teams [in] how data is recorded, reported and interpreted*" **[P37:Team Lead-C]** which were perceived to make it "*difficult to benchmark with other trusts*" **[P53:Team Lead-C]**. These discrepancies were attributed to a lack of shared understanding regarding a variety of aspects, for example "*What does a seven-day service mean – full service, or assessment only? I'm not sure the same thing is always being measured across services*" **[P75:MDT5+]**.

However, several participants inferred that teams intentionally submit inaccurate data to improve their apparent performance. This varied from data *"manipulated to the advantage of teams"* where aspects were *"open to interpretation"* to suggestions of purposeful misrepresentation **[P71:Team Lead-NC]**.

"I suspect some teams and trusts use it to make themselves look good rather than to honestly record their intervention. This happens in small ways to tweak the data slightly to their advantage" **[P184:Team Lead-NC].**

More than one participant reported feeling under pressure from those in leadership positions, to misrepresent the performance of their services. *"It is difficult to resist senior managers wanting us to record data in a way which bends the truth slightly!"* **[P184:Team Lead-NC].** Participants did not state what motivated intentional misrepresentation. However external scrutiny, specifically with regards to the commissioning of services was alluded to as a potential factor. *"It makes me anxious if* [commissioners] *are going to use it for funding"* **[P1:Team Lead-NC]**.

Although only a minority of participants stated they intentionally submitted inaccurate data, many speculated that this was commonplace elsewhere. In addition to contributing to a lack of confidence in the "*conclusions you can draw from the report"* **[P196:Commissioner]** these discrepancies were also reported to impact on the morale of teams. *"If we feel it gives a less than favourable reflection of us – then how are those teams getting away with it. It's demotivating for staff"* **[P35:Team Lead-NC]**.

d. Report utility

Despite the reported limitations, many participants described how audit feedback reports were used within their organisation for service improvement purposes. Examples included the "*establishment of ESD* [Early Supported Discharge] *services*" **[P165:Manager-G]** and "*extending 5 to 7 day* [service]" **[P196:Commissioner]**. However, participants identified a number of barriers, which they perceived limited the utility of the report. These include the ease of accessing and interpreting data within the report, the organisational support available, how it is perceived by stakeholders and the timeliness of the report.

Participants described challenges in scrutinising feedback reports. For example, stating they "*cannot interpret the community reports"* **[P105:Manager-S]** describing them as "*clunky*" and salient details being "*inaccessible to lay* [people]" **[P:96Team Lead-C]**. These challenges were suggested by one participant as a barrier to the wider dissemination of the report. *"I feel more support in interpreting the results would be useful, as I wonder if this is one of the barriers to why our trust doesn't disseminate the results"* **[P147:MDT5+]**.

The acute and post-acute audits were contrasted by many participants, highlighting the greater detail and the use of an A to E rating system to indicate performance both present in the acute component of the audit. *"Data is less specific than acute services reports which makes it difficult to use for service development in the way we do for acute services"* **[P25:Team Lead-NC]**. These differences were perceived to reduce impact of the post-acute feedback report, resulting in difficulties gaining "*senior management buy-in to monitor against previous performance or other trusts"* **[P110:Team Lead-C]**.

For those participants who described report availability as too infrequent in the quantitative data, they highlighted this as a barrier to their utility as *"reports aren't helpful because they are so delayed"* **[P62:Admin]**. Concerns were raised regarding the potential impact of delayed reporting where "*data used for commissioners may not be accurate...but we won't know that for several months*" **[P1:Team Lead-NC]**.

4.3.3 Integration for theory refinement

The following sections are organised around the four CPTs in turn. For each CPT:

i. Quantitative results relevant to the CPT are summarised.

ii. Qualitative findings relevant to the CPT are presented to offer greater detail and illuminate perspectives provided by quantitative data. This process is summarised, and greater detail provided in Appendices 4-5 to 4-8.

iii. **(C)**, **(M)** and **(O)** are used to indicate findings related to context, mechanisms or outcomes that have informed theory refinement.

iv. Finally the CMO configurations for each refined CPT is presented figuratively as an IPT.

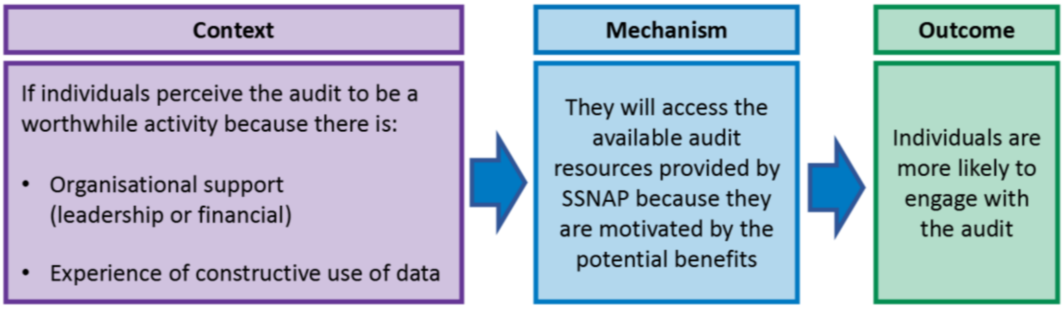
CPT-1: An individual's perception of audit influences their engagement

When asked, 60% of participants agreed that participating in the audit was a worthwhile use of their time **(C)**. All participants reported engaging in at least one audit activity as part of their role **(O)**. When asked about the perceived benefits of the audit, 58% agreed it benefitted their service and 55% agreed it benefitted their patients. 86% of participants accessed resources to support their engagement in audit e.g. SSNAP webinars or newsletters **(M)**.

Qualitative data identified contextual features that influenced perceptions of the audit being a worthwhile activity **(C)**. These included experiences of feedback being used critically *"It can feel like the data and report is a stick to beat us by not an enabler for conversations and improvement."* **[P26:Team Lead-NC]**, as well not experiencing change following engagement with audit.

Participants reported they experienced a lack of support to act on audit findings, both leadership and financial **(C)**. The perceived lack of leadership support to act on audit findings in the community was described as resulting from "*organisational priorities lying elsewhere* [acute services]" **[P153:MDT5+]** **(C)**. Participants described these experiences as reducing motivation towards **(M)**, and ultimately reducing engagement with audit activities **(O)**. *"It's difficult to get motivated or motivate the team if we know there is no funding to make changes."* **[P178:Team Lead-C]**.

These qualitative findings support the refinement of the proposed context, offering a deeper understanding of the contextual features that contribute to a perception of the audit being a worthwhile activity. The IPT1 is illustrated in Figure 4-19.



If individuals perceive the audit to be a worthwhile activity because there is:

- Organisational support (leadership or financial)
- Experience of constructive use of data

They will access the available audit resources provided by SSNAP because they are motivated by the potential benefits

Individuals are more likely to engage with the audit

Figure 4-19: IPT1 - Perceptions of audit influence engagement

CPT-2: If information regarding audit is available, individuals are enabled to participate

As highlighted earlier, 86% of participants reported they accessed resources to support their engagement in audit such as webinars or guidance documents **(C)**. The majority of participants agreed they understood the purpose of the audit (96%), the different processes involved (64-95%) and their role within it (90%) **(M)**.

Despite participants reporting insight into the audit, only 31% of participants agreed they were able to participate fully and complete the activities required for their role **(O)**. This suggested an additional contextual feature influenced audit participation. For those who reported being unable to complete audit activities, time was the most commonly cited barrier in free text responses. This was frequently reported for those with combined roles such as clinical and administrative or managing multiple clinical pathways **(C).** Less than half (48%) of participants reported they were able to prioritise audit tasks against competing demands **(M)**. *"When I'm busy patient discharge takes priority."* **[P180:MDT<5]** Participants with responsibilities for multiple services also described a lack of dedicated time for audit **(C)** as resulting in challenges prioritising audit activities **(M)**. *"This is one of many areas I am responsible for I can't always ring-fence time."* **[P196:Commissioner]** Audit was described as an additional activity to complete, rather than an acknowledged part of a core role. *"SSNAP is not a recognised (time given) part of my role, therefore it is in addition."* **[P32:Team Lead-NC]**

Findings support the proposed context-mechanism configuration whereby individuals gain insight into the audit as a result of accessing provider information. However, without audit being an acknowledged part of their role, individuals described challenges to participation. Therefore, recognising audit as part of an individual's role has been added as an additional contextual feature than enables participation. The IPT2 is illustrated in Figure 4-20.

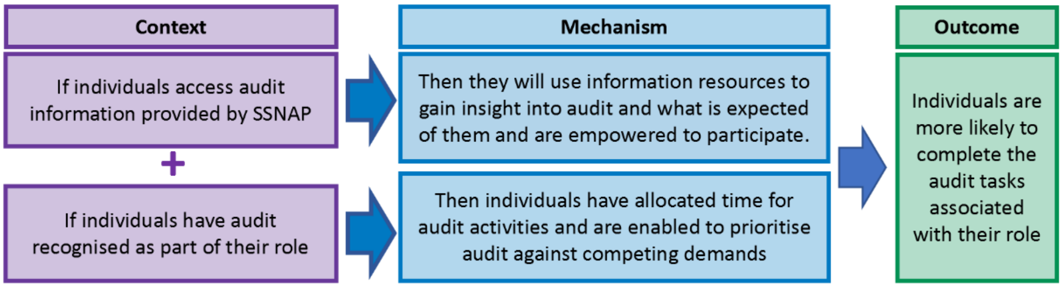


Figure 4-20: IPT2 - Influences on stakeholder participation

CPT-3: If equipment is available to support participation, data will be inputted completely and reflect the caseload

The majority of participants (91%) reported they had the equipment necessary to support their participation in the audit e.g. computers / tablet devices **(C)**. Despite this, just over half (54%) reported data to be complete for all stroke patients seen by their service **(O)**. Free text responses suggested that rather than the availability of physical resources such as computers, a context of challenges with the online platform were responsible for data being incomplete **(C)**. Therefore the context was refocused to explore this specifically.

Participants described challenges associated with this context such as "*incompatible IT systems*" **[P59:Admin] (C)**. A dependence on others to complete and lock records on the online platform **(C)**, which required "*a huge amount of time chasing the acute teams to input their data.*" **[P204:Admin]**

Findings suggested the challenges posed by the platform **(C)** can overwhelm individuals **(M)**, impeding their ability to submit complete data for all patients **(O)**. *"Transferring records is such an arduous task…some patients just never get done."* **[P54:Admin]** IPT 3 is illustrated in Figure 4-21. The outcome of interest has remained the same as the proposed CPT, however the context and associated mechanism have changed in light of survey findings.

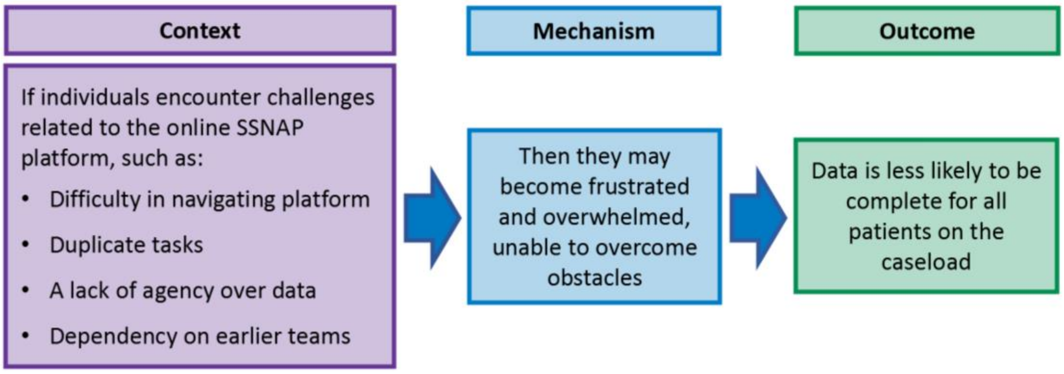


Figure 4-21: IPT3 - Challenges regarding the online platform

CPT-4: If data is perceived as accurate then it will be used to inform quality improvement

The audit feedback report consists of summative data and a portfolio of key performance indicators for teams that submit sufficient data. 71% of participants reported they accessed this feedback. 39% of all participants were aware of feedback being used to inform quality improvements within their organisation **(O)**. This included informing business cases for reviewing the skill mix of teams, funding for additional staff or resources.

When asked, only 28% of those with access to audit feedback perceived it accurately reflected the recovery made by patients and 35% agreed the report accurately reflected the service they delivered **(C)**. Only 18% of participants perceived the report accurately reflected the service delivered by other teams **(C).**

Of those participants with access to feedback, 44% agreed the report was trustworthy. Participants described their confidence in data accuracy as undermined **(C)** by mistrust regarding the reporting practices of other teams **(M)**. Concerns were raised regarding *“huge discrepancies between teams in how data is recorded, reported and interpreted”* **(C) [P37:Team Lead-C]**. Perceived discrepancies were described as making it *“difficult to benchmark with other trusts”* **(O) [P53:Team Lead-C]**.

Concerns regarding the accuracy of audit feedback were expanded upon in free text responses **(C)**. These reservations were reported as reducing confidence to act upon the report **(M)**. Participants reported the data “*fails to capture the entirety of a service”* as a result of limiting data collection to six-months **(C) [P13:Team Lead-C]**. In contrast to acute care which was perceived as more accurately captured by the audit, community feedback was described as *“failing to reflect the myriad of community commissioning models*” **[P112:Manager-S]**. This was perceived as failing to acutely reflect the services delivered **(C).**

These concerns were reported as contributing to a lack of confidence in acting upon audit feedback **(M)**. *"If this is replicated across the country, I'm not sure what conclusions you can draw from the report"* **[P35:Team Lead-NC]**. Participants described being unable to use their data for quality improvement because they lacked confidence in it **(O)**. This was reported to result from incomplete data "*Our reports are incomplete so we can't use the data*" **[P72:Manager-S]** or delays in receiving feedback "*means we can't use it to develop our service because it's out of date by the time we get it*" **[P123:Team Lead-C].**

These findings suggest that reservations regarding data accuracy reduced confidence to use audit feedback for quality improvement. The IPT4 is illustrated in Figure 4-22.

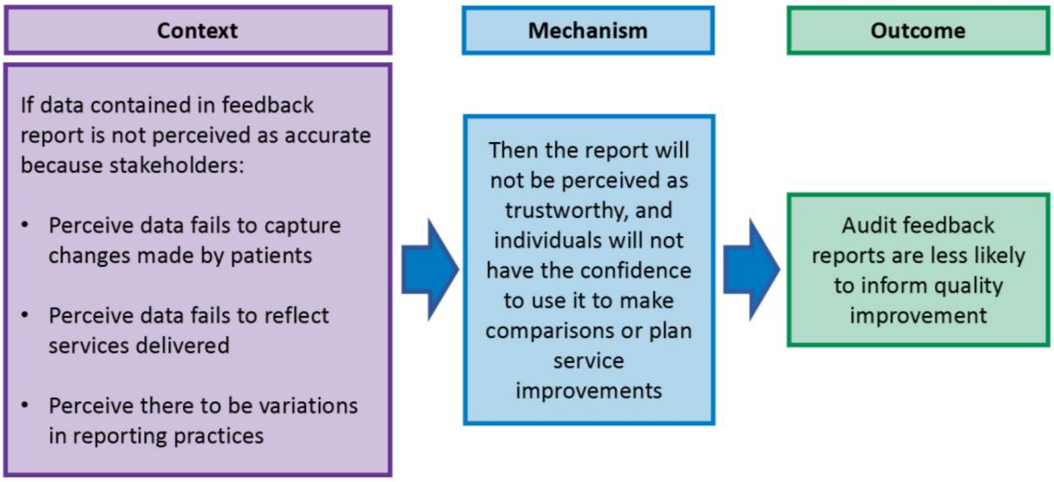


Figure 4-22: IPT4 - The influence of perceptions of data accuracy

4.4 Discussion

This study used four CPTs as a framework to investigate stakeholder experiences of using SSNAP in the community setting. Specific areas of investigation included experiences of engaging with the audit, participating in the audit and using audit feedback for quality improvement. Findings were used to explore and refine the proposed CPTs, resulting in four IPTs.

Community stakeholders reported being engaged in the audit and described using feedback to successfully inform a variety of quality improvements within their services. A number of challenges to audit participation were highlighted. These included the organisational culture, administrative support, online audit platform and ability of the audit to reflect the services delivered in this setting.

Individual perceptions of audit are informed by prior experiences. These include the organisational culture such as the behaviour of leaders or the response to feedback[230]. Participants in this study perceived organisations to be acute-focussed, resulting in a lack of leadership support for change in community services. This is in agreement with the wider audit literature that suggests that if change isn't experienced in response to audit, this can fuel low motivation and disillusionment for clinical staff[17,32]. An organisational culture of perceived leadership disinterest in audit impacts its ability to result in quality improvement. This study suggests these negative perceptions may be a potential barrier to future engagement with audit in the community.

Audit roles are rarely built into job specifications[160]. Instead, as highlighted by this study, audit activities are often perceived as an additional task assigned to clinicians rather than a resourced activity. Historically, community services have evolved to meet demand, and recruitment has prioritised clinical staff, resulting in a shortage of administrative support[56]. Consequently, community services in general often lack administrative support when compared to larger and more established acute hospitals. Absorbing administrative duties into clinical roles may be perceived as being a cost-effective use of limited resources in community services. However, this study highlights a lack of dedicated administrative support as a barrier to audit participation, impacting both audit efficacy and a team's clinical capacity. This echoes findings from Alvarado et al. where resources allocated to support participation in national clinical audit were reported as constraining its use as a tool for quality improvement[34].

This study highlighted challenges related to the online platform that contributed to data being incomplete. These concur with the wider literature where barriers such as duplicate data entry and incompatible IT systems are reported as barriers to audit participation[181]. Dixon-Woods et al. suggest that "*these mundane obstacles have a powerful impact on clinicians' ability and willingness to complete data entry*" which in turn impacts audit participation[160]. Similarly to issues with administrative support, these factors may be more conspicuous in the community setting where services may lack the established infrastructure and centralised organisational resources found in acute services. These factors may contribute to the varying ability of audit to bring about improvements at different points in the stroke pathway, as identified by Cappadona et al.[231].

Perceived inconsistencies in audit practices between community teams were described as resulting in reduced confidence to use feedback to make comparisons. This concurs with Taylor et al. who found mistrust regarding auditing practises between hospital-based stroke teams prompted concerns regarding the use of audit data for commissioning purposes[13]. Interestingly, the largest proportion of neutral responses in the survey was provided in response to a question about the perceived accuracy of data from other services (figure 4-12). This is logical as it highlights that participants did not have the lived experience to be confident in either the accuracy, or inaccuracy of other teams' data. The distribution of responses to this survey item illustrates the importance of presenting complete responses, including neutral, rather than dichotomised categories which may be misleading.

Both Wagner et al. and Sarkies et al. proposed that capturing the full scope of local workflows leads to greater clinician "buy-in" to the audit process[183,232]. This is echoed by this study, where participants described a lack of confidence to engage with, or act upon audit findings that were perceived as failing to reflect the impact of community services. Further research is required to understand which measures would reflect the services delivered in the community or capture the changes made by stroke survivors in the community.

Despite reservations regarding data collected, respondents did describe using feedback reports to make comparisons between services. This suggests that in spite of the acknowledged limitations, stakeholders perceive there to be utility in data comparison. These findings are in agreement with the wider literature that suggests the use of routine data with known limitations is commonplace in healthcare[233]. Wolpert and Rutter coined the acronym FUPS to describe this flawed, uncertain, proximate and sparse data. Whereas FUPS data has previously been dismissed as unreliable, Wolpert and Rutter argue this data should be embraced. They propose the transparent reporting of FUPS, acknowledgment of limitations and triangulation with other findings in order to develop a greater understanding of complex health systems[234].

There has been a steady increase in the proportion of stroke survivors being discharged into community services in the UK over the last 10 years, reaching over 60% in 2023[36]. This is partly as a consequence of the publication of the Integrated Community Stroke Service Model by NHS England[42] and the publication of evidence informed national clinical guidelines[38,39]. These initiatives reflect an increased emphasis on the efficacy and cost effectiveness of community-based services. Alongside this policy emphasis and evolution in the stroke pathway, there is a need for increased scrutiny of effectiveness and quality. If these policy initiatives are to be successful, consideration must be given to how best to evaluate delivery and outcomes both at a national and local level. SSNAP offers an opportunity for such evaluation. However, the resources that community providers require to engage with the audit and utilise the feedback must be considered. This study has generated novel findings that offer insight into these resources, and how engagement and utilisation of the audit could be maximised, thus adding to the literature.

This study has been conducted using realist methodology and as such is theory driven. Quantitative data provided contextual information such as the resources used, and activities undertaken as well as the perceived outcomes of the audit. Qualitative findings have expanded upon the proposed contextual features and illuminated potential mechanisms by which quality improvement may be achieved. The use of an online mixed methods survey is a novel methodological approach in RE, offering strengths and limitations as outlined below.

4.4.1 Strengths and limitations

Broad representation was achieved from across both regions of England and categories of stakeholders. It is acknowledged that the self-selection of online surveys is inherently biased towards individuals with strong feelings regarding the subject matter[222]. This study used a self-selected sample of convenience and as such, the response rate as a proportion of the potential workforce was expected to be low. The anonymous nature of the survey, combined with an opportunity to expand using free text options, generated candid responses which may not have been the case in a face-to-face scenario. This collection of qualitative, in addition to quantitative data offered a greater depth of understanding.

The distribution of role of participants reflects the reality of clinical practice, larger numbers of clinicians with fewer service managers and commissioners. The smaller samples from commissioners and senior managers did not support comparison between roles. Another limitation of the study is that the reliability of survey items was not established. However, where possible these items were based on or informed by the existing literature as well as being piloted with feedback from a variety of sources including clinicians, academics, audit professionals and lay individuals.

Although the CPT outcomes were proposed as absolute e.g. participation or non-participation, findings implied these were influenced by contextual features to a greater or lesser extent instead i.e. they are more or less likely. The interplay between context and mechanism may be more complex than can be revealed using an online survey. Surveys lack the opportunity for probing or clarification. Therefore, these four IPTs have been taken forwards for further exploration using realist interviews, in the following chapter, where deeper scrutiny is possible.

4.4.2 Conclusion

The advancement of the evidence base and renewed policy emphasis on community rehabilitation necessitates an increased focus on performance and delivery of rehabilitation in this setting. Findings from this study have provided insight into stakeholder engagement and participation with SSNAP as well as their use of national stroke audit feedback for quality improvement. Findings highlight the work needed in terms of the data captured by the audit, organisational audit support and engagement with audit feedback if the potential of SSNAP as a tool for quality improvement in community rehabilitation is to match that seen in the acute sector. Specific measures to support audit participation and the implementation of audit findings identified by this study are key to successful quality improvement in community stroke care.

4.5 Chapter summary

This chapter details the development of a realist mixed-methods online survey and the use of findings to refine four CPTs. This process formed the first cycle of RE (stages 2-5) as illustrated in Figure 4-1. Four IPTs exploring the role of SSNAP in driving quality improvement in community stroke care have been developed. These are scrutinised and tested using realist interviews in the following chapter.

5 Exploring influences on SSNAP in the community setting

Using realist interviews to refine and test IPTs.

5.1 Introduction

The previous chapter explored stakeholder perceptions of, and participation in the audit and how data from it was utilised. Survey findings were used to develop four IPTs that propose how SSNAP contributes to quality improvement for community stroke services. This chapter investigates the contextual features and associated mechanisms by which the IPTs propose SSNAP contributes to quality improvement in community stroke care.

To summarise the four IPTs:

i. If individuals perceive SSNAP as a worthwhile activity, they are more likely to engage with the audit.

ii. If individuals have audit recognised as part of their role and access to information to support participation, they are more likely to complete audit tasks.

iii. If individuals encounter challenges related to the online platform, data is less likely to be complete for the caseload.

iv. If data contained in feedback reports is not perceived as accurate, it is less likely to be used to inform quality improvement.

Despite the earlier survey generating a large amount of rich data regarding stakeholder experiences and perceptions of the audit, this method did not allow for deeper scrutiny with individual participants. Therefore, realist qualitative interviews were chosen to refine and expand upon these theories as they offer opportunities for elaboration and a depth of questioning that may uncover rich contextual details and mechanisms that lie beneath the surface[235]. Most importantly, in contrast with surveys, realist interviews offer an opportunity to test and confirm programme theories with participants[236].

5.1.1 Aim

The aim of this chapter was to refine and test the four IPTs in order to gain an understanding of the following question:

What influences the ability of SSNAP to contribute to quality improvement in community stroke care?

Consistent with the previous phase, stakeholders were defined as anyone working in, leading or commissioning community stroke rehabilitation services that contribute to SSNAP.

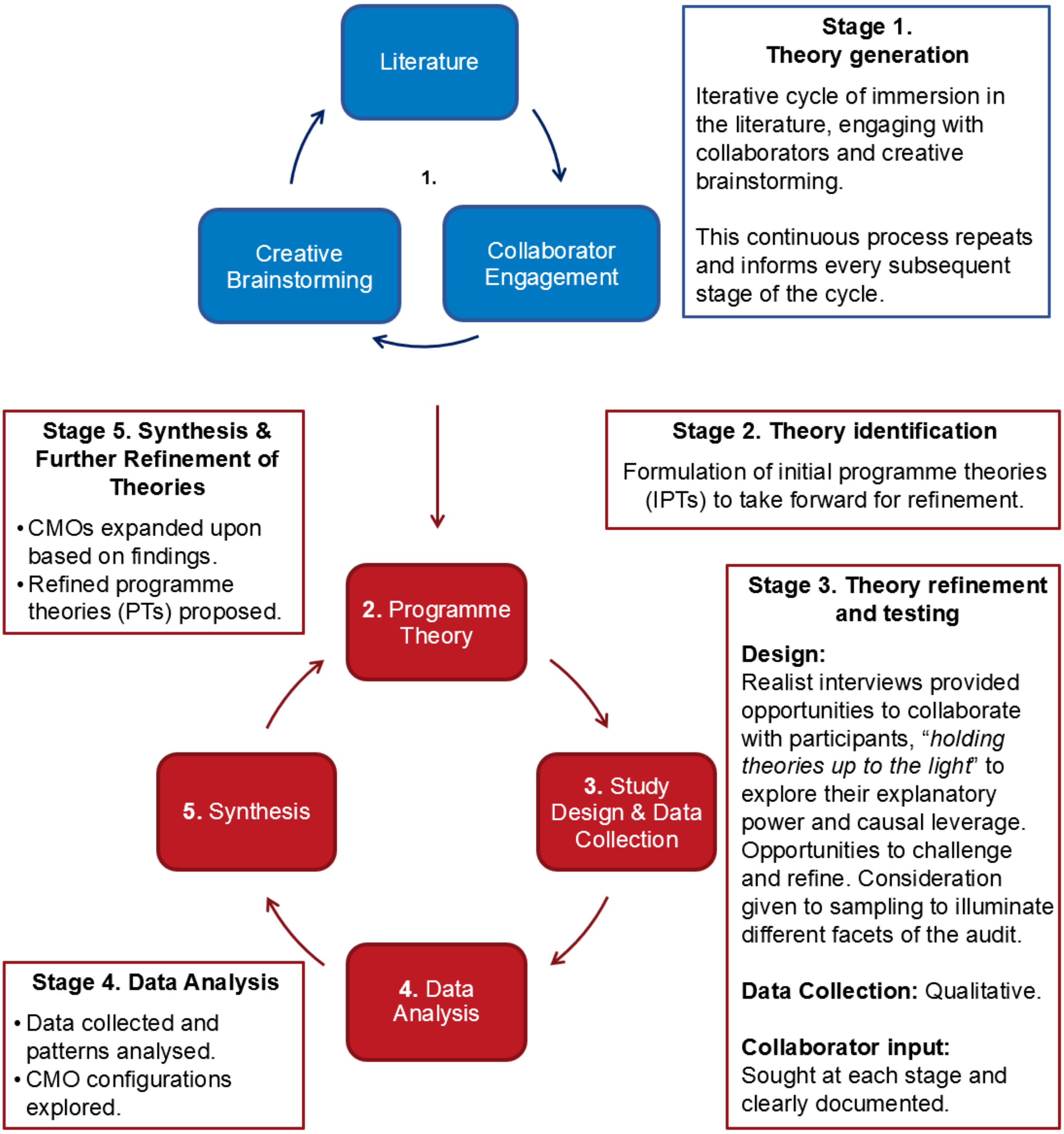
5.1.2 Objectives

1. To investigate how audit engagement is influenced by stakeholder perceptions.
2. To investigate the influence of dedicated time for audit within a team.
3. To investigate the influence of the online platform on data submission.
4. To investigate perceptions of data accuracy and the influence this has on whether data is used for quality improvement.
5. To refine and test IPTs that seek to explain how SSNAP contributes to quality improvement in community stroke care.

5.2 Methods

5.2.1 Methodological framework

RE seeks to develop, refine and test programme theories that explain "*what works, for whom, under what circumstances and how*?"[138]. This chapter describes the use of realist interviews for a second circuit (stages 2-5) of the RE cycle as illustrated in red in Figure 5-1. Four IPTs developed previously were used as a framework to explore how SSNAP contributes to quality improvement in community stroke services.



Stage 1. Theory generation

Iterative cycle of immersion in the literature, engaging with collaborators and creative brainstorming.

This continuous process repeats and informs every subsequent stage of the cycle.

Stage 2. Theory identification

Formulation of initial programme theories (IPTs) to take forward for refinement.

Stage 3. Theory refinement and testing

Design: Realist interviews provided opportunities to collaborate with participants, "*holding theories up to the light*" to explore their explanatory power and causal leverage. Opportunities to challenge and refine. Consideration given to sampling to illuminate different facets of the audit.

Data Collection: Qualitative.

Collaborator input: Sought at each stage and clearly documented.

Stage 4. Data Analysis

- Data collected and patterns analysed.
- CMO configurations explored.

Stage 5. Synthesis & Further Refinement of Theories

- CMOs expanded upon based on findings.
- Refined programme theories (PTs) proposed.

Figure 5-1: The Realist Evaluation Cycle

As described in Chapter 2, collaborator engagement is fundamental to RE[123,144]. Collaborator meetings were completed virtually, either individually or in groups of two or three; contributions are detailed at the relevant point in the chapter. Ethical approval for this study was granted by the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS 387-1021) (see Appendix 4-1). All data were collected, and all methods carried out in accordance with relevant guidelines and regulations. To aid transparency and rigour, the consolidated criteria for reporting qualitative studies (COREQ) framework was adhered to[237] (see Appendix 5-1 for checklist). Informed consent was obtained from all participants prior to the interview, the participant information sheet is included in Appendix 5-2.

As detailed in Chapter 2 (section 2.2) scientific realism sits between the interpretivist and positivist philosophical paradigms, with a number of overlapping features that inform both the design and analysis of interviews, as discussed in the following sections. An overview of the distinctions between interviews in these paradigms is presented in Table 5-1[238].

Table 5-1: Differences in interview paradigms

Paradigm	Interpretivism	Scientific Realism	Positivism
Format	Unstructured	Semi-structured	Structured
Purpose	Theory building	Theory gleaning, refining and testing	Theory testing
Collects	Idiosyncratic narratives and individual experiences	Causal insights	Standardised data for aggregation
Framework	Inductive	Both deductive and inductive	Deductive
Interviewer contribution	Introduction to topic area (participant led conversation)	A collaborative exploration to establish a shared understanding	Standardised approach to questioning, avoiding interviewer contamination
Sampling	Purposeful identification and selection of information-rich cases related to topic	Diverse representation to illuminate different facets of an intervention	Large scale representative of wider population

The choice of online interviews reduced potential barriers to participation such as minimising time commitment and removing the burden of travel[239]. The online platform MS Teams™ is freely available and is routinely used for work purposes by potential participants employed within the NHS, therefore would not be perceived as a barrier to participation for reasons of accessibility or digital literacy.

Much consideration was given to the content, format and structure of the interview in order to enable flexibility in the moment and capitalise on participant insights. Considerations are outlined in the following section, for original interview schedule see Appendix 5-3 (these were adapted as part of programme theory refinement as discussed in sections 5.3.3 -5.3.6).

5.2.2 Design

Purpose

Programme theories regarding how, when, where and why SSNAP may or may not contribute to quality improvement were the explicit subject matter of the interview. Participants were asked to confirm, refute, refine or expand upon these theories[236,240]. The purpose was to unpack potential mechanisms that may bring about the outcome of interest and identify key features of influential contexts. By holding these "*up to the light*" together, researcher and participant are able to collaboratively question their explanatory power and causal leverage[241].

Structure and Content

The structure and framing of interview questions were informed by the RAMESES II project interview guidance[240]. All interviews began with an introduction to the purpose and scope of the study. This was followed by an exploration of the participant role and their understanding of the audit[242]. To facilitate participant collaboration, interview purpose was articulated and the premise of theorising explained as part of the introduction[241]. Details of this introductory conversation are included in the interview schedule in Appendix 5-3. Theories were not always presented in their entirety as participants may have viewed these as intransigent. Instead partial theories were offered, to allow participants to "*fill in the blanks*" and offer causal claims in their own words[241]. This provided an opportunity for participants to explore possible connections between elements, offering rival explanations for discussion[243]. In addition, participants were invited to speculate on the experiences of others, what they have heard, observed or perceived. This conjecture provided opportunities to gain greater depth of understanding[244].

The direction of travel within the interview was influenced by the researcher, circling back to revisit points of interest and drilling down to gain greater understanding. The pace of dialogue was also intentional, supporting participant contemplation and allowing for periods of silence in order for researcher and participant to reflect, paraphrase and confirm a shared understanding[241]. If appropriate, the researcher introduced rival theories or alternative outcomes, offering an opportunity to compare, contrast and explore the relative explanatory power of each[245].

Finally, three different approaches were used to test and validate theories which are outlined below[244]. Data collection in RE should ideally be iterative, revisiting the same participants to re-test and validate theories as they evolve. However there are circumstances such as limited resources, time and ethical approvals where it is acknowledged that a different approach is appropriate. In these situations, such as this study, theories can be cyclically refined and tested using consecutive participants[236].

1. “There is an idea that….” This approach introduces a broad concept without explicitly stating it as formal theory, giving participants scope for modification. Using an objective tone creates distance between researcher and theory, allowing participants to challenge propositions more easily.

2. “What is it about ‘X’ that makes a difference / brings about…? This offers an opportunity for retroduction to explore aspects of the intervention that can be used to reveal context or mechanism related insights.

3. “I see, so you are saying that ……is that correct?” This circular line of questioning enables the researcher to paraphrase whilst re-organising participant responses into implicit configurations of context, mechanism and outcomes for validation.

Interview questions were reviewed and updated as theories were refined, this was captured and tracked using linked memos in NVivo^{TM} for transparency. See data analysis section 5.2.5 for details.

Piloting

The format, structure and ordering of questions were informed through extensive piloting with a variety of collaborators (KB, JH, ED, SL, MJ, RF and NC), some with an understanding of the topic area and some without. This process refined the articulation of both programme theories and the principles of realist interviews for participants without realist experience.

Despite changes to terminology used or framing of questions, the manifest content of programme theories remained unchanged. Realist training opportunities were sought including online interview role play with international research students from a variety of health and social care backgrounds. This activity offered insights into not only using a realist approach but also the experience of being interviewed using these techniques.

5.2.3 Recruitment

Alternative perspectives are essential in RE to investigate the many facets of an intervention, rather than gain consensus[240]. On completion of the survey detailed in Chapter 4, participants were invited to provide their contact details, role and region as an expression of interest to participate in a subsequent online interview. The same invitation and eligibility criteria were circulated using social media and established clinical networks (Appendix 5-4).

An aspirational target was set for twenty participants. Variability was purposely sought to explore outcomes across a spectrum of contexts and reveal different facets of the audit [236]. Consideration was given to, and efforts made to purposefully disseminate the advert to reach diverse stakeholders. Representation was sought from different roles to provide a variety of perspectives and experiences. Representation was sought from across the twenty ISDNs in England to capture variation in terms of geography and services.

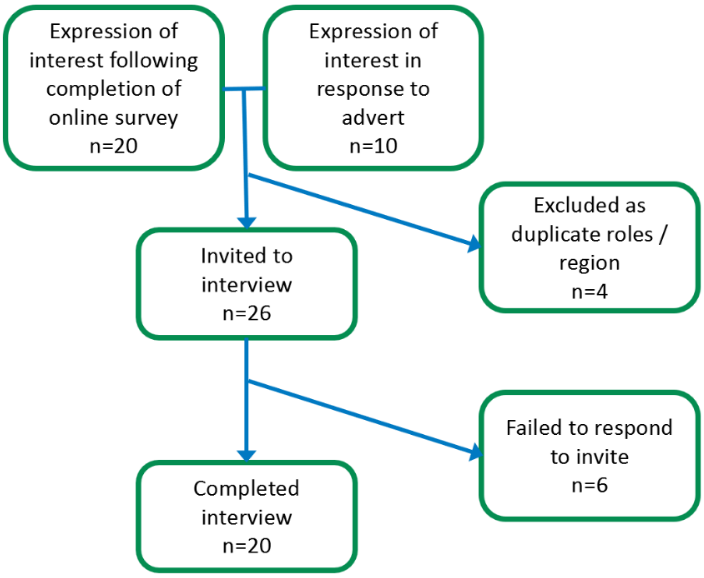


Figure 5-2: Recruitment process

There were twenty-eight expressions of interest, from geographically diverse stakeholders in a variety of roles, excluding the commissioning category. Therefore further efforts were made through professional networks to circulate the advert and recruit specifically from this participant category. This resulted in two additional expressions of interest, bringing the total to thirty potential participants. Four were excluded due to duplicate roles or regions. They were contacted by email, thanking them for their interest and explaining the reasons for non-selection (as outlined in the initial expression of interest invitation). Invitations were sent in batches, recruiting four participants at a time. In total twenty-six invitations were made and six failed to respond. This process is illustrated in Figure 5-2. All those who expressed an interest in participating received participant information electronically (Appendix 5-2). Contact details for the researcher were available on the advert if individuals wished to receive additional information. All those who participated completed and returned an online consent form prior to the interview. No participants withdrew after consent.

5.2.4 Data collection

Interviews were completed using the online platform MS Teams™. No one else was present during interviews other than the researcher (LR) and interviewee. Transcripts were exported into MS Word™ documents for cleaning, these were checked against original recordings for accuracy. NVivo™ software was used for organisation, assisting data management and supporting analysis.

5.2.5 Data analysis

This study has been informed by realist methodology. As such analysis was both deductive using the frame offered by the four IPTs and open to new inductive insights from participants to explore generative causation[246]. Analysis does not report aggregate data in an attempt to demonstrate "strength by numbers" causation. Instead, it sought to provide an ontologically-deep understanding of phenomena[140]. This required continuous re-evaluation in light of new insights, which was underpinned by a transparent and cumulative approach to theory development[140]. This process is described in the following paragraphs.

Preparation

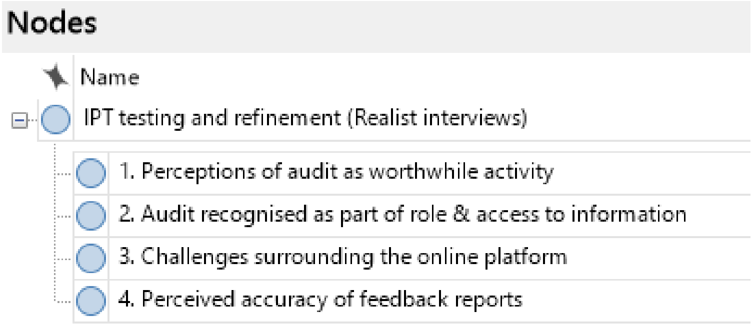
Interviews were organised in "batches" of four, allowing for iterative cycles of coding and analysis to inform subsequent interviews[229]. This provided an opportunity to refine and expand on theories with the knowledge that confirmation may be explored in subsequent interviews[247]. None of the participants were known to the researcher prior to the study. As per Manzano et al., the first two batches were organised predominantly with Team Leads / Service Managers who were more likely to have a macro-level overview of the audit and its purpose, followed by Clinicians and Administrators to explore the reality of audit activity at a micro-level[236]. Subsequent interviews were based upon participant availability. Prior to coding of each interview, complete transcripts and field notes were read and re-read to gain a better contextual understanding, before attempting data extraction[128]. Each interview was stored within NVivo™ as an individual data source.

Rigour

To achieve rigour within this study a number of steps were taken. The RAMESES II reporting standards for RE were followed[138]. Ten of the twenty interviews were independently analysed. All linked memos tracking theory development and field notes were reviewed by a second researcher with expertise in realist methods (NC), enhancing the trustworthiness of findings. In addition, realist interviewing requires researchers to directly test their hypotheses with participants, seeking confirmation or clarification regarding the programme theory under exploration. Trustworthiness in this study was further established by discussing findings with collaborators (KB, CL, RS, ED and JH) and the PhD supervisory team (SL, RF, NC and MJ).

Coding

A separate node was created for each IPT with an associated linked memo to track any changes during analysis [128,227] (see Figure 5-3). Therefore coding used a primarily deductive framework, whilst being open to inductive insights.



Nodes

Name

IPT testing and refinement (Realist interviews)

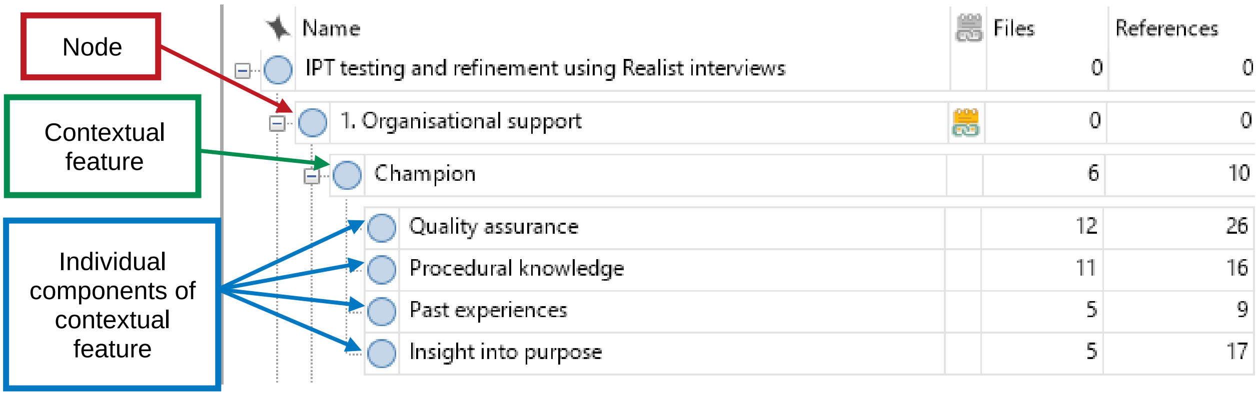
1. Perceptions of audit as worthwhile activity
2. Audit recognised as part of role & access to information
3. Challenges surrounding the online platform
4. Perceived accuracy of feedback reports

Figure 5-3: The four initial nodes

A combination of export coding and referential coding was used. Export coding, sometimes termed *evidence-based* coding extracts highly relevant passages from transcripts to test against programme theory and refine context, mechanisms and outcome configurations. This is particularly beneficial when a causal insight is clearly articulated within the data[229]. Referential coding highlights and annotates sections of a transcripts without direct extraction. These passages are used “indirectly” as their contents are paraphrased and are therefore described as being *evidence-informed*. This is beneficial when insights from a passage are “causally vague” or less succinct[229].

Context, mechanism and outcome extraction

In some situations, a single data source provided causal insights supporting an entire context, mechanism and outcome configuration. However multiple data sources were commonly used to support dyadic components, i.e. context-mechanism or mechanism-outcome[128,248]. Once each transcript was read and coded, each IPT was reviewed. This included evaluating the source and associated field notes to fully understand the context of the interview, adding any notes to the linked memo for transparency[128]. Where data was sufficiently rich and distinct features of a context were apparent, child nodes were used to organise coded data. Where further components of a contextual feature were evident, these were organised using grandchild nodes. Figure 5-4 illustrates the refined IPT-1 "*Organisational support*", which began as "*Perceptions of audit as a worthwhile activity*" (Figure 5-3). This refinement, and the creation and development of nodes were tracked using the linked memos.



Name	Files	References
IPT testing and refinement using Realist interviews	0	0
1. Organisational support	0	0
Champion	6	10
Quality assurance	12	26
Procedural knowledge	11	16
Past experiences	5	9
Insight into purpose	5	17

Figure 5-4: Example of node development

Refinement

This was an iterative process which required sufficient data to confirm, refute or expand upon components of an IPT[128]. A clear record of any changes and the associated justification were made in the linked memo [128,227]. Once all interviews, field notes and linked memos had been scrutinised and data extracted to support refinement, the resultant IPTs were examined collectively. This enabled the relationships between theories to be examined, clarifying any overlaps and articulating distinctions. This "tidying up" is described by Gilmore et al. as an essential final process by which greater clarity and linkages between theories can be achieved[128]. In contrast to alternative methodological stances, this reflexivity contributes directly to analysis rather than discussion in RE[228].

5.3 Findings

The following section describes the interview participants before detailing findings related to each IPT in turn. Online interviews were completed as planned with twenty participants, lasting between 35 and 97 minutes (mean 57, median 56).

5.3.1 Description of participants

The roles and regional distribution of the twenty participants are illustrated in the following graphs. Participants self-reported their role category as the role they spent the majority of their time undertaking. However, during conversation it became apparent that many Team Lead roles were combined with either clinical responsibilities or strategic leadership within their ISDN. Participants in these joint positions were able to offer deeper insights into causal relationships and simultaneously consider alternate perspectives to questions. Their ability to appreciate the proposed programme theories at a more abstract level proved invaluable when attempting to test and validate theories.

Figure 5-5: Chart to illustrate the role distribution of participants.

To reduce the risk of identification, regions have been coded 1-20 to reflect the twenty ISDNs within England and illustrate the geographical spread of participants. Representation was gained from twelve of the twenty regions, exceeding the aspirational target of ten.

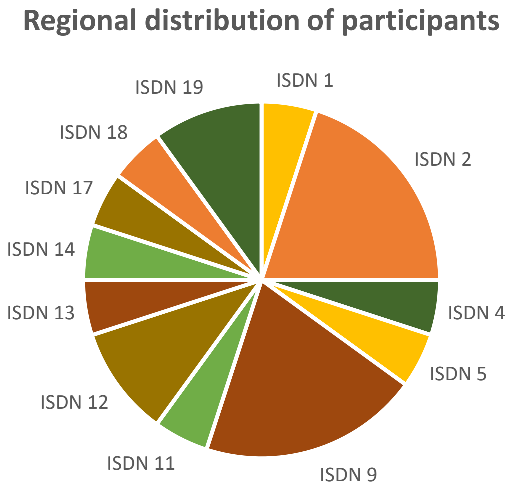


Figure 5-6: Chart to illustrate the regional distribution of participants.

5.3.2 Initial Programme Theory refinement and testing

The following sections describe the process by which interview findings were used to refine the four IPTs.

Each section begins with a black and white figure containing the proposed context, mechanism and outcome configuration for the IPT. Findings are then organised in the following format:

a. The outcome of interest is stated, and any refinements described.

b. Contextual features that influence the outcome of interest are summarised. Each contextual feature is detailed in turn (bold heading). Findings are used to illustrate refinements made to each context-mechanism configuration. Individual CMO configurations are presented separately (black and white).

c. The refined programme theory (PT) is presented as a coloured figure containing all the underpinning CMO configurations.

Interviews offered opportunities to delve deeper into mechanisms and explore with participants their reasoning and responses to the situations they have experienced. This has enabled the identification of resources and responses within proposed mechanisms. Dalkin et al. have advocated for this explicit disaggregation of resources and reasoning in RE. They suggest this explicit articulation supports the investigation of causality and reduces ambiguity when making causal claims[115].

Collaborative interviews enabled exploration regarding the levels at which contextual features and outcomes were manifest (e.g. team, service, organisation)[123]. These processes have supported the refinement and expansion of the proposed IPTs, enhancing the explanatory power of the resultant PTs. This refinement process is detailed in the following pages.

5.3.3 IPT1:

If individuals perceive SSNAP as a worthwhile activity, they are more likely to engage with the audit.

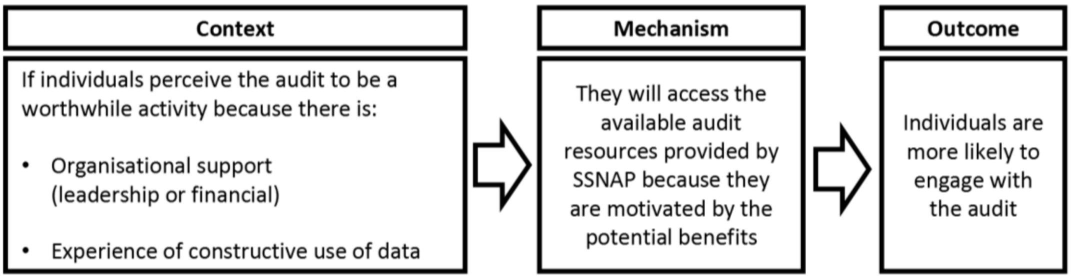


Figure 5-7: IPT1 proposed CMO configuration.

a. Outcome of interest

The proposed outcome of interest for IPT1 was engagement in the audit process, at the level of individual stakeholders. However participants more commonly described engagement at the level of the team, rarely using first person singular. Instead participants used first person plural “we, us, ours” to describe the wider engagement of team members in the audit process.

Although *all* participants reported their teams to be engaged in audit, the degree to which varied. There was a clear distinction between those teams *actively* engaged and those with minimal engagement beyond data collection. *“I don’t think anyone looks at it [SSNAP feedback] or really cares, so we just do the minimum.”* **[P1-Team Lead]** Some participants described their team’s level of engagement as “*just tick a box to say you've done it.*” **[P14-Support Worker]**

In contrast, active engagement of teams was characterised by activities beyond data collection alone, such as quality assurance or communication of feedback reports. “*We look at our reports in the monthly therapy forum…our data quality is everyone's responsibility”*. **[P4-Service Manager]** These additional actions suggested insight into the potential use of data, if not an appreciation of the full audit cycle. *“Teams completely understand it. They review it before me ….they’re very keen at looking at it.”* **[P20-Commissioner]**

The outcome of IPT1 was therefore refined to:

Teams are more likely to be actively engaged in the audit process.

b. Contextual features

Participants described *leadership interest* to be of paramount importance with regards to the support offered by their organisation, over and above financial support. It was seen by many as a prerequisite for engaging teams or securing funding. When exploring participants' experiences of the constructive use of data, it became apparent that this was a facet of a larger contextual feature, that of having an *audit champion* within a team. The champion encompassed a number of components including procedural knowledge, insight into purpose and experience of the positive impact of audit.

Leadership Interest

In the context of leadership interest in audit data, a number of factors were described as influencing a team's motivation to actively engage in the audit process. These included the prospect of comparison, the potential consequences of scrutiny and the value attributed to the post-acute audit by those in leadership.

Participants who expressed concerns about the potential of appearing as a negative outlier in feedback reports, described taking additional steps to ensure data was complete and accurate prior to submission. "*It's quite nerve wracking, like oh gosh what we are doing is going to be seen* [by commissioners] *and how do we make sure this looks accurate".* **[P1-Team Lead]** The prospect of comparison by those in leadership was reported as motivating a team's engagement with audit. "*You know what you're doing is being noticed. I think it's a good thing, they* [managers] *can compare nationally and say, you know ours is pretty good in comparison. Yeah, it definitely helps*." **[P2-Administrator]**

In teams where leadership were attentive to audit data, participants described being motivated to actively engage in the audit by the potential consequence of scrutiny. "*Within our team, I know that our senior managers take it seriously. Whenever the report comes out, there's quite a buzz around it, everybody is interested, they take a lot of pride*." **[P2-Administrator]** However, where data was reported as not being acted upon this was described as disheartening for individuals. *"Our team lead will look at the data, but nothing really happens above her to be honest, no. Nothing's really come from it, it's sad to be honest."* **[P14-Support Worker]**

For organisations where post-acute data was reported as not being scrutinised by those in leadership, this was described as demotivating for teams. This resulted in a reluctance to commit efforts beyond data collection and a perception that performance was without consequence. "*Nobody is sat in a room with a chief exec talking them through, what the community performance looks like. Whereas with acute we absolutely get hauled to the clinical commissioning meeting and I'd be stood there with our SSNAP data, talking people through it. That's not happening for community teams. So the accountability aspect of it, I just don't think it's there."* **[P5-Service Manager]**

This perceived disparity in interest between acute and post-acute audit data was described as demoralising for teams. Participants alluded to this as contributing to a broader perception of community activity lacking value or respect within their organisation. *"In our meetings with the trust, it's all about inpatient hitting the inpatient targets and community they don't bother about. Which is such a shame because a lot of the hard work is done in community. So it does feel like community is left behind."* **[P14- Support Worker]** These perceived differences were reported as contributing to a lack of motivation to engage with the audit, beyond data collection. "*Even the head of stroke isn't interested [in the post-acute report]. He's very interested in the acute SSNAP report. But he's not interested in the rehabilitation wards or community, why should we bother."* **[P8-Service Manager]** Figure 5-8 describes the refined CMO configuration for the contextual feature: leadership interest.

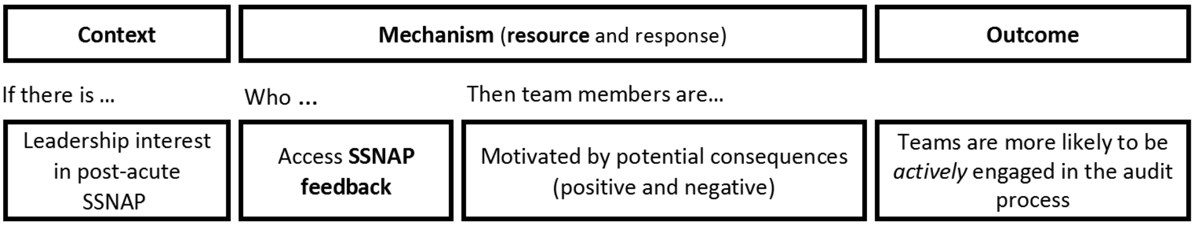


Figure 5-8: PT1 Contextual feature - Leadership interest

Audit champion within a team

The presence of an *audit champion* was reported as instrumental in the active engagement of the wider team in the audit process. A variety of manifestations were described by participants, across roles including administrative, team lead and management. These individuals were not employed specifically for audit purposes, nor were they formally identified as responsible for the audit. Instead their roles had naturally evolved to include aspects of the audit. In some teams, participants reported this role as being shared between two people. Despite the variety described, there were four common components. These components were described as facilitating the active engagement of the wider team in the audit process via a number of different mechanisms which are summarised in the following paragraphs.

Procedural knowledge

Champions were described as possessing a tacit understanding of the audit, characterised by their ability to support the participation of others. This knowledge exchange often occurred informally. "*It's something we just take for granted, that it just happens. There is a lot of understanding that goes into pulling all the data and getting it in the right place."* **[P12-Administrator]**

Insight into purpose

Sharing an appreciation of the purpose of audit, and its potential leverage in quality improvement was described as motivating team members' engagement with the audit. *It's the understanding as to why this is so important. It's not a nice to have, it's absolutely must-have because it is the only thing that gives us weight in arguments with Commissioners, for service development…It's not going to work until we can get that feedback loop.* **[P9-Service Manager]** One participant who identified as an audit champion within their team described how she motivated others to engage, by raising insight into the purpose of audit amongst team members. "*Showing them what it can offer….how can they use that data to their advantage or to develop things for their patients. It's about making that link back, isn't it? How powerful it could be if we get it right."* **[P5-Service Manager]**

Past experiences

Although IPT1 proposed first-hand experiences contributed to engagement in the audit, interview participants commonly reported the influence of vicarious experiences. *“I've seen it make a difference in other places… We saw the impact in the data so I know it can work.”* **[P5-Service Manager]** These observations of positive outcomes in other contexts were reported as motivating teams by providing hope that given similar opportunities change was possible.

For those teams with negative experiences, for example data being used critically, this was described as reducing their motivation to engage with the audit, beyond the collection of data. “*The general feeling about SSNAP it's a bit of a stick to beat you with*.” **[P18-Clinician]** Participants described champions as using their experiences to role model positive behaviours and attitudes towards the audit. This was described as motivating the wider team to engage. *“She was very much at the forefront; she very much led it and pushed the benefits. She encouraged everybody”.* **[P2-Administrator]**

Quality Assurance

Quality assurance was described as being provided by champions at two distinct points in the audit. Firstly ensuring the curation of accurate data for submission. *“She coordinates SSNAP, so we have the right people, under the right teams. That is her job - data quality*.” **[P17-Clinician]** Secondly, they compared feedback reports with secondary information such as local clinical data to identify any differences. “*If SSNAP is telling us that we have provided less occupational therapy, they should be able to start to investigate…is that down to data capture?”* **[P17-Clinician]** Quality assurance varied from an in-depth triangulation with local data, to a cursory double-check of patient numbers. Figure 5-9 describes the refined CMO configuration for the contextual feature: audit champion.

Context	**Mechanism** (**resource** and response)		**Outcome**
If there is ...	Who ...	Then team members are...	
An audit champion who has: • Insight into the purpose of audit • Procedural knowledge of audit • Experience of positive impact of audit • Ability to undertake quality assurance	• **Role models** positive attitudes / behaviours • Shares **knowledge and skills**	• Motivated by positive role modelling • Enabled to participate	Teams are more likely to be *actively* engaged in the audit process

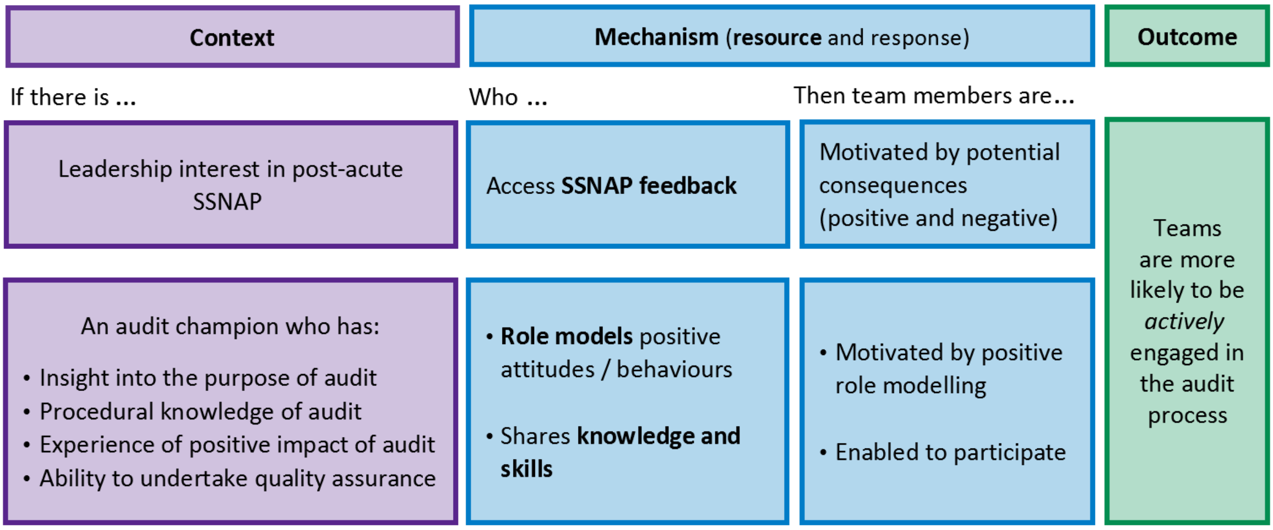
Figure 5-9: PT1 Contextual feature - Champion

This section has highlighted two contextual features that contribute to teams being actively engaged in SSNAP, leadership interest and the presence of an audit champion. Participants who were unable to identify either, described a lack of engagement with SSNAP by their team. *“I’m the only one who sees it* [feedback report]…*I don't really do an awful lot. We have pinned it on a notice board, but I don't get feedback or questions. I couldn't tell you how many people look at it or what they take from it.”* **[P8-Service Manager]**

c. The refined Programme theory (PT)

The proposed IPT1 has been refined, expanded upon and reframed through collaborative realist interviews, resulting in the following programme theory (PT1) and underpinning context, mechanism and outcome configurations.

PT1: If there is organisational support for SSNAP, then teams are more likely to be actively engaged in the process.



Context	**Mechanism** (**resource** and response)		**Outcome**
If there is ...	Who ...	Then team members are...	
Leadership interest in post-acute SSNAP	Access **SSNAP feedback**	Motivated by potential consequences (positive and negative)	Teams are more likely to be *actively* engaged in the audit process
An audit champion who has: • Insight into the purpose of audit • Procedural knowledge of audit • Experience of positive impact of audit • Ability to undertake quality assurance	• **Role models** positive attitudes / behaviours • Shares **knowledge and skills**	• Motivated by positive role modelling • Enabled to participate	

Figure 5-10: PT1 underpinning CMO configurations

5.3.4 IPT2:

If individuals have access to information to support participation and audit is recognised as part of their role, they are more likely to complete audit tasks

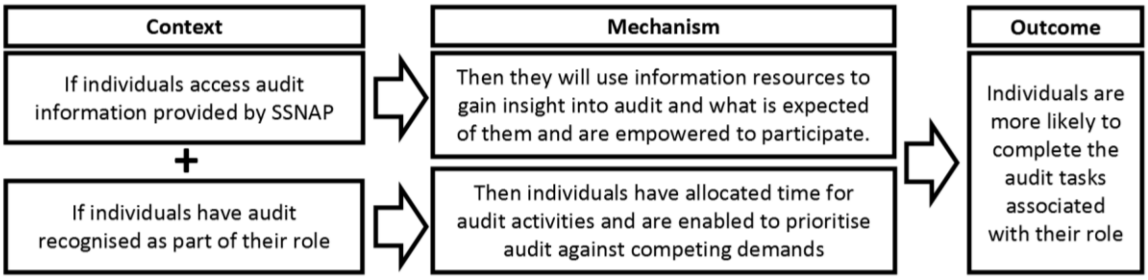


Figure 5-11: IPT2 proposed CMO configuration.

Early in interviews it became apparent that the completion of audit tasks was influenced by different contextual features depending on whether a stakeholder was clinical or non-clinical. Therefore, CMOs have been considered separately for these two distinct categories of role.

Clinical Stakeholders

a. Outcome of interest: clinical stakeholders

For clinical stakeholders the outcome of interest was the completion of audit tasks. The tasks most commonly described were the collection and uploading of audit data. Non-completion of audit tasks for clinical staff was described as resulting in poor quality or incomplete data. Participants reported this commonly resulted from prioritising patient care over data collection. "*She* [Rehabilitation Support Worker] *deprioritised it all the time because she put patients first and quite rightly, and the backlog was insane*". **[P1-Team Lead]** This was described as compromising their ability to conclude audit tasks, resulting in incomplete data. "*When we're really busy we can't afford for that rehab assistant to be inputting into SSNAP. We're going to have to leave it this month*". **[P5-Service Manager]**

One participant highlighted the differences evident in regional reports, contrasting those teams with and without dedicated administrative support. *"The ISDN level reports…I can always tell the teams that haven't got that dedicated admin because their results are really low. I know how many referrals are going into that team, so why are only 25 coming out?"* **[P9-Service Manager]**

b. Contextual features: clinical stakeholders

IPT2 proposed that if stakeholders access information provided by SSNAP this empowers participation. However, there were insufficient findings to support this from the interviews. Instead, participants pointed to significant obstacles that prevented the completion of audit tasks, despite information being readily available. A lack of dedicated administrative support was described as the strongest influence on whether audit tasks were completed. This was perceived as encompassing the second contextual feature proposed by IPT2, having audit recognised as part of a role. Therefore, the single contextual feature of dedicated administrative support was explored.

Dedicated administrative support

There was broad agreement that a lack of dedicated administrative support negatively impacted a team's ability to complete both audit and clinical tasks. Without dedicated admin support for audit, audit tasks were perceived as lacking legitimacy and failing to contribute to patient outcomes. "*The therapy support workers put it in* [SSNAP data]. *So, while they're doing that, they're not treating patients, which is what we're here to do".* **[P8-Service Manager]** As a result of these perceptions, when teams were busy participants reported a low threshold for ceasing data collection. "*When the chips are down, and people are busy, it's* [data input] *the first thing to go*". **[P5-Service Manager]**

Participants alluded to the absence of administrative support as an indication of the low value placed on the post-acute audit by their organisation, describing the negative impact this had on morale. "*Maybe if we're not trying to squeeze it in amongst everything else, and therapists didn't feel it stopped them seeing patients, they would value it more."* **[P16-Team Lead]**

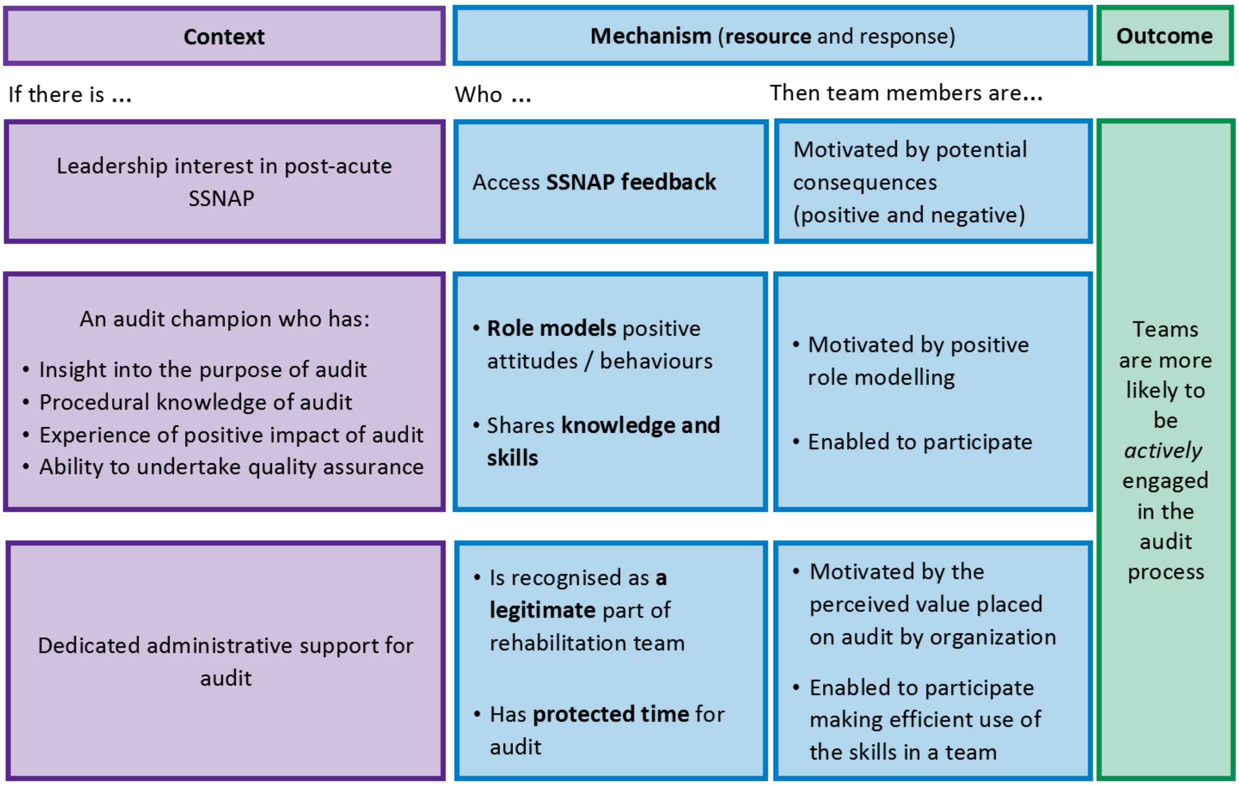
A number of participants reported their teams had taken steps to avoid combined roles by employing dedicated administrative support for the audit. In the presence of this contextual feature, two distinct mechanisms were identified. Firstly, having a dedicated post was perceived as an indication that the organisation valued the audit. This acknowledgement of audit as a legitimate contribution to rehabilitation was described as motivating team engagement. "*She* [dedicated administrator] *is 100% responsible for it and people know what to expect from her…. she is very much part of the team"*. **[P15-Team Lead]**

Secondly, participants described how dedicated support enabled the efficient use of resources, recognising and respecting the unique skills required for clinical *and* administrative roles. *"It means I'm not pulling clinical staff away from doing what they are good at, it's the best use of our resources".* **[P9-Service Manager]**

On later reflection with clinical collaborators and supervisors (CL, KB, RF, SL, NC and MJ), it was suggested that the outcome of completing audit tasks strongly influenced the ability of the teams to engage in audit. Dedicated administrative support was proposed as a contextual feature of the organisation, that enable teams to actively engage in audit. The inclusion of this contextual feature and its associated mechanisms was deemed to provide greater explanatory power to PT1, which describes the impact of organisational support on team engagement.

c. The complete, expanded PT1 is illustrated below.

PT-1: If there is organisational support for SSNAP, then teams are more likely to be actively engaged in the process.



Context	**Mechanism** (**resource** and response)		**Outcome**
If there is ...	Who ...	Then team members are...	
Leadership interest in post-acute SSNAP	Access **SSNAP feedback**	Motivated by potential consequences (positive and negative)	Teams are more likely to be *actively* engaged in the audit process
An audit champion who has: • Insight into the purpose of audit • Procedural knowledge of audit • Experience of positive impact of audit • Ability to undertake quality assurance	• **Role models** positive attitudes / behaviours • Shares **knowledge and skills**	• Motivated by positive role modelling • Enabled to participate	
Dedicated administrative support for audit	• Is recognised as **a legitimate** part of rehabilitation team • Has **protected time** for audit	• Motivated by the perceived value placed on audit by organization • Enabled to participate making efficient use of the skills in a team	

Figure 5-12: PT1 and underpinning CMO configurations - expanded

Returning to the proposed IPT2 (Figure 5-11) for non-clinical stakeholders.

a. Outcome of interest for non-clinical stakeholders

Non-clinical stakeholders were predominantly in leadership roles. In the context of this study, leadership roles included the Service Managers (not limited to Divisional or General), Team Leads (clinical or non-clinical) and Commissioners. The completion of audit tasks for these individuals commonly involved using audit feedback to inform strategic conversations, such as commissioning.

b. Contextual features

IPT2 proposed that the availability of information provided by SSNAP and having audit recognised as part of a role, both empowered and enabled participation. However for those in leadership roles such as Service Managers, Team Leads or Commissioners, interviews provided insufficient findings to support either of these propositions. Despite information resources and additional support being readily available via a number of channels such as website and helpdesk, challenges were described to accessing information contained in feedback reports. Participants in leadership roles reported they were able to ring-fence time but had difficulties in navigating reports and extracting information.

Information accessibility

A number of components of the report were described as influencing the ease by which information could be accessed. Participants proposed that these would improve the accessibility of the audit report, via a number of mechanisms. These included the use of common metrics, having a consistent format across the stroke pathway, signposting to salient details and including a concise summary.

Common metrics

Participants described the challenges of using metrics perceived as unique to stroke. "*I'm looking at data from all sorts of different places and they all use different measures, you have to stop each time and remind yourself what it means. If they could just measure a few common, core things that would make using them and comparing them easier at my level.*" **[P19 Commissioner]** It was suggested that this lack of familiarity with stroke specific measures, could be a potential barrier to commissioners understanding stroke data. "*It depends upon their* [Commissioner] *experience and what measures they're familiar with. I don't think there's a good understanding of our data, because we don't use a common language*." **[P17 Clinician]**

Consistent format

Differences were described in the format of the acute and post-acute reports. This was reported as presenting challenges in navigating the report and when making strategic decisions across a pathway. “*Having such a wide variation in the way in which data is presented is a problem for the pathway. You’ve got apples and oranges*.” **[P17 Clinician]** Participants alluded to these differences contributing to an underlying perception of a lack of parity between the post-acute and acute components of the audit. “*The problem is that community SSNAP doesn't look like acute SSNAP. It doesn't give you the same information, it looks completely separate, like it doesn’t belong”.* **[P7-Service Manager]** Participants speculated about the difference consistent reporting across the pathway would make. “*I'd be able to track the outcomes from acute, community through to discharge and six-month review and see…have we made a change?”* **[P5-Service Manager]**

Signposting

Feedback reports were described as lacking clear signposting to salient details, therefore time consuming to read and appraise. “*That's one thing I do struggle with, finding my way around the reports. I need a sort of guide to point me in the right direction, suppose signpost me to the important bits for me to know about”* **[P19-Commissioner]** Participants commonly described “*digging”* for information and highlighted a variety of strategies to locate pertinent information within the reports. *“The reports are huge; you can't always find the thing you need. So, I download the Excel spreadsheet and search for keywords…which is really time consuming”.* **[P5-Service Manager]** Participants suggested that clearer signposting within the report would improve its accessibility. “*It would be easier to get around data quickly. If I can do that, it makes it more useful for me when we're looking for gaps and where we need to improve*.” **[P19-Commissioner]**

Concise summary

Those overseeing a number of different services articulated a desire for clear headlines that could be easily located and digested quickly. *“When I'm jumping from hypertension and heart failure to cardiac rehab, to stroke, seeing what the picture is quickly is important”*. **[P19-Commissioner]** As a result, some teams provided Service Managers and Commissioners with executive summaries of the feedback report, to highlight salient details make efficient use of their time. *"I send the highlights; I don't send all of it because it’s overwhelming...to try and make it easier for them to read, so they're not digging for information.* **[P12-Administrator]**

Some participants expressed frustrations with a lack of performance headlines in comparison with acute services who were rated A-E by SSNAP. "*It's just a dead quick* [for acute services]. *You're an A, you're B. Whereas for us* [post-acute] *there's no headlines.*" **[P1-Team Lead]** This contrast between the ease with which performance data could be extracted from the acute and post-acute feedback reports was described as further contributing to a perceived lack of parity between acute and post-acute services*. "You go into the acute office, and they've got congratulations cards from the consultants and certificates from the trust "Well done on your A!" And I'm like we're working bloody hard too. You just need to read 5 graphs to realise it*." **[P1-Team Lead]** However, there was a lack of consensus regarding the rating of post-acute services. Concerns were raised regarding the psychological impact poor rating could have on teams. Participants pointed to the experiences of acute services where ratings reportedly impacted morale when they were introduced. "*It can be really demoralizing for teams. They can be trying their best to improve, and it doesn't necessarily play out in the SSNAP results." * **[P5-Service Manager]** Participants acknowledged the power of a poor rating to mobilise services to work towards improvement but were unsure whether the benefits of rating outweighed the risk to team morale.

This section has used interview findings to explore the contextual features and associated mechanisms that influence the ability of those in leadership roles to use audit feedback to inform strategic conversations.

c. The refined PT2 is articulated below, with the underpinning context, mechanism and outcome configuration.

PT2: If the audit feedback report is accessible, then it is more likely to be used by those in leadership to inform strategic conversations

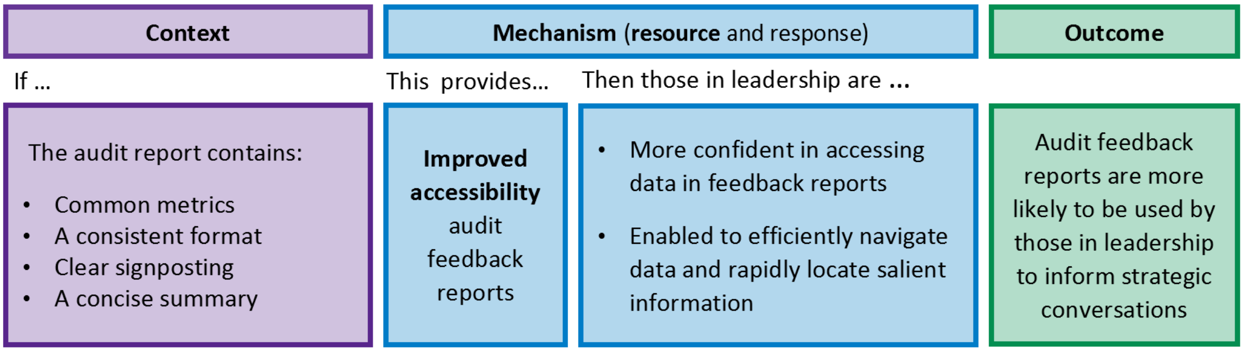


Figure 5-13: PT2 and underpinning CMO configurations

5.3.5 IPT3:

Platform challenges influence completeness of data

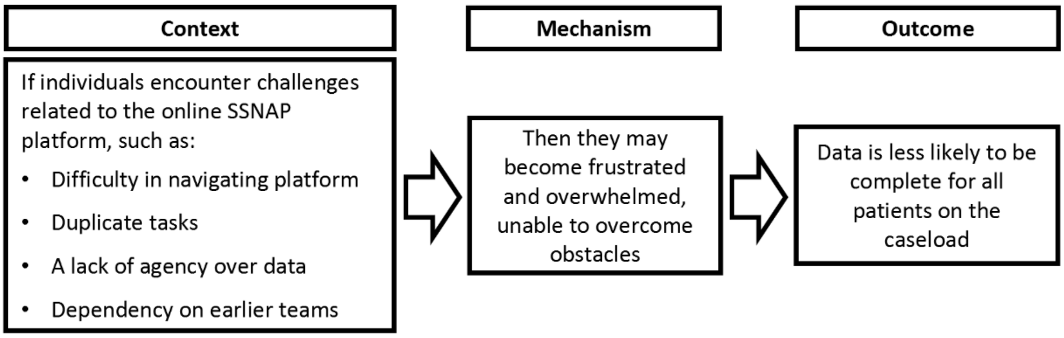


Figure 5-14: IPT3 and underpinning CMO configurations

a. Outcome of interest

The proposed outcome of interest for IPT3 was data being less likely to be complete. In early interviews it became clear that this negative framing of the outcome prevented participants expanding on underlying mechanisms. The outcome was reframed to offer opportunities for speculation and expansion on the proposed IPT3. The refined outcome was:

Data is more likely to be submitted for all stroke patients,
therefore represents the full post-acute caseload.

Complete data included compliance (completing individual items within a dataset), case ascertainment (completing the datasets for patients transferred to the team) and acquiring the datasets for all patients transferred to the team. Participants highlighted the importance of data being complete, otherwise they reported it failed to reflect the full post-acute caseload. This is explored in more detail in IPT4 as this outcome (complete data) underpins the context for IPT4.

b. Contextual Features

Although the proposed contextual features related to the online platform, interviews provided an opportunity to explore underlying causes of frustration when attempting to submit data. This IPT required a significant amount of circling back and exploring rival theories with participants to understand what it was about the online platform that contributed to data completeness. Ultimately, it became apparent that although difficulties manifested when entering data onto the online platform, the underlying causes were systemic. Instead, participants described the overarching influence of communication across the stroke pathway.

Communication across the stroke pathway

Effective channels of communication across the pathway were identified as a context contributing to the ability of teams to submit complete data. One participant described their frustrations "*For those twenty percent of patients not on there* [not transferred]*, it might be we've e-mailed three times, and they still haven't replied to me*." **[P15-Team Lead]** Participants described three components of this context that influenced their ability to submit data. These were a network of SSNAP users locally, a forum in which to collaborate and the availability of contact details for teams in other regions.

Networks

Participants described networks as being instigated or led by either audit champions or administrative support within their team dedicated to SSNAP. The aim of these networks was to support communication between teams on the stroke pathway. "*We're trying to get a regional network of SSNAP administrators. Our administrator is "on it" and has got key people she links with. She goes out of her way to build relationships with the new SSNAP administrators*". **[P15-Team Lead]** Networks were described as evolving organically in response to the development of new teams, or purposefully following the identification of issues regarding communication. "*We had a meeting to understand what each team did. Now we're trying to get communication once a month and hopefully things can be a bit smoother than before."* **[P13-Support Worker]**

Forums

Forums such as in-person meetings were described as an opportunity for knowledge exchange between SSNAP users across the pathway. Participants described their purpose as two-fold, firstly to ensure a shared understanding between teams regarding audit processes. *"Inpatient SSNAP, they're not in our care group but we've got a good relationship with them. We have meetings to make sure therapists are entering the information correctly."* **[P14-Support Worker]** Secondly, participants described forums as an opportunity for quality assurance of the data they are submitting, and records transferred to them. "*The other way that she's using it* [meeting with acute team], *is as a safety net. She'll be checking who has been transferred to our service. If they're not names she recognises, we'll be going back to the referring unit."* **[P15-Team Lead]**

In the presence of opportunities for knowledge exchange, participants described a perception of shared goals around SSNAP. These goals included the timely and accurate curation and completion of SSNAP records. “*There's a weekly cross check with the inpatient colleagues, we’re all really keen that transfer of records from inpatient to community is timely.”* **[P4-Service Manager]** For those teams employed by the same organisation, their existing relationships were described as facilitating collaboration towards these shared goals. “*We are different teams within one organization, but she can the transfer the records along to six-month provision.*” **[P17-Clinician]** This ability to transfer records across a pathway was described as less frustrating and more time efficient for administrative staff, as well as reducing the incomplete data submitted.

Availability of information

Stakeholders used information about other teams submitting to SSNAP for two purposes. Firstly it highlighted the teams they interacted with to help them understand their clinical pathways and secondly it provided contact details for those teams. SSNAP resources such as the transfer tree helped to identify teams they referred to or accepted referrals from. This resource enabled them to have a greater understanding of their clinical network and transfer patient records more efficiently. *“SSNAP data has been really useful, especially the transfer tree. Knowing who are the common people referring in and out to. Linking in with contacts to ensure the SSNAP record is transferred seamlessly. In a big area with multiple different providers, knowing who to pick up the phone to when you want records sent over. The transfer tree was probably the most useful thing for that.”* **[P9-Service Manager]**

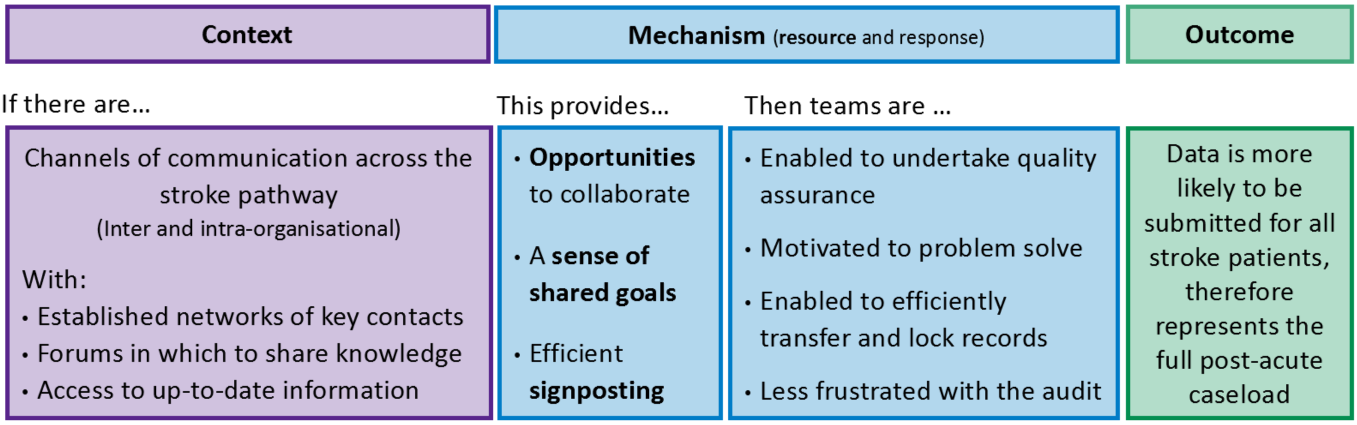
In the absence of up-to-date contact details, participants described the challenges of communicating with providers outside their region and the subsequent impact in terms of ineffective use of resources (time) and the resulting frustrations for the team. “*Locally the pathway is smooth, and we know all the names. But when you go wider than our borders, then it gets very difficult. You ring wards and they won't have a clue. So, it's a lot of phone calls and we have to ring them again and again. You collect a list of names for different hospitals and then obviously people change jobs. It’s annoying it takes up loads of time.”* **[P1-Team Lead]**

In addition to the extra administrative burden, participants reported these challenges often resulted in incomplete data submission, therefore not representative of their full stroke caseload. "*Lots of patients don't get transferred across on SSNAP. We do chase, they don't always have the contact details of the right person. There's only so much you can do. So some patients fall off SSNAP*.**"** **[P8-Service Manager]** When using resources offered by SSNAP such as the helpdesk, participants described finding the available information of limited use. *"The SSNAP team…they give you the person who registered ages ago, usually the head of service. It's not the actual admin people who are inputting the data now."* **[P8-Service Manager]** There was agreement that teams would benefit from up to date and accurate information regarding key contact details for teams submitting to SSNAP (both acute and post-acute). It was suggested that this would not only enable them to submit more complete data, but also be a more efficient use of their time and be less frustrating for those attempting to submit data.

This section has highlighted how communication across a clinical pathway contributes to the submission of data that represents a complete caseload. Three components underpin this communication, a network of SSNAP users locally, a forum in which to collaborate and the availability of contact details for teams in other regions.

c. The proposed IPT3 has been refined, expanded upon and reframed through collaborative realist interviews, resulting in the following programme theory (PT3) with the underpinning context, mechanism and outcome configuration.

PT3: Channels of communication across a clinical pathway support data completeness



Context	**Mechanism** (resource and response)		**Outcome**
If there are…	This provides…	Then teams are …	
Channels of communication across the stroke pathway (Inter and intra-organisational) With: • Established networks of key contacts • Forums in which to share knowledge • Access to up-to-date information	• **Opportunities** to collaborate • A **sense of shared goals** • Efficient **signposting**	• Enabled to undertake quality assurance • Motivated to problem solve • Enabled to efficiently transfer and lock records • Less frustrated with the audit	Data is more likely to be submitted for all stroke patients, therefore represents the full post-acute caseload

Figure 5-15: PT3 and underpinning CMO configurations

5.3.6 IPT4:

Perceptions of data accuracy influence the use of feedback

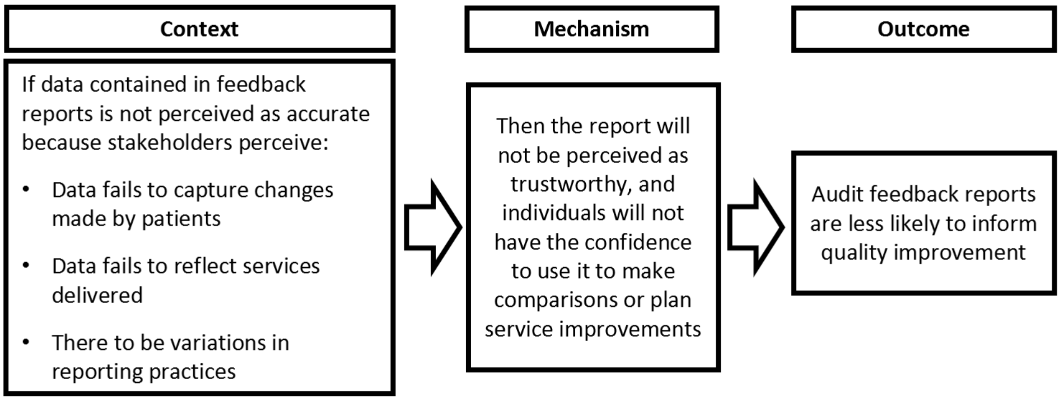


Figure 5-16: IPT4 and underpinning CMO configurations

a. Outcome of interest

The proposed outcome of interest for IPT4 was audit feedback reports being less likely to inform quality improvement. It became apparent in early interviews that this negative framing of the outcome limited the scope of participant responses. This was therefore reframed to offer opportunities for speculation and expansion on the proposed IPT4. The refined outcome of interest:

Audit feedback reports being more likely to be used for quality improvement.

b. Contextual features

Findings identified two distinct contextual features that were described as influencing the likelihood of feedback reports being used for quality improvement. Firstly, the degree to which stakeholders perceived the report to be accurate and secondly whether stakeholders had access to and understanding of local data collected by their organisation. These are summarised in turn in the following paragraphs.

Stakeholder perceptions of the accuracy of audit feedback reports

Three components were highlighted as influencing a participant's perception of accuracy. These were its ability to reflect a complete and recent caseload, reflect the service delivered and finally capture changes made by patients. IPT4 proposed that perceptions of variations in reporting practices influenced the likelihood of stakeholders using audit feedback reports for quality improvement. Although acknowledged by participants, this was not described as influencing the use of feedback reports. Potential reasons for this will be discussed later in this chapter.

Reflects recent and complete caseload

A lack of contemporary data was reported to impact the perceived relevance and utility of the feedback report for the team. This was described as presenting challenges when teams attempted to explain trends in performance. "*By the time I get information back… it's not relevant or fresh in my mind. If it showed an up-to-date caseload, it would mean more to me and the team, and we could use it.*" **[P1-Team Lead]** This perception of data being "*out of date*" impacted their ability to confidently use it for quality improvement. *"By the time you get the report, it's not an accurate reflection of what you're doing now. So, it's difficult to use confidently…if you want quality improvement you've got to wait six months before the next report comes out."* **[P3-Team Lead]**

Two sources were highlighted as resulting in the inaccurate reporting of patient numbers. Firstly, participants described patients being referred to post-acute teams without existing SSNAP records. "*There's no one offender... it might be they come through TIA clinic, they've had a subarachnoid haemorrhage…a fracture and then a stroke, so they don't go on SSNAP from the acute*." **[P15-Team Lead]** Participants reported this impacted their confidence to use feedback. *"On SSNAP, last year the number of patients actually transferred through to us was probably half what we actually saw, so it's quite a significant difference."* **[P1-Team Lead]** Secondly, the necessity to lock records at six-months, often before rehabilitation ceased. *"Do we capture every patient? No, we don't. A lot of our input is past six months and SSNAP is only interested in six months."* **[P17-Clinician]** As a consequence, some participants reported a reluctance to using it for quality improvement. *"We know we lose so much data, we don't feel it's an accurate reflection of what we do. We haven't got to a point where we felt that we could use it for service improvement*." **[P3-Team Lead]**

In contrast, a number of participants challenged the need for absolutely complete data. "*Are we going for 100% or are we saying actually this is a good enough…enough to give us an indication."* **[P17-Clinician]** Participants questioned whether the benefit of capturing every patient, was worth the resources. *"The efforts put in to get data are huge, and the difference between a rough match and the exact fine detail, aren't huge. In terms of manpower and effort and cost, it's just not worth it. I'm happy as long as it's roughly there."* **[P19-Commissioner]**

Reflects service delivered

Participants described feedback as failing to reflect either the service model or the interventions provided. Concerns were raised that teams were registered for SSNAP based on historical time-limited service models, which no longer match current guidance. Participants described these discrepancies as influencing their confidence to use feedback reports for quality improvement. "*It's just not easy to pin down how you measure up against other teams so I wouldn't be that confident using it*." **[P8-Service Manager]** Distinctions were made between the delivery of acute and post-acute rehabilitation, not reflected in the audit report. Participants described the challenges of capturing aspects such as self-management and interdisciplinary working, reported as more common in the post-acute setting. Interdisciplinary working is where a single professional is skilled in delivering interventions from more than one discipline. "*You might be doing really well at providing psychological support as a team that's not captured in SSNAP because it's not provided by a clinical psychologist.*" **[P3-Team Lead].**

The exclusion of activities other than direct treatment, such as phone calls and initial assessments was described as failing to reflect the activities undertaken by services. "*If a physio's out there for an hour doing an initial assessment it doesn't get captured in SSNAP*". **[P3-Team Lead]** This was described as specifically pertinent in the post-acute setting due to time traveling between patients. "*We cover a really big area. So a lot of our therapist time is spent getting to that patient so no, not always true reflection*." **[P14-Support Worker]** Participants expressed a desire for greater detail with regards to describing services but acknowledged the potential consequences on the burden of data collection. *"It's a tricky balance … you don't want to create something that's going to take forever to fill out. At the same time, I don't think it's hugely meaningful data that comes back or necessarily representative of what we're doing.*" **[P16-Team Lead]**

Captures changes made by patients

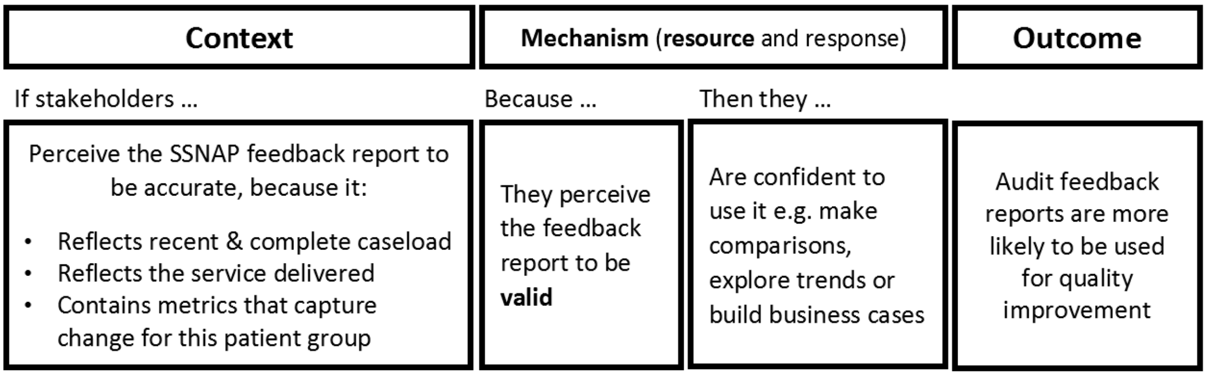
Participants described SSNAP as failing to capture the impact of rehabilitation services, or the progress made by stroke patients in the post-acute setting. A number of perceived limitations were reported with regards to the measures used. These included the time at which measures were completed, their sensitivity to change and the absence of patient reported outcome measures. Participants questioned the value of recording measures at a single point in time. "*I'd like to track the outcomes from acute, inpatient, community, through to discharge and six-*

month review. To see actually, have we made a change and at the minute, I can't do that.” **[P5-Service Manager]**

There was broad agreement regarding the perceived limitations of the mRS which is currently collected on discharge from services, in terms of its sensitivity. “*The mRS is a bit of a blunt object in terms of measurement*.” **[P9-Service Manager]** Participants expressed frustrations at its failure to capture changes made by patients. “*Patients might have made really good improvements in terms of quality of life and functional improvements, but that won't be demonstrated on mRS at all. So it doesn't look like they've improved*.”**[P18-Clinician]** Consequently, participants reported reservations with sharing audit feedback in strategic conversations. “*So it's still not giving a true reflection of the change. That worries me about sharing this document more widely because if I was a Commissioner, I'd look and go that's not good, why are we commissioning that?”* **[P15-Team Lead]**

Participants expressed a desire to collect patient reported outcome measures. “*PROMS would be really helpful. To see what the impact of the services are, and I don't get that from SSNAP now. And that would be really useful.”* **[P5-Service Manger]** Specific examples were given regarding the EQ5D which is currently only collected at six-months post stroke. Participants from both commissioning and service manager roles highlighted the lack of a repeated measure as limiting the strategic utility of SSNAP feedback. “*If they had one done [EQ5D] in the acute and then it's done at the six-month review to see how far that patient has come. From a commissioning point of view it would be useful*.” **[P20-Commissioner]**

Figure 5-17 describes the refined CMO configuration for the contextual feature: Perception of report accuracy.



Context	**Mechanism** (**resource** and response)		**Outcome**
If stakeholders ...	Because ...	Then they ...	
Perceive the SSNAP feedback report to be accurate, because it: • Reflects recent & complete caseload • Reflects the service delivered • Contains metrics that capture change for this patient group	They perceive the feedback report to be **valid**	Are confident to use it e.g. make comparisons, explore trends or build business cases	Audit feedback reports are more likely to be used for quality improvement

Figure 5-17: PT4 – Contextual feature perceptions of report accuracy

Access to local service-level data

The second contextual feature identified as influencing the likelihood of feedback reports being used for quality improvement was stakeholder access to and understanding of their own local data. This was described as enhancing confidence to use data in strategic conversations via two mechanisms. Firstly by using local data to support or compliment SSNAP feedback and secondly by using local data to provide a narrative for SSNAP feedback.

Participants described comparing their local data with SSNAP feedback, looking for differences that may indicate data collection or reporting errors. This quality assurance was described as enhancing the credibility of SSNAP feedback. *“But it's not always 100% accurate. So we also collect manual data that's cross checked until we're a bit more confident. It’s getting much more accurate.”* **[P11-Team Lead]** In addition to quality assurance, participants described using local data to supplement SSNAP feedback. Where additional metrics were collected as part of a local data-set, this provided greater detail for strategic conversations. *“I'm putting together a business case, what’s SSNAP telling us? Then we back it up against what we collect on Rio, to cross reference and they can put both in their business cases*.” **[P12-Administrator]**

Local data was described as providing a narrative and offering context for SSNAP feedback. Details such as staffing establishments and referral trends were reported as being used to support strategic conversations regarding performance. *“You have to give a narrative around it. So yes, we're coordinating the data source with other data sources as to why performance is where it is.”* **[P17-Clinician]** Participants who used local data to support the scrutiny of audit feedback, reported this contributed to their confidence in using feedback for strategic conversations. “[By cross-checking data] *we get a good picture of what’s going on, if there are any caveats, we add those as appendixes, on the whole I feel confident in our data set yeah.”* **[P12-Administrator]**

This section has highlighted two contextual features that influence the likelihood of SSNAP feedback reports being used for quality improvement purposes. These were the perceived accuracy of the SSNAP feedback report and access to local data, both of which increase stakeholder confidence in using feedback reports for quality improvement.

c. The proposed IPT4 has been refined, expanded upon and reframed through collaborative realist interviews, resulting in the following programme theory (PT4) and its underpinning context, mechanism and outcome configurations.

PT4: If teams are confident in the accuracy of feedback reports and understand their local context, reports are more likely to be used for quality improvement

Context	**Mechanism** (**resource** and response)		**Outcome**
If stakeholders …	Because …	Then they …	
Perceive the SSNAP feedback report to be accurate, because it: • Reflects recent & complete caseload • Reflects the service delivered • Contains metrics that capture change for this patient group	They perceive the feedback report to be **valid**	Are confident to use it e.g. make comparisons, explore trends or build business cases	Audit feedback reports are more likely to be used for quality improvement
Have access to, and understanding of local service level data	This provides: • **credibility** to the report • **local context** for SSNAP report	•Are confident in the collective explanatory power of the data •Are enabled to provide a local narrative for data	

Figure 5-18: PT4 and underpinning CMO configurations

Realist interviews have been used to refine and test four IPTs, resulting in four PTs that seek to explain the mechanisms by which SSNAP contributes to quality improvement in community stroke care. An overview of the four PTs is provided in Figure 5-19.

Four theories that seek to explain the mechanisms by which SSNAP contributes to quality improvement in community stroke care

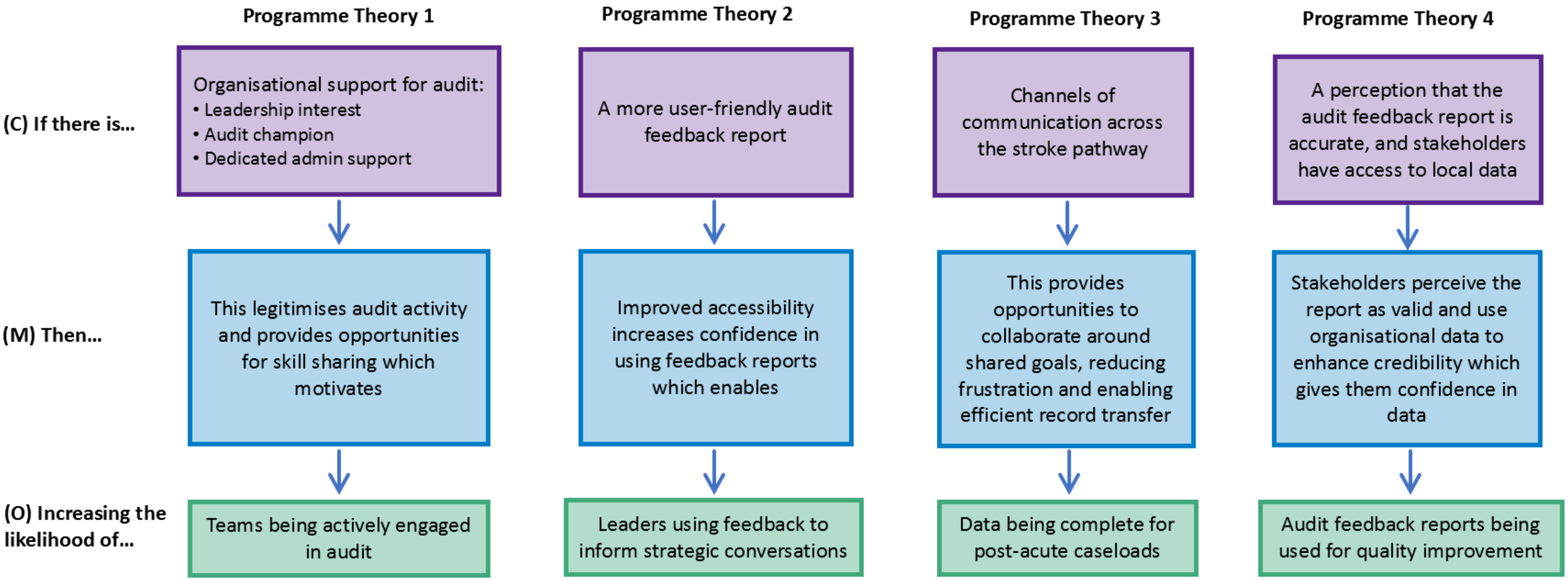


Figure 5-19: Overview of the four proposed programme theories

5.4 Discussion

This chapter builds on findings from previous chapters, exploring how SSNAP contributes to quality improvement in community stroke rehabilitation. Findings have been used to refine and test IPTs, resulting in four PTs that seek to explain this contribution. The following section situates findings in the context of existing audit and feedback literature and highlights what is added to the evidence base. Study strengths and limitations are detailed. The implications for research, policy and practice are discussed later in Chapter 7.

Organisational support (PT1)

Addressing challenges to accessing and using audit feedback has the potential to increase leadership interest in SSNAP. PT1 proposes leadership interest, along with the presence of an audit champion and having dedicated administrative resources, are features of organisational support. Findings from this study suggested that the organisational support offered by the healthcare provider (commonly an NHS Trust), motivated and enabled teams to be engaged with SSNAP in the community setting.

A systematic review regarding the influence of context on the effectiveness of healthcare quality improvement by Kringos et al. found a substantial body of literature referring to the enabling effects of organisational support[249]. For national clinical audits specifically, there was a suggestion that a "*lack of active interest*" from leaders contributed to a failure to engage clinicians in audit[32,33,173]. A number of studies proposed leadership engagement to be a prerequisite for another contextual feature, the presence of a champion, highlighted by this study as influencing team engagement in audit[16,30].

Hut-Mossel et al. proposed champions to be "*vital*" if healthcare professionals were to perceive audit as a worthwhile activity[16]. Brown et al. also identified champions as a variable in four theories that contributed to the Clinical Performance Feedback Intervention Theory (CP-FIT)[30]. Champions may be defined as individuals who *"work within an organization and who dedicate themselves to promoting a change within the organization"*[250]. In Miech et al.'s integrative review of the literature regarding champions in health care settings, they found the presence of champions to be associated with successful implementation[193].

This study found *champions* to be conceptually fluid, not consistently undertaken by someone in the same role in each team, and sometimes shared between more than one individual. This echoes suggestions from both Soo et al.[251] and Damschroder et al.[252] who point to the advantages of multiple champions who "*leverage their respective organisational position*", especially where the intervention requires a change in behaviour. Where participants in this study described the champion role being shared, they commonly alluded to this being what Miech et al. describe as a "*champ-and-chief*" model[193]. In other words, the champion role is shared between two individuals, the more junior motivates via role modelling, whilst the more senior has the authority or expertise to enable engagement. The most common configuration of shared champion roles in this study was that of an Administrator and a Team Lead working together to support the implementation of SSNAP findings. Where the champion role was described as being fulfilled by a single individual, this was commonly reported as someone acting in multiple capacities. For example, a Team Lead also employed by the ISDN at a strategic level. In the literature these individuals are described as organisational boundary spanners, possessing both an appreciation of different perspectives and the ability to influence more widely[250].

The champion roles identified by participants in this study were described as exclusively emergent, in that they evolved naturally rather than individuals being selected and appointed. Although there is a clear distinction between emergent and appointed champions within the literature, there is little evidence to support which is more effective[250]. A number of studies have made suggestions as to the key characteristics that a champion should possess. These include "*influence, ownership, physical presence at the point of change, persuasiveness, grit, and participative leadership*"[192] as well as "*negotiation skills, advocacy, communication across organisational boundaries, enthusiasm and energy*"[193]. However, there is both ambiguity and debate in the literature as to whether these terms describe the characteristics of a champion, or the activities they undertake[250]. To address this challenge, Shea proposed a model that distinguishes between the characteristics, activities and outcomes of a healthcare champion. This model suggests that a champion's commitment and experience influences their activity, in turn influencing their engagement with peers and ultimately their impact[250].

There are a number of similarities between this conceptual model and PT1 as proposed by this study including the activities undertaken by a champion to support effective implementation. However, when seeking to understand the contribution made by champions in using SSNAP to drive quality improvement in community stroke rehabilitation, PT1 provides greater explanatory power for a number of reasons. Firstly, it is nuanced to this setting, informed by stakeholder experiences and insight. Secondly, it provides ontological depth through the explication of the underlying causal mechanisms of role modelling and skill sharing. Finally, it is focussed explicitly on an outcome of team engagement in SSNAP. Findings from this study suggest team engagement to be fundamental in achieving the potential of SSNAP as a tool for quality improvement in the community setting.

Dedicated administrative support, or a lack thereof, is widely acknowledged in the literature as influencing the ability of an audit to contribute to quality improvement[32,34,173]. However, this study found that beyond the obvious *resource* offered by dedicated administrative support, their presence triggers other mechanisms that may have a more profound influence on the engagement of teams in SSNAP in the community. This study suggests that the availability of dedicated administrative support indicated the value placed on SSNAP by the organisation. This in turn legitimises audit activities and raises the profile of any SSNAP-related activities. The presence of dedicated administrative support enabled the efficient use of a team's skills. In this context, SSNAP was seen as enhancing rehabilitation as opposed to detracting resources from it. Shea's model suggests that the impact of a champion is dependent on organisational support specifically for the individual. In contrast, PT1 proposes that together leadership interest, administrative support and the presence of a champion *are* the organisational support required to engage team level stakeholders with audit in the community setting.

Findings from this study highlighted distinctions between acute and community stroke services with regards to organisational support for teams to engage with SSNAP. Firstly, there was a perception that leaders were less interested in SSNAP feedback reports from community teams in comparison with acute services. Findings suggest a lack of clear headlines within the community report may contribute to this perception. Secondly, champions were described as pivotal to team engagement in the community setting. Although this study did not explore the acute setting in order to enable comparisons, there are acknowledged features of community services that may generate a greater reliance on champions to motivate and engage the wider team in this setting. These include the heterogenous nature of community services, dispersed team location and less routinised team activity compared with acute services. Finally as mentioned in Chapter 1 (section1.2.3), due to the evolution of community services and their relatively small size, community teams often lack the administrative capacity or established infrastructure when compared with acute stroke services.

Accessibility of feedback (PT2)

This study found the accessibility of feedback influenced the likelihood of those in leadership roles using it to inform strategic conversations, such as commissioning or service development. However, there is a national shortfall in analytical capability within healthcare organisations in the UK[253,254]. This may present challenges for stakeholders without analytical skills and expertise, who lack the technical support to interpret audit feedback for quality improvement purposes. In this situation, there could be an argument against healthcare organisations investing in upskilling selected individuals to analyse such data. Instead, should the onus be placed on data providers to improve the accessibility of their reports? This would not only reduce the analytical burden on healthcare providers but also enable scrutiny by a wider audience.

Studies have pointed to a lack of clear, easily understood feedback as contributing to the failure of audits to result in quality improvement[184,204,231]. A recent randomised controlled trial by Willis et al. investigated the optimisation of national clinical audit outputs[255]. Willis et al. highlighted the limited time stakeholders have to evaluate audit findings, noting that "*minimising extraneous cognitive load was effective…improving intended enactment, intention to review performance and ease of understanding*". Their results echo not only the findings of this study, but also a number of earlier studies regarding necessity for focussed audit feedback[26,30,196].

This study proposed the use of "headlines" to support stakeholders in digesting and navigating the findings of feedback reports. This is supported by McVey et al. who suggested a single headline metric would reduce frustration for stakeholders who were often presented with extensive narrative reports containing multiple tables of data[33]. In some respects, this is already addressed within the acute component of SSNAP by the grading of sites as A-E. However, this is not offered within the post-acute component of SSNAP. Although there was much debate within interviews, participants were equivocal regarding the relative advantages of grading services in the community setting.

The inclusion of EQ5D was proposed by a number of participants as an alternate headline, potentially summarising the impact of community services. This PROM is already collected by SSNAP at six-months post stroke and is widely used internationally in both clinical practice and research for stroke and other conditions. The inclusion of this measure when commencing community rehabilitation would satisfy recommendations made by an international group of experts in stroke audit methodology[256]. Yu et al. proposed measures be collected across the stroke care continuum, harmonised to enable ease of comparison both along the clinical pathway and between organisations. The inclusion of a common metric may go some way towards reducing the barrier of heterogeneity within UK national clinical audits, described by McVey as impacting the ease with which they can be used to make comparisons between services[33].

Channels of communication (PT3)

Quality improvement requires systems to be in place for knowledge sharing, coordinating activity and fostering cultures that support improvement efforts[257]. A number of existing theories highlight the role of these inter- and intra-organisational networks in effective audit and feedback[16,30]. These networks provide transactional opportunities for individuals to share information such as contacts or favours[257]. Powell describes networks as invaluable for the exchange of "*know-how*"; tacit organisational or procedural knowledge which is commonly implicit and rarely written down[258].

The networks described in the audit and feedback literature predominantly concern the communication of feedback, sharing of learning, and support of subsequent action[16,30]. In contrast, the networks explored in this study were concerned with supporting the implementation of audit, specifically the submission of complete data. (It is acknowledged these networks may serve other purposes which were outside the scope of this study). However, PT3 suggests that established networks alone are insufficient. This study proposes that in addition to networks, up to date information and knowledge sharing opportunities are required to effectively signpost and enable collaboration around a shared goal (the submission of complete data). This is echoed by Martin and Dixon-Woods who propose "*collaboration cannot exist without a network, a network on its own does not equate to a collaboration*"[257]. They suggest that whilst networks may lack a *raison d'être*, collaborations are always purposeful.

Whilst the evidence base for collaboration-based approaches is equivocal[257], there are examples of multidisciplinary teams using collaboration-based approaches resulting in quality improvement in acute stroke care. Results from a cluster randomised trial involving hospitals in the Northwest of England in 2008-09 suggested that quality improvement collaboratives were associated with improvements in relation to core process measures such as delivery of medication and completion of specific assessments [259]. The impact of collaboratives was found to be inconsistent across the process measures collected. Authors suggested outcomes may be dependent on the degree of control participants have over specific processes[259]. This may explain an advantage of collaboration reported by participants in this study. Where individuals with limited personal control worked together across organisational boundaries, this increased their collaborative influence. In an earlier study, Kilbride et al. described the development of stroke services in London in 2000-02. The collaboration-based approach used was attributed as bridging professional boundaries, generating mutual commitment to a common purpose[260]. Again, this concurs with participants in this study who reported being motivated around a shared goal of submitting timely and accurate data.

Martin and Dixon-Woods suggest there is limited understanding of components of collaboration-based approaches that may influence change and how causal mechanisms operate[257]. However, this study has used realist methods to illuminate the mechanisms by which collaboration across the stroke pathway increased the likelihood of efficient and complete data submission for the post-acute stroke caseload. Findings suggested a sense of shared goals, efficient signposting and opportunities to collaborate enabled the appropriate and efficient transfer of records, resulting in more timely data submission. Community teams are often in the middle or end of a chain, preceded by multiple providers, on whom they are dependent for the timely transfer of records. Consequently, collaboration-based approaches could be invaluable in overcoming some of the many challenges of communication and data transfer reported by participants in the community setting.

Perceptions of data accuracy (PT4)

Consistent with the existing audit and feedback literature, this study found a participant's perceptions of feedback accuracy and credibility influenced their likelihood of using it to inform quality improvement[19,26,30,255]. PT4 uses the term *validity* to encompass four conditions, described by participants as underpinning perceptions of feedback accuracy in this setting. These are echoed in the wider literature and include the timeliness of feedback[30,33,261], completeness of data[75] (i.e. representing a full caseload), reflecting the services delivered[30,232,261] and capturing changes made by patients in this setting[173].

Findings highlighted a conflict between the burden of data collection and a desire for process measures that accurately reflect the services delivered or outcome measures that capture changes made by patients. Participants described a desire to collect a greater number of metrics, aligning with the detail and perceived status of the acute SSNAP report. However, the wisdom of increasing the data burden was questioned when many teams lacked the administrative support to collect or leadership interest in, the current community dataset. Findings highlight concerns regarding limitations of outcome measures included in the dataset namely the mRS. The mRS was consistently described as failing to capture changes perceived by stroke survivors in the community as important, such as their quality of life or mood. Whilst health-related quality of life may improve during inpatient rehabilitation, evidence suggests it may deteriorate in the six-months after discharge[262,263]. This presents challenges for community services, who wish to capture changes in this population and demonstrate the impact of their needs-led services.

With limited capacity for increasing the number of metrics collected by community teams, this study suggests prioritising the inclusion of a single PROM to capture health-related quality of life, the EQ5D. The EQ5D is already collected by community teams as part of the six-month review assessment. The addition of EQ5D on commencement of community rehabilitation has the potential to demonstrate the impact of services on a patient's health-related quality of life.

Willis et al. found stakeholders were more likely to engage with feedback they perceived as credible[255]. This in turn facilitated a number of subsequent steps in the CP-FIT cycle: interaction, verification, acceptance, intention and behaviour[30]. This study suggests that the incorporation of local service level data provided credibility for audit feedback as well as a local context. Stakeholders described being more confident in the explanatory power of audit feedback when they were able to combine this with local service level data. This is echoed by Sarkies et al. who suggested a combination of "*externally validated feedback with local, codified knowledge*" provided greater leverage when using audit feedback to develop business cases for quality improvement[232].

Local service level data may be more valuable for community services than acute for three reasons. Firstly, the need to contextualise national clinical audit data may be greater in community services which are more diverse than acute services. Secondly, with the reliance on others to transfer records appropriately and artificially end records at six-months, SSNAP feedback may not reflect community caseloads as accurately as it does for acute services. In situations such as this where data is incomplete, Wolpert and Rutter suggest a strategy of triangulation with other data sources (such as local data) builds a more robust understanding of outcomes[234]. Finally, SSNAP only provides feedback every six months for community services, in contrast with every three months for acute services. Few participants were aware of the underlying reason for the frequency, namely insufficient data to provide meaningful analysis without significant spontaneous variation. Many participants described this frequency as challenging, and as a result required supplementing with local data.

This RE has generated four refined PTs that seek to explain the mechanisms by which SSNAP contributes to quality improvement in community stroke care. They have been tested and refined with a spectrum of participants from different contexts, purposely limited to community stroke care. Although the theories generated have a level of abstraction, they are sufficiently granular to enable their practical application at an organisational or team level. This discussion section has situated these PTs in the context of the existing audit and feedback literature, demonstrating their applicability beyond stroke. It is proposed that these findings may be relevant to multidisciplinary teams seeking to undertake quality improvement in the community setting.

5.4.1 Strengths and limitations

Research into national clinical audits has predominantly been concerned with either organisational or clinical perspectives. In contrast, this study explored a broad variety of perspectives from audit stakeholders representing administrative staff, clinicians, team leads, managers and commissioners. This study is also the first of its kind to specifically explore multidisciplinary audit in the community setting. These factors have enabled both the generation of new insights and the nuancing of existing understanding regarding the role of national clinical audit in quality improvement in the community setting. The involvement and detailing of the contribution of collaborators has provided specialist expertise and objectivity, enhancing the rigour of this study.

The survey in Chapter 4 identified variability in reporting practices as undermining perceptions of feedback accuracy. However, interview findings did not suggest this reduced stakeholder confidence in using audit feedback. Instead, participants described a tacit expectation that teams may interpret guidance differently, resulting in subtle systematic differences in reported performance. Although participants denied these differences influenced their confidence in data, it is possible that interviews inhibited participant candour. In contrast with online surveys which are known to reduce the normative pressures on participants to provide socially desirable responses, the presence of a researcher in the interview scenario may influence findings[264]. This is an acknowledged limitation of qualitative interviews and may occur for a number of reasons. These include a participant's perceived risk of disclosing information that may be contentious[265] or their desire to offer responses deemed to be socially acceptable[264]. Other considerations such as a perceived link to SSNAP are discussed in the reflexivity section in Chapter 7.

Study strengths include participants being geographically diverse, with broad representation of roles to illuminate different facets of the audit process. In addition, these were in similar proportions of roles (e.g. Commissioners, administrative staff, clinicians) as employed within community stroke. It is acknowledged that stakeholders who volunteered to participate in both the survey and interviews, may have been those with particularly strong views regarding SSNAP and this may be a limitation to this study. It is possible that participants from teams that were either unable or disinclined to participate in SSNAP (or this research), may have provided different perspectives regarding SSNAP or quality improvement in general.

5.4.2 Conclusion

This realist study proposes four programme theories that explain specific mechanisms by which SSNAP contributes to quality improvement in community stroke care. Unique features of the community context have been identified that influence these mechanisms. Findings add to the existing literature, providing transferable insights into the role of national clinical audit in driving quality improvement in community services. These include the importance of organisational support for audit including dedicated administrative support, leadership interest and the fostering of audit champions. There was a recognition of the importance of accessible audit feedback to enable its strategic use and the role of collaboration-based approaches along the clinical pathway. Finally, the metrics collected must be perceived by stakeholders as reflecting both the service they deliver and the populations they serve.

5.5 Chapter summary

This chapter has used realist interviews to refine and test IPTs resulting in four PTs which it is proposed explain the mechanisms by which SSNAP contributes to quality improvement in community stroke care. Recommendations informed by these findings regarding policy, practice and future research are made in Chapter 7.

However, there is a specific proposition made by this study that requires further investigation, the use of EQ5D to demonstrate the impact of services on patient recovery. Before such attempts are made, a greater understanding is required regarding the properties of this measure, and its use within this population. These are explored in the following chapter.

6 Exploring EQ5D in the context of community stroke care

Using national clinical audit data to understand what influences the EQ5D in this population.

6.1 Introduction

At first glance, a quantitative exploration may appear to be incongruent with RE. However, this line of inquiry sought to scrutinise a specific contextual feature of PT4, proposed in chapter 5 (see figure 6-1). PT4 suggested that if the audit collected a metric, perceived as capturing change for this patient group, this would increase the likelihood of stakeholders using SSNAP feedback for quality improvement.

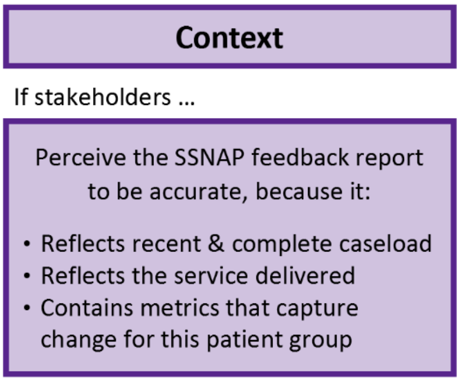


Figure 6-1: Contextual features of Programme Theory 4

Two main factors were considered regarding the merits of undertaking this final phase of study. Firstly, it would provide an opportunity to explore and build upon the existing evidence-base regarding a measure that study participants had suggested would capture changes for their patient group, the EQ5D. Participants in both study phases two (survey) and three (interviews) expressed a desire to use the EQ5D for quality improvement. Discussion with clinical collaborators highlighted a lack of understanding regarding the information offered by the EQ5D and how this could be used by clinical teams for quality improvement. Any new understanding arising from this quantitative exploration could support the implementation of theoretical findings from the study.

Secondly, the student had aspirations to explore a variety of methods and present a well-rounded thesis, that demonstrated a breadth of learning. The supervisory team were divided over whether this final phase of study was necessary as the preceding RE was thought by some to be sufficient. However they were happy to support and acknowledged the potential value of any new understanding to the interpretation of national clinical audit data.

This chapter details a quantitative exploration of the EQ5D in the context of community stroke rehabilitation and comprises three sections. Firstly, the measurement of health-related quality of life is introduced, the EQ5D is described and the evidence-base for its use in stroke summarised. Secondly, the influences on both EQ5D, and change in EQ5D over time for community dwelling stroke survivors are explored using statistical analysis of national clinical audit data from SSNAP. Finally informed by this analysis, the interpretation of EQ5D in this population is discussed.

6.2 Health related quality of life

Before considering the EQ5D, it is important to understand the purpose of such a measure. Therefore, the following section provides an introduction to health-related quality of life (HRQoL) and patient reported outcome measures (PROMs).

6.2.1 What is health-related quality of life?

Diseases, such as stroke may impact HRQoL, however the correlation between observable symptoms and perceived HRQoL is not absolute[266]. In reality, patients reporting poor HRQoL may not necessarily present with severe disease. Instead, HRQoL is the culmination of an individual's personal attributes, cognitive responses and social environment[267]. The subjective nature of these contributions means conceptualising HRQoL can be challenging. This has resulted in the use of vague or inconsistent definitions in the literature[268]. For the purposes of this study, the definition below, offered by Brazier et al.[269] has been used. Although brief, when discussed with clinical collaborators it was found to be self-explanatory and used language accessible to all stakeholders.

> "*The impact of the health aspects of an individual's life, on that person's quality of life or overall well-being*."

6.2.2 How and why is health-related quality of life measured?

Although medical interventions may save and therefore prolong life, it is important to understand the consequences for patients. Without assessing HRQoL, interventions may be perceived as successful despite poor outcomes such as psychological impairment or restricted participation[270]. For example, following mechanical thrombectomy a stroke survivor may score highly on the Barthel Index but struggle with social activities or mood. Outcomes that are important to stroke survivors such as HRQoL and the psychological effects of stroke are acknowledged as intrinsically difficult to collect at scale[64]. For these outcomes, patient reported outcome measures (PROMs) may offer a potential solution.

PROMs are a recognised approach to capturing HRQoL. They are questions that patients respond to in order to establish their perspective of their own health[202]. PROMs have been demonstrated to complement established outcome measures such as the mRS when used with stroke survivors, providing additional and valuable information for this population[81].

In circumstances where stroke survivors are unable to respond independently e.g. significant cognitive or communication impairment, caregivers (or proxies) may respond on their behalf. However, studies have suggested that proxies commonly report higher levels of disability than stroke patients[271-273]. This proxy bias has been found to increase with increasing stroke severity[274]. More recently, Lapin et al. suggested proxy-provided PROMs to be unreliable for individuals less than three months post stroke. Responses were shown to have reduced validity and responsiveness[275]. Based on the subjective nature of HRQoL, the inherent limitations to proxy-provided perspectives are acknowledged.

PROMs play a crucial role in demonstrating the benefits of new health technologies by providing a patient-centred assessment of treatment outcomes. Their endorsement by leading healthcare organisations, such as the National Institute for Health and Care Excellence (NICE), in the UK and the Food and Drug Administration in the United States highlights their significance in informing clinical practice, healthcare policy, and patient care[276,277]. The routine collection of PROMs data was introduced in England by the NHS in 2009 as part of its PROMs programme[202]. As part of this, the collection of PROMs, (specifically the EQ5D) for all NHS patients undergoing surgery in four clinical pathways was mandated by the NHS Standard Contract. These pathways were knee replacement, hip replacement, varicose vein and groin hernia surgeries[202].

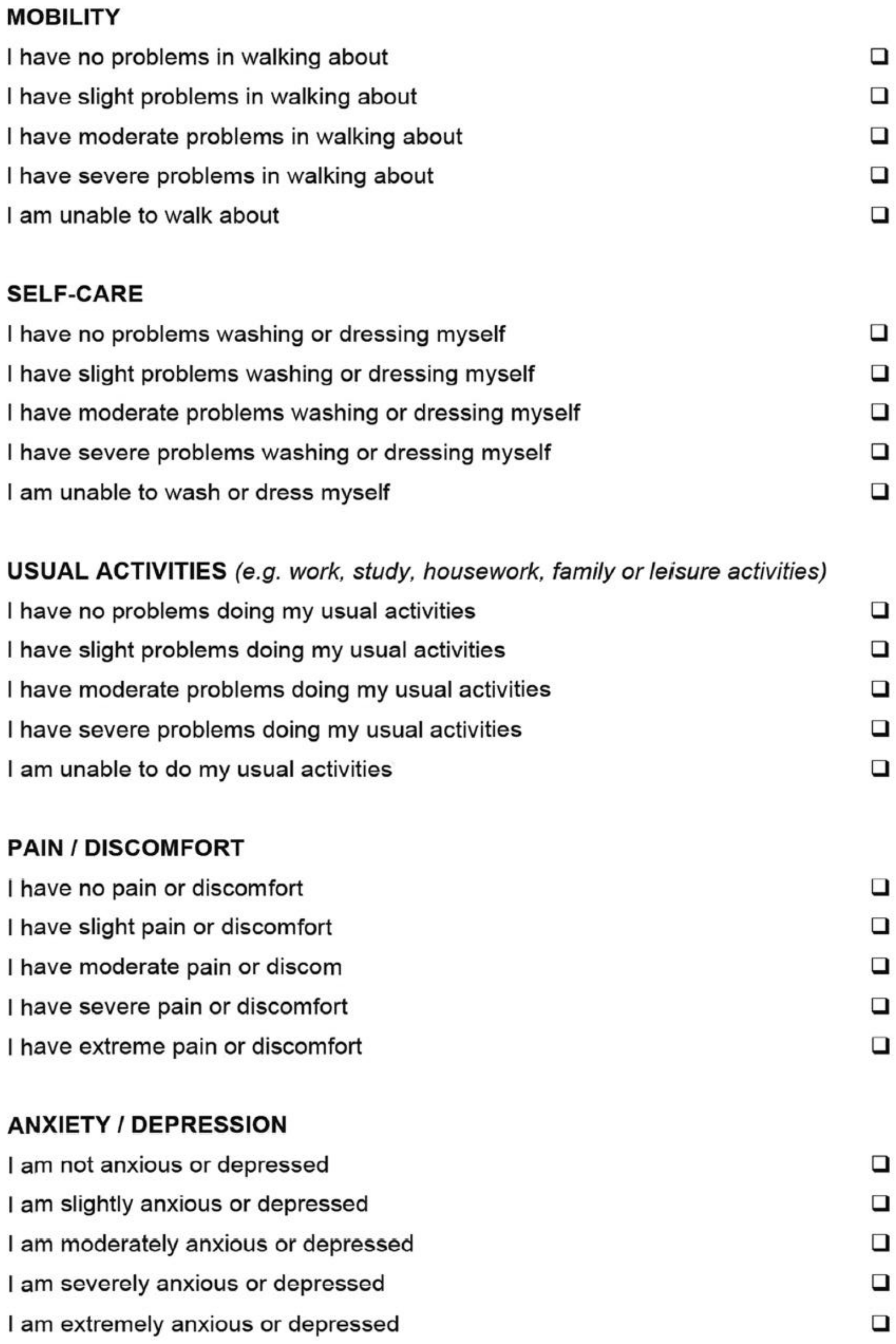
Although lauded as a “landmark development” with an aspiration to facilitate quality improvement, patient choice and performance measurement[202], minimal impact on either patient or provider behaviour was demonstrated[278,279] and the programme ceased in 2017. Despite the official programme evaluation supporting the ongoing collection of PROMs as part of local services, it questioned the ability of the programme to deliver on patient benefit without significant change[279]. Amongst other suggestions, recommendations were made that future work focussed on supporting providers to interpret and utilise their PROM data and seeking improvements in the efficiency of data capture[279]. Critics of the NHS PROMS Programme have urged a shift in focus, away from attempts at using PROMs for provider comparison and instead towards individual patient level use[276].

6.2.3 What is the EQ5D?

The EQ5D is a standardised measure of health status which can be used across health and social care settings, reported by either patient or proxy. Developed by the EuroQol foundation, it is widely used internationally for the purposes of research, clinical practice and economic evaluation[280]. The EQ5D is not disease specific[281] but has been validated for use in assessing quality of life in adult stroke survivors[282]. Although increasingly used as a standalone measure, the EQ5D was initially intended as a broad assessment of HRQoL to be used alongside more detailed condition specific measures[283].The current iteration of the EQ5D is the EQ5D-5L.

The EQ5D-5L consists of a five-domain questionnaire (Figure 6-2), and a visual analogue scale (EQ-VAS) (Figure 6-3). Questionnaire domains comprise mobility, self-care, usual activities, pain and anxiety. Each domain has a five-point scale, with options ranging from *no issues* (one) to *extreme issues (five)*[97]. The patient is asked to indicate the most appropriate level for each, which generates a score from one to five. Originally, each domain had three levels (EQ5D-3L), but in response to concerns regarding a lack of sensitivity and substantial ceiling effect this was increased to five (EQ5D-5L) in 2009[284]. The expanded EQ5D-5L has been found to have a lower ceiling effect and improved discriminatory power in comparison with the original EQ5D-3L[285].

Once all five domains have been scored, these numbers describe the individual's health state e.g. 11231, 21322**.** For the purposes of statistical analysis, health states can be converted into a single value from zero to one (higher scores indicating best possible health), called an EQIndex. This transformation uses the 3,125 unique health states (each possible combination of domain scores), and an EQ5D-5L value set which has been calculated and validated for individual countries[286]. This process provides weighting that is specific to a country, based on studies of HRQOL preference data in their population. See Devlin et al. (2018) for details regarding the ED5D value set for England[287]. Although intended to result in a number between 0 and 1, value sets may generate a negative EQIndex indicating a HRQoL "worse than death"[288].



MOBILITY

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discom ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

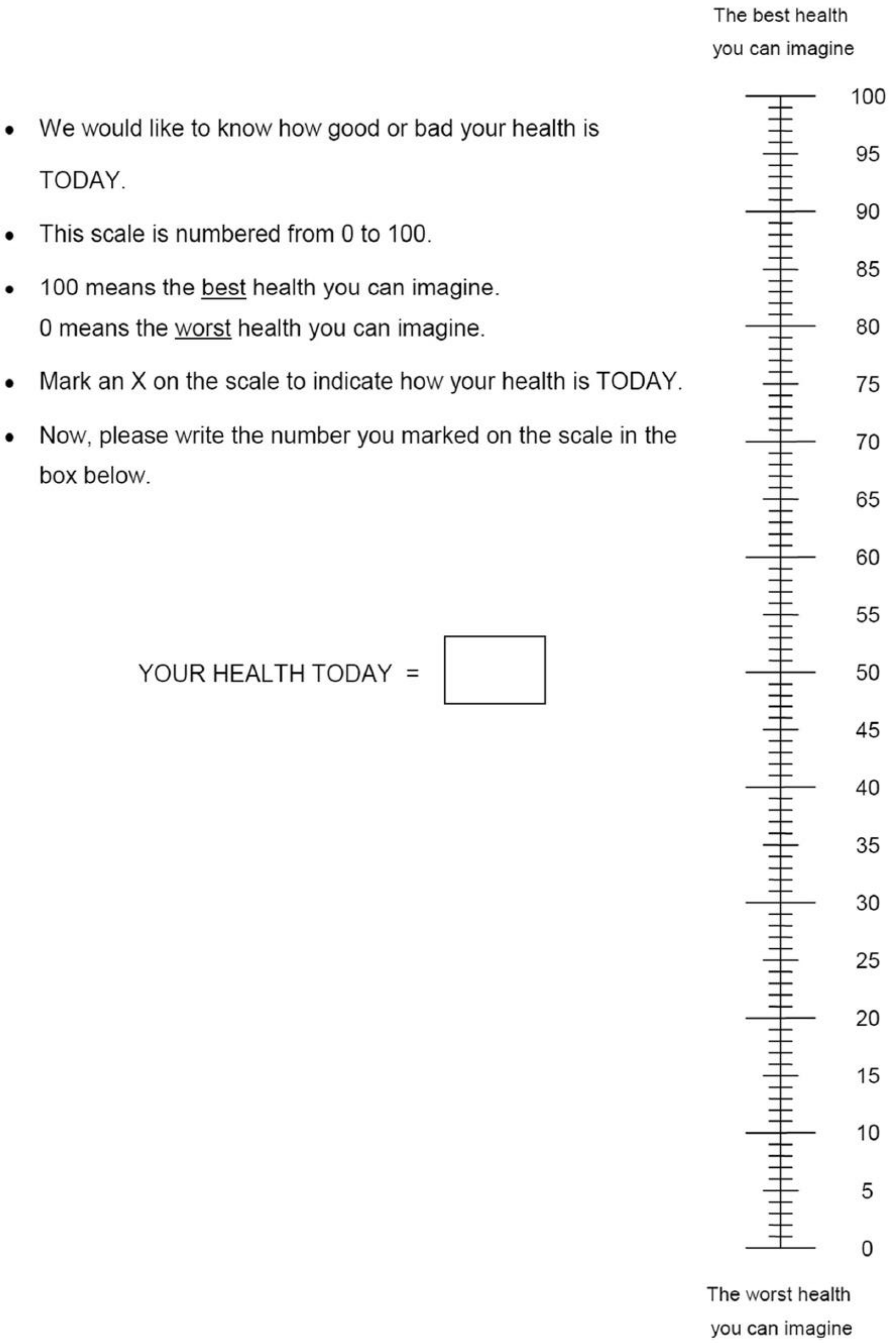
I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

Figure 6-2: EQ5D-5L Questionnaire

The EQ-VAS is a vertical line, numbered 0 to 100 and marked out in units of 5. The patient is asked to indicate with an “X” on the scale their perceived health on the day of assessment, 100 is best possible health and 0 is worst[202].



- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

Figure 6-3: EQ-VAS

The majority of published research undertakes statistical analysis using the EQIndex as this simplifies analysis[281] and has been shown to be more responsive than the EQ5D-VAS[289,290]. There is a lack of consensus regarding the statistical methods applied to analysing EQ5D-5L data, with a variety of approaches evident in the literature [286,291]. These are often poorly described and frequently compromise statistical assumptions, such as the normality of the distribution of residuals[292]. Common statistical approaches include dichotomising domains responses into *no problems reported* and *problems reported*[293-295], Tobit regression models for non-normally distributed EQIndex (or assuming normal distribution and using multivariate linear regression[296]) and multivariate linear regression for EQ-VAS[293].

Historically the EQIndex has predominantly been used for economic evaluations[297]. However, for clinical research into patient outcomes there is a suggestion that EQ5D-5L data should be interpreted at the domain level to distinguish the influence of separate domains on HRQoL[292]. This echoes participant feedback from Chapter 5 and discussions with clinical collaborators regarding a desire to capture patient outcomes across a variety of domains such as pain and mood. As described earlier, HRQoL is multidimensional and unique to an individual's physical, cognitive and social circumstances. Therefore, reducing the EQ5D-5L outcome to a single number limits the insights that may be drawn with regards to the factors that influence individual domains[202,293].

6.2.4 Use of EQ5D-5L in stroke

The EQ5D-3L and EQ5D-5L are widely used in stroke research and their psychometric properties have been evaluated by a number of studies in the stroke population ([285,289,290,298,299]). A recent systematic review of instruments that capture self-reported HRQoL described the EQ5D as demonstrating the "most promising psychometric properties" for stroke survivors[282]. The review found it had limited to moderate test-retest reliability, construct validity, responsiveness and floor and ceiling effects.

As described earlier, the EQ5D-5L was introduced in 2009 to overcome some of the limitations reported in the EQ5D-3L. It has been more than ten years since both Janssen et al. and Golicki et al. explored the use of the EQ5D-5L in stroke survivors and found it to be a valid tool to capture HRQoL for this population, as well as having psychometric advantages to the original EQ5D-3L[284,285]. It is interesting to note that despite these advancements, the majority of published literature utilised the original EQ5D-3L. The apparent reluctance to embrace the extended EQ5D-5L may be partly because EuroQol are yet to publish value sets for all countries[300]. However, it may also be driven by the potential challenges of collecting and analysing domain responses at five levels in comparison to three[281].

A relatively small number of studies have used the EQ5D-5L in the stroke population. Table 6-1 contains an overview of those studies that report EQ5D-5L outcomes. Døhl et al. investigated the factors contributing to post-stroke healthcare utilisation[301]. They found the EQ5D-5L performed equally as well as the Motor Assessment Scale, Hospital Anxiety and Depression Scale, Barthel Index and modified Rankin Scale (mRS) for predicting healthcare need and identifying specific groups for intervention post stroke[301]. Hernández et al. explored associations between the EQ5D-5L and the mRS[294]. Findings supported a correlation between EQ5D-5L and the mRS. Stronger associations were evident in the physical domains of mobility, self-care and activity. Authors suggested the EQ5D-5L provided additional information not captured by mRS in this population. Mei et al. explored factors influencing HRQoL for stroke survivors[293]. They found stroke survivors in rural areas reported lower HRQoL when compared with those in urban areas.

Oemrawsingh et al. developed and compared case-mix adjustment models for mortality, mRS and EQ5D-5L for community dwelling stroke survivors in Malaysia[302]. They found the predictor variables differed between EQ5D-5L and other outcomes. Sex, socioeconomic status and nationality were specific to EQ5D-5L, whereas age, National Institutes of Health Stroke Scale (NIHSS) on admission and heart failure were common across all three models. The NIHSS is a clinicians' assessed tool used to evaluate various neurological functions such as consciousness, movement, sensation, speech and vision. The 15-item scale is used to measure the stroke severity. Scores range from 0-42, with a higher score indicating greater severity of impairment[303].

Wong et al. explored the factors associated with the individual domains of the EQ5D-5L as well as the EQ-VAS[295]. Researchers interviewed each patient (or proxy) and gathered data from a variety of secondary sources. Eighteen separate factors were explored. They found the following associations with domains: malnutrition risk with mobility, self-care and activity, wheelchair use with self-care and activity, speech impairment with activity and pain, previous stroke with self-care and pain. Body mass index, level of physical activity and stroke type were associated with activity, and age with anxiety.

These findings echo an earlier systematic review of validated models for predicting outcomes in stroke undertaken by Teale et al.[304]. They found the predictors commonly included in models were measures of stroke severity, premorbid function and comorbidities. A number of specific patient characteristics have been proposed in the literature [302,304]. These include age, sex, socio-economic status, comorbidities such as previous stroke or diabetes, NIHSS and mRS.

Table 6-1 Summary of study EQ5D-5L outcomes in stroke survivors

Study	**Sample**	**Time poststroke**	**Percentage of participants reporting problems in specific domain (scoring >1)**					**EQIndex** Mean (SD) *Median(IQR)	**EQ-VAS** Mean (SD)
			Mobility	**Self-Care**	**Activity**	**Pain**	**Anxiety**		
Døhl et al.[301] (2020) Norway	N=380	10-16 week	Not provided					0.83 (0.17)	Not provided
	Aim: To test whether a generic HRQoL predicts health care utilisation for stroke survivors as well as more disease specific indexes								
Hernández et al. [294] (2023) Columbia	N=91	6-12 months	55	48.3	59.5	52.8	55.1	*0.63 (1.0-0.26)	80 (not provided)
	Aim: To assess HRQOL in Colombian patients with stroke and correlating its results with the modified Rankin Scale								
Mei et al. [293] (2020) China	N=1709	Unlimited 38% > 5yrs	61	26	38.8	69.8	23.3	0.88 (0.20)	68.4 (17.76)
	Aim: To identify influencing factors of HRQoL and its domain-specific contents in stroke patients in rural areas								
Oemrawsingh et al.[302] (2019) Netherlands	N=1022	3 months	Not provided					*0.65 (1.0-0.83)	Not provided
	Aim: To develop and compare case-mix models for stroke mortality and a patient-reported outcome measure.								
Wong et al.[295] (2021) Malaysia	N=366	Unlimited (49% > 1yr)	85	41	82	63	51	*0.67 (+/- 0.37)	60.3 (14.2)
	Aim: To assess the HRQoL profiles and explore dimension-specific factors of HRQoL among stroke survivors.								
Abbreviations: SD – Standard deviation, IQR – Interquartile range									

6.3 What influences EQ5D-5L variability in community dwelling stroke survivors?

An analysis of national clinical audit data.

6.3.1 Rationale for study

In September 2021, NHS England established stroke rehabilitation pilot sites in three ISDNs in England (see Chapter 1 for details). The aim was the evaluation of different models of community stroke service delivery[305]. As part of the pilot, a team within each ISDN collected an enhanced dataset. The enhanced dataset included EQ5D-5L at admission to the community stroke service, in addition to its routine collection as part of the stroke survivor's six-month review (see Chapter 1 for details). SSNAP routinely collects a variety of patient characteristics, a number of which are established predictors of HRQoL. This provided a unique opportunity to explore their influence on EQ5D-5L for community dwelling stroke survivors, not only cross sectionally, but also longitudinally. This chapter follows the STrengthening the Reporting of OBservational studies in Epidemiology guidelines (STROBE), a checklist is included in Appendix 6-1.

6.3.2 Aim

To understand what influences EQ5D-5L variability in community dwelling stroke survivors.

6.3.3 Objectives

i. To explore associations between predictors and EQ5D-5L at six-months post stroke.
ii. To explore associations between predictors and change over time in EQ5D-5L.
iii. To explore the interpretation of the EQ5D-5L for this population.

6.4 Methods

The study was articulated as two research questions:

Q1. What associations are there between predictors and the EQ5D-5L at six-months?

Q2. What associations are there between predictors and EQ5D-5L change over time?

6.4.1 Patient populations

Eligibility criteria

Q1. Stroke survivors who:

- Received rehabilitation in three ISDNs (ISDN A, B and C). Chosen as they each contained a pilot team collecting an enhanced dataset.
- Had a six-month stroke review between 01.10.2021 and 31.12.2022 (therefore excluding any patients who died before completing a review).
- Had a completed EQ5D-5L as part of their six-month review.

Q2. Stroke survivors who:

- Received rehabilitation from three pilot teams that collected an enhanced dataset (Team 1, 2 and 3).
- Had a six-month stroke review between 01.10.2021 and 31.12.2022 (therefore excluding any patients who died before completing a review).
- Had a completed EQ5D-5L at two time-points (i.e. on commencing community rehabilitation and as part of their six-month review).

Figure 6-4 illustrates the relationship between team and ISDN. The map is for explanatory purposes only and is not intended to identify the location of team or ISDN. An ISDN represents a designated geographical area in which multiple teams may operate.

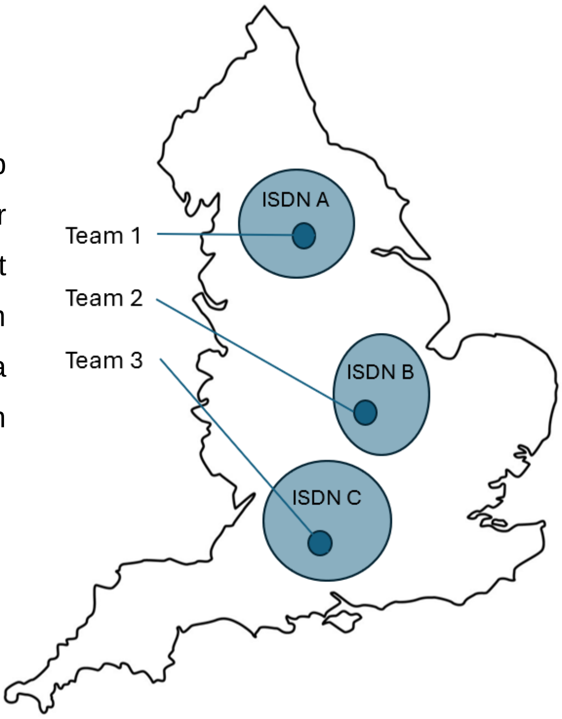


Figure 6-4: Map outlining relationships between Team and ISDN

6.4.2 Informed consent

SSNAP has approval under Section 251 to collect patient level data on the first six months of patient care (ECC 6- 02(FT3)/2012). The rationale for this legal basis is that many stroke patients are extremely unwell in the acute phase of their treatment and it is therefore not feasible to rely on patient consent during this time period. However, patient consent is explicitly sought at six-months post stroke. Where a patient refuses consent for inclusion in SSNAP, all personal identifiable information is wiped from the dataset and no further linkages to other data sources is possible. Once anonymised SSNAP data has been exported, participant withdrawal is not possible as data is unlinked.

6.4.3 Data collection

This retrospective analysis used national clinical audit data from SSNAP. Ethical approval was gained from the University of Nottingham Faculty of Medicine and Health Sciences ethics committee ref: FMHS-221-0223 (Appendix 6-2). Data required for this study was obtained via the data provider, SSNAP. A specific sample of data, collected as part of the national stroke audit, was exported based on data fields specified in the data access request form (DARF). To comply with requirements for depersonalised data, some fields were transformed by the SSNAP team prior to data transfer to reduce the possibility of patient identification through linkage of data items. These fields included age and social deprivation.

Governance procedures involved submitting a completed DARF to the Healthcare Quality Improvement Partnership (HQIP) who acted as data controller and provided approval. The data sharing agreement was approved between HQIP, SSNAP and the University of Nottingham (data applicant) ref: HQIP-440. Relevant excerpts of the DARF are included in Appendix 6-3.

The data export consisted of limited access anonymised data prepared by the SSNAP data team. The data export was uploaded securely by the SSNAP data team, using a password protected file. The password for the file was provided over the phone by the SSNAP data manager. This file was then transferred to secure IT systems at the University of Nottingham. Data was stored on a secure database within the University of Nottingham IT systems, as per the Data Management Plan in the DARF (Appendix 6-3).

6.4.4 Choice of predictors

The choice of predictors was informed by the existing literature as detailed earlier in section 6.1.4 [302,304]. SSNAP is evidence-based, therefore routinely collects the majority of relevant predictors. The following patient characteristics were requested:

Age To comply with requirements for depersonalised data, age was transformed into five ordered categories (<60, 60-69, 70-79, 80-89 and >89).

Sex Measured as a binary characteristic: male or female

Indices of multiple deprivation (IMD) IMD is a relative measure of deprivation for small geographical areas, linked to individual patient postcodes. Calculated using 37 separate indicators including employment, income, education, health and crime[306]. These were transformed into five ordered categories, with lower numbers indicating greater deprivation.

Comorbidities (Measured as a binary characteristic, i.e. presence of)

- Congestive Heart Failure (CHF)
- Hypertension
- Atrial Fibrillation (AF)
- Diabetes
- Prior Stroke
- Dementia **The number of comorbidities** (NoC) was included as an ordered category (0-6), to explore any associations between number of comorbidities and EQ5D-5L.

NIHSS If complete, scores range from 0-42, with a higher score indicating greater severity of impairment[303]. Of the 15 items, only one is mandated by SSNAP, loss of consciousness. Scores were transformed into four ordered categories (<5, 5-14, 15-20 and >20) to align with SSNAP reporting nationally and other literature[307].

mRS The mRS is a seven-point ordinal scale, increasing score represents higher disability[93]. **PremRS**: Clinician reported to reflect ability prior to stroke event, based on patient history (either direct, via proxy or established from health records). **DCmRS**: Clinician reported on discharge from hospital following stroke.

ISDN / Team This was included to explore the influence of different patient populations.

6.4.5 Statistical analysis

Calculation of NIHSS

As only one NIHSS item is mandated, there is the potential for missing items to result in the NIHSS score being artificially low. This may provide an inaccurate reflection of stroke severity. Rather than excluding these patients, the logic used by Gittins et al. was applied to calculate those NIHSS scores identified as having missing items[307]. In summary, the level of consciousness score was used as a proxy indicator for stroke severity. However, Gittens et al. disregarded any patient scoring 0 for loss of consciousness if all other NIHSS items were missing as these individuals were deemed a "*special set of cases*".

Following discussion with collaborators (MJ and RF) it was agreed that these individuals would not be excluded from analysis in this study. Instead, for those scoring 0 and missing all other components, change in mRS (from PremRS to DCmRS) would be used as a proxy indicator for stroke severity. It was hypothesised that those patients who made larger improvements in terms of disability would be more likely to have had a more severe stroke in the first place. It is proposed that the application of this combined logic provides a more accurate and comprehensive reflection of stroke severity than that offered by the unadapted SSNAP data. A sensitivity analysis was completed comparing adapted and unadapted NIHSS scores and did not lead to any marked differences in primary findings in either question one or question two.

Calculation of EQIndex

All statistical analysis was completed using IBM SPSS version 28.01.01(15). The EQIndex was computed using the Devlin EQ-5D-5L index value set[286], version 1.2 (updated 31.08.2022), syntax for which is included in Appendix 6-4.

Descriptive statistics

For both questions, patient characteristics and EQ5D-5L outcomes were explored using descriptive statistics. Domains scored were converted into ordinal scales using the established convention: *no problems* =1, *slight problems* =2, *moderate problems* = 3, *severe problems* = 4, *unable* = 5[281].

Univariate analysis

Univariate analysis was undertaken to establish whether any characteristics were significantly associated with outcomes at the level of domain, EQIndex or EQ-VAS. For domain-level analysis, independent-Samples Mann Whitney U test was used for binary predictors, Spearman's Rank Correlation for ordinal predictors and Independent-Samples Kruskal-Wallis for categorical predictors.

Neither the EQIndex nor EQ-VAS were normally distributed therefore non-parametric tests were again used. Independent-Samples Mann Whitney U test was used for binary predictors, Independent-Samples Kruskal-Wallis for ordinal and categorical predictors. Jonckheere-Terpstra was used to ascertain if there was any significant linearity within the ordinal predictors.

The intention was to understand the univariate associations with domains, EQIndex and EQ-VAS. Options were explored to conduct multivariable analysis to better understand the independent effects of individual characteristics, on EQIndex. However, to date, there is a lack of consensus regarding the most appropriate statistical model for analysing EQIndex, since the distribution of this index is not standard[281,291]. Various transformations of the index, and alternative regression models, are being explored elsewhere. However, upon discussion with supervisors, these were considered to be beyond the scope of this thesis. The focus was therefore restricted to the interpretation of univariate associations.

6.5 Results: Question One

Associations between predictors and EQ5D-5L at six-months post stroke.

6.5.1 Sample Characteristics

7,506 patient records were transferred. 3,813 stroke survivors met the inclusion criteria, and their datasets were included in the analysis, illustrated by Figure 6-5.

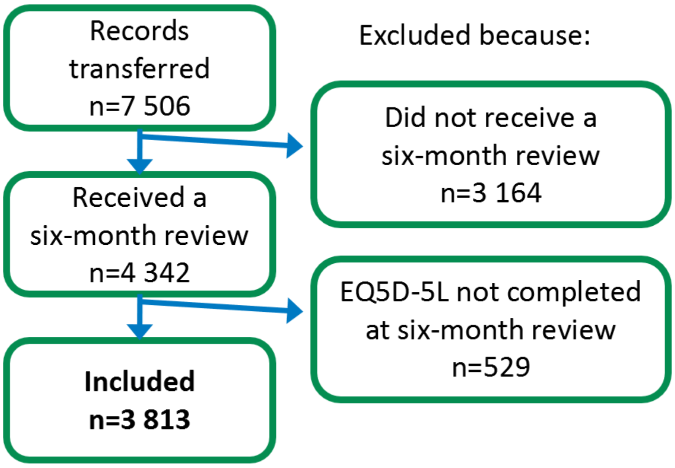


Figure 6-5: Question One - exclusion flowchart

To establish whether those included (n=3,813 with completed EQ5D-5L) were similar to those stroke survivors without EQ5D-5L (n=3,695), descriptive statistics were used to compare the characteristics of both groups.

Overall, the groups appear to be relatively similar. However, there are subtle differences including a slight tendency for those without EQ5D-5L to be in higher NIHSS categories, slightly more of those with EQ5D-5L had fewer comorbidities and were in the independent category prior to stroke. Individual comparisons for each predictor are included in Appendix 6-5.

Characteristics of those meeting the criteria, and therefore included in analysis are detailed in Table 6-2.

Table 6-2: Characteristics of stroke survivors (question one)

Characteristic	Category	Total (n= 3813) %	ISDN A (n=1487) %	ISDN B (n=1144) %	ISDN C (n=1182) %
Age category	<60	20.2	18.7	23.4	19.8
	60-69	20.8	19.1	20.3	21.6
	70-79	30.9	28.6	29.1	30.8
	80-89	23.5	26.5	22.2	23.1
	>89	4.7	7.0	4.9	4.8
Gender (Male)	Y	54.4	55.0	56.2	53.8
Congestive Heart Failure (CHF)	Y	4.3	3.8	6.1	3.0
Hypertension	Y	56.4	53.4	62.4	54.4
Atrial Fibrillation (AF)	Y	13.6	15.2	14.0	13.8
Diabetes	Y	26.1	24.1	29.5	25.1
Prior Stroke	Y	21.1	21.9	21.0	23.1
Dementia	Y	2.9	3.6	3.3	3.4
Number of comorbidities	0	28.5	29.5	25.3	29.3
	1	33.8	33.6	31.5	33.1
	2	25.3	24.8	28.6	25.4
	3	10.1	9.9	11.2	10.4
	4	2.1	1.9	2.9	1.6
	5	0.2	0.3	0.5	0.3
	6	0.0	0.0	0.0	0.0
Index of multiple deprivation (IMD Quintiles) Missing data n = 62	1	25.3	17.2	28.6	33.2
	2	24.9	21.6	27.6	26.3
	3	16.7	19.0	19.3	14.0
	4	16.4	20.5	15.2	13.9
	5	15.1	21.7	9.3	12.5
Premorbid modified Rankin Score (Pre mRS)	0	56.8	63.0	48.5	49.5
	1	20.7	18.5	22.9	22.6
	2	12.1	9.3	11.9	16.1
	3	7.3	5.4	11.6	9.3
	4	2.8	3.4	4.5	2.4
	5	0.3	0.5	0.5	0.2
Discharge modified Rankin Score (DC mRS)	0	8.5	14.3	2.0	11.3
	1	20.1	24.8	11.1	30.2
	2	25.3	16.7	26.1	26.7
	3	25.9	20.9	34.0	20.9
	4	18.7	19.5	24.3	9.7
	5	1.5	3.9	2.4	1.3
National Institute of Health Stroke Score on arrival (NIHSS)	<5	56.3	55.4	52.3	59.1
	5-14	33.8	33.4	36.2	31.9
	15-20	7.1	7.4	8.6	5.9
	>20	2.9	3.8	2.9	3.0
ISDN	A	26.4			
	B	36.6			
	C	36.9			

6.5.2 Differences in population characteristics between ISDNs

Table 6-2 details the characteristics of those included in the analysis. These are provided for the total sample as well as for individual ISDNs. Although the focus of analysis was on the total sample, detailing the ISDNs separately highlighted the underlying differences in patient characteristics between ISDNs. Descriptive statistics were used to contrast the characteristics of the patient populations from each ISDN, these are illustrated in Appendix 6-6.

In summary, participants in ISDN A had a tendency to be older, more independent prior to stroke and live in less deprived areas. Participants in ISDN B had a tendency towards having more comorbidities, being more dependent on discharge from hospital and were from more deprived areas. Participants in ISDN C had slightly fewer comorbidities and lived in more deprived areas.

6.5.3 Missing data

NIHSS

Of the n=3 813 included in analysis, 172 (4.5%) had one or more missing NIHSS items, of which 96 (2.5%) had no items other than the mandatory loss of consciousness. A comparison of the NIHSS as reported by SSNAP and the NIHSS adapted using the logic described in section 6.3.5 is illustrated below (Figure 6-6). This distribution is similar to those patients who were excluded from analysis on the basis of not having an EQ5D-5L (n=3,695).

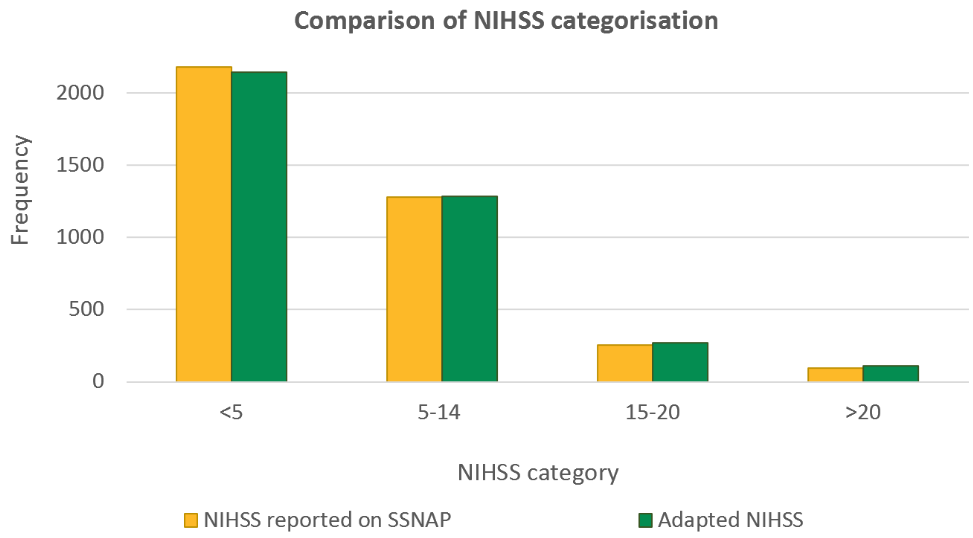


Figure 6-6: Comparison of NIHSS categorised by SSNAP and this study

When comparing the NIHSS reported by SSNAP, and that calculated using the logic described earlier, there appears to be a broadly similar distribution between NIHSS categories. However, differences are more evident at extremes of the scale (<5 and >20). For the lowest (least severe stroke) there is only a small difference of 1.8% more patients categorised as having least severe stroke by SSNAP data. However, for those categorised as most severe (>20) this is more pronounced due to the smaller numbers in this category. SSNAP categorised 15.8% fewer patients as having had severe strokes, than when scores were adapted using the logic used in this study.

Index of Multiple deprivation

The IMD is usually populated automatically by the patient's postcode which is held on a provider's electronic health system. This data is not mandated as those without formal a residence i.e. those patients classified as homeless will not have this information. Of the 3,813 included in analysis, 62 (1.6%) did not have IMD available.

EQ-VAS

Although the study inclusion criteria stated a completed EQ5D-5L, it was possible for providers to submit the EQ5D-5L with a missing EQ-VAS score and enter 999 for this item. Therefore, when data was scrutinised, 473 (12.4%) of patients were found to have missing EQ-VAS.

The distribution of missing data for binary characteristics is detailed in Appendix 6-9. Except dementia, missing EQ-VAS was similarly distributed across binary characteristics. For dementia there were substantial differences, 26.4% missing for those with dementia compared to 12% for those without dementia

6.5.4 Distribution of outcomes

The following section describes the distribution of outcomes, measured at domain level, EQIndex and EQ-VAS in turn.

i. Domains

Figure 6-7 illustrates the distribution of responses for each domain.

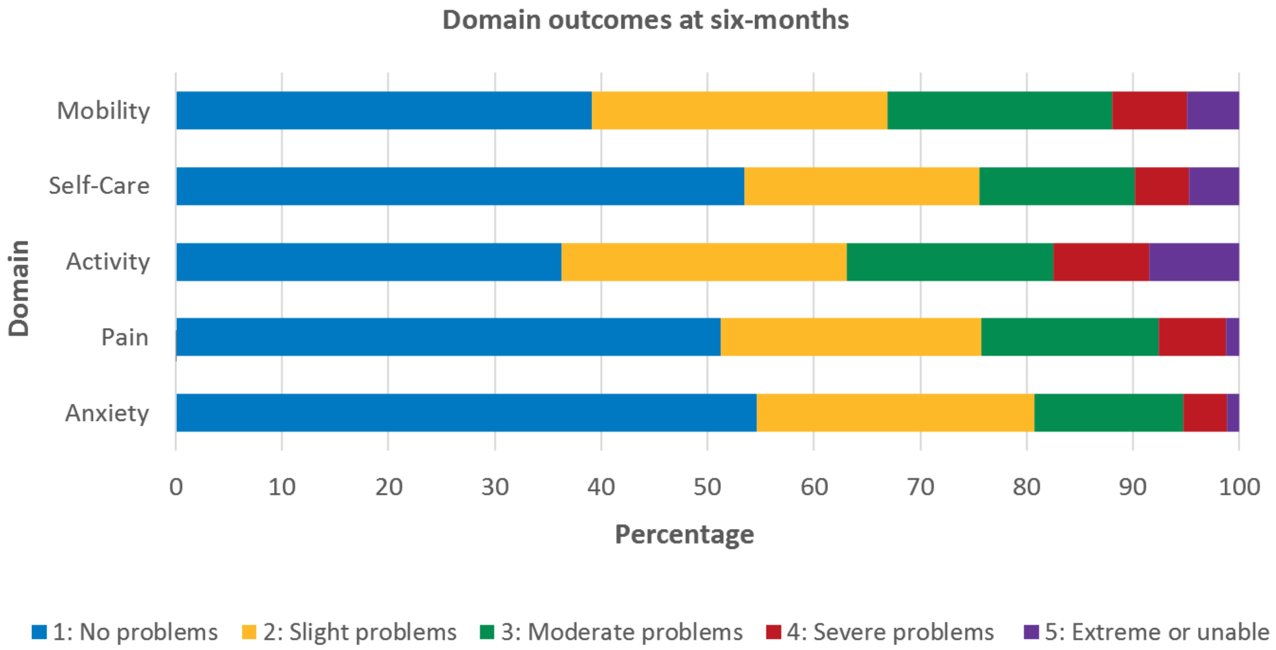


Figure 6-7: Bar chart illustrating the distribution of responses for each domain

Mobility and activity had the greater variety and spread of responses compared to self-care, pain and anxiety which each have more than half of participants reporting *no problems* at six-months. Table 6-3 summarises the domain distribution.

Table 6-3: Statistics describing domain distribution

Statistic	**Mobility**	**Self-Care**	**Activity**	**Pain**	**Anxiety**
Median	2.00	1.00	2.00	1.00	1.00
Interquartile Range	2.00 (1.00 to 3.00)	1.00 (1.00 to 2.00)	2.00 (1.00 to 3.00)	1.00 (1.00 to 2.00)	1.00 (1.00 to 2.00)
Skewness	.849	1.270	.756	1.040	1.253
Kurtosis	-0.078	0.760	-0.471	0.204	0.982
Max	5	5	5	5	5
Min	1	1	1	1	1

ii. EQIndex

Figure 6-8 illustrates the distribution of the EQIndex.

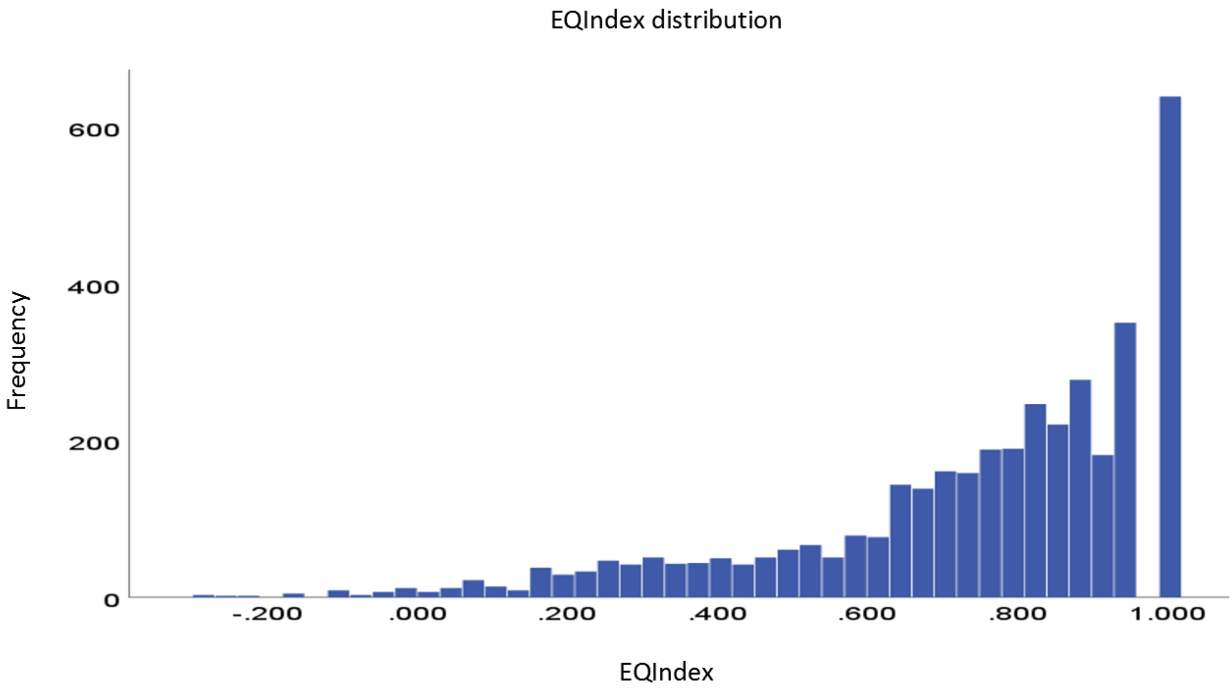


Figure 6-8: Histogram illustrating distribution of EQIndex

Values are non-normally distributed (Kolmogorov-Smirnov and Shapiro-Wilk both <.001). Distribution is substantially negatively skewed towards full health. There is a ceiling at one (16.8% achieving best possible health state) and a gap between full health and the second-best health state. Table 6-4 summarises the EQIndex distribution.

Table 6-4: Statistics describing EQIndex distribution

Statistic	Total (n=3813)
Median	0.820
Interquartile Range	0.283 (0.640 to 0.937)
Skewness	-1.237
Kurtosis	1.128
Max	1.000
Min	-0.285

iii. EQ-VAS

Figure 6-9 illustrates the distribution of the EQ-VAS.

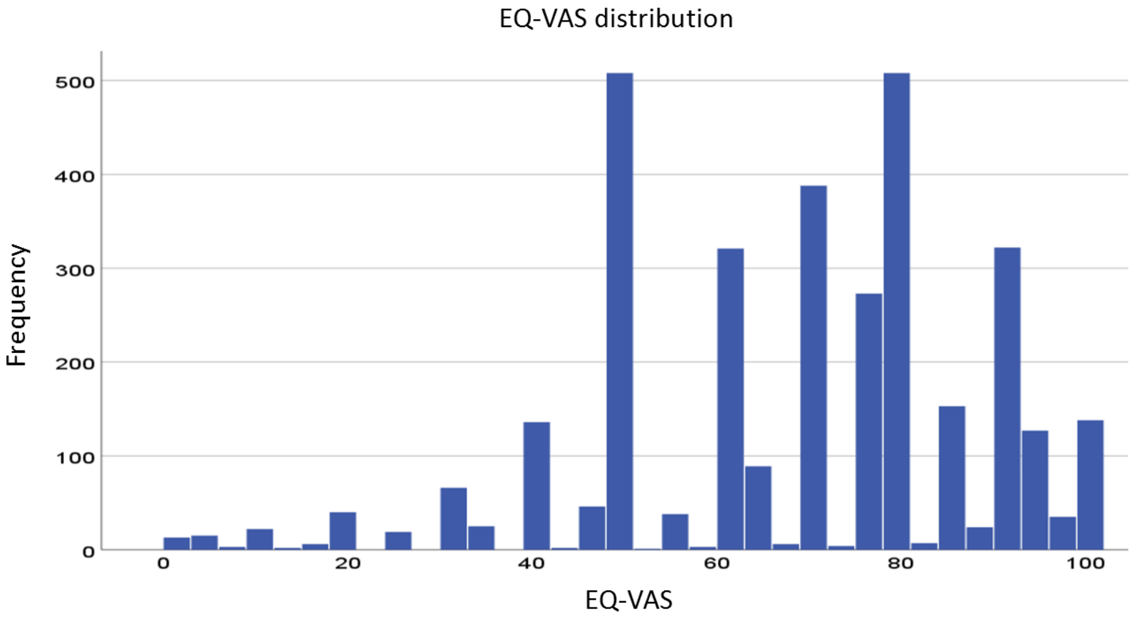


Figure 6-9: Histogram illustrating distribution of EQ-VAS

Values are non-normally distributed (Kolmogorov-Smirnov and Shapiro-Wilk both <.001). Distribution is negatively skewed towards full health. There is a clear digit preference, i.e. tendency towards choosing numbers ending in 0 or 5, with the highest frequency of responses for 50 and 80. Table 6-5 summarises the EQ-VAS distribution.

Table 6-5: Statistics describing the EQ-VAS distribution

Statistic	Total (n=3340)
Median	70.00
Interquartile Range	30.00 (50.00 to 80.00)
Skewness	-.685
Kurtosis	.256
Max	100
Min	1

6.5.5 Univariate analysis of patient characteristics

This section describes the univariate analysis of patient characteristics with EQ5D-5L outcomes, measured by domain, EQIndex and EQ-VAS six-months post stroke.

Significance is based on *p* values from the statistical tests described in section 6.3.5. Descriptive data and outputs of statistical tests are detailed in Appendices 6-7 (domains), 6-8 (EQIndex) and 6-9 (EQ-VAS).

Table 6-6: Univariate analysis of characteristics with EQ5D-5L outcomes

Characteristic	**Domain**					**EQIndex**	**EQ-VAS**
	Mobility	**Self-Care**	**Activity**	**Pain**	**Anxiety**		
Gender (Male)	🟩 <.001	🟩 <.001	🟩 <.001	🟩 .001	🟩 <.001	🟩 <.001	🟩 .020
CHF	🟦 .002	.052	🟦 .033	🟦 .032	.534	🟦 .015	.391
Hypertension	🟦 <.001	🟦 <.001	🟦 .002	.094	🟦 .034	🟦 .005	🟦 <.001
AF	🟦 .006	.092	🟦 .018	.543	.497	.097	🟦 .005
Diabetes	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001	🟦 .012	🟦 .001	🟦 <.001
Prior Stroke	🟦 <.001	🟦 <.001	🟦 <.001	.105	.300	🟦 <.001	🟦 <.001
Dementia	🟦 <.001	🟦 <.001	🟦 <.001	.438	.442	🟦 <.001	🟦 .008
Age	🟦 <.001	🟦 <.001	🟦 <.001	🟩 .001	🟩 <.001	🟨 .003	🟨 .041
IMD (Higher = less deprived)	🟩 <.001	🟩 <.001	🟩 <.001	🟩 <.001	🟩 <.001	🟩 <.001*	🟩 <.001*
Number of Comorbidities	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001	.852	🟦 <.001*	🟦 <.001*
NIHSS (Higher = more severe)	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001*	🟦 <.001*
Pre mRS (Higher = greater disability)	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001*	🟦 <.001*
DC mRS (Higher = greater disability)	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001	🟦 <.001*	🟦 <.001*
ISDN	🟨 <.001	🟨 <.001	🟨 <.001	🟨 <.001	🟨 <.001	🟨 <.001	🟨 .011

🟩	Outcome significantly improved with presence of binary predictor or increase in ordinal predictor	Significance *p*<.05 *Significant linear trend
🟦	Outcome significantly worse with presence of binary predictor or increase in ordinal predictor	
🟨	Outcome differs significantly between categories (non-linear)	

Domain

Mobility and activity domains were significantly associated with all patient characteristics. Pain and anxiety had the least number of significant associations. Better outcomes were associated with being male, living in a less deprived area, having fewer comorbidities, less pre-morbid disability, a less severe stroke and less severe disability on discharge.

For mobility, self-care and activity, increasing age was associated with worse outcomes, though for pain and anxiety domains, increasing age was associated with reporting better outcomes. There were also significant differences between ISDNs.

EQIndex

EQIndex was significantly associated with all but one patient characteristic (AF). On the whole, better outcomes were associated with the same characteristics as domains. For all ordinal characteristics except age, the trend was significantly linear. There were also significant differences between ISDNs.

EQ-VAS

EQ-VAS was significantly associated with all but one patient characteristic (CHF). Better outcomes were associated with similar characteristics as EQIndex and domains. For all ordinal characteristics except age, there was a significant linear trend in EQ-VAS across ordered categories. There were also significant differences between ISDNs.

6.6 Results: Question Two

Associations between predictors and change over time in EQ5D-5L.

6.6.1 Sample characteristics

1,300 patient records were transferred. 619 stroke survivors met the inclusion criteria, and their datasets were included in the analysis, illustrated by Figure 6-10.

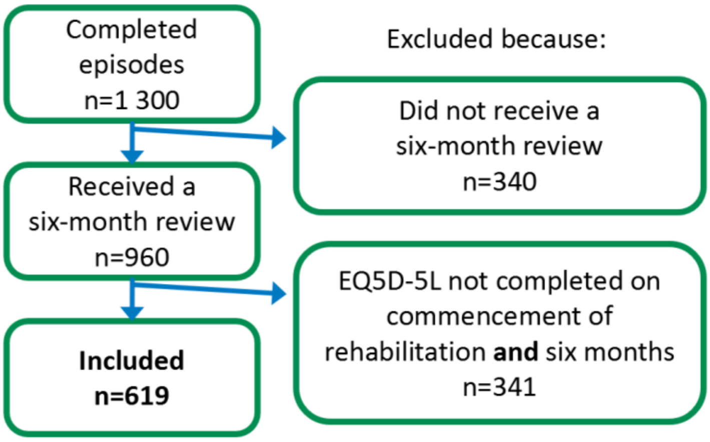


Figure 6-10: Question Two - exclusion flowchart

To establish whether those included (n=619 with completed EQ5D-5L) were similar to those stroke survivors with completed episodes but without EQ5D-5L at two time-points (n=681), descriptive statistics were used to compare the characteristics of both groups.

Overall, the groups appear to be relatively similar. However, there were subtle differences including a slight tendency for those without EQ5D-5L to be in higher NIHSS and discharge mRS categories and slightly more of those with EQ5D-5L in the independent category prior to stroke. Comparisons for each predictor are included in Appendix 6-10. The distributions of characteristics of those included for analysis were similar to those included question one.

Characteristics of those meeting the criteria, and therefore included in analysis are included in Table 6-7.

Table 6-7: Characteristics of stroke survivors (question two)

Characteristic	**Category**	**Total n=619 %**	**Team 1 n=259 %**	**Team 2 n=286 %**	**Team 3 n=74 %**
Age category	<60	19.7	19.3	18.9	24.3
	60-69	19.5	16.6	22.4	18.9
	70-79	33.0	32.8	32.9	33.8
	80-89	22.0	23.2	22.0	17.6
	>89	5.8	8.1	3.8	5.4
Gender (Male)	Y	45.1	47.5	42.0	48.6
Congestive Heart Failure (CHF)	Y	5.2	3.5	7.0	4.1
Hypertension	Y	60.1	61.8	60.5	52.7
Atrial Fibrillation (AF)	Y	13.7	15.1	14.0	8.1
Diabetes	Y	24.9	22.0	27.6	24.3
Prior Stroke	Y	20.0	20.8	18.2	24.3
Dementia	Y	2.3	1.2	3.8	0.0
Number of comorbidities	0	24.4	21.3	25.9	29.7
	1	37.8	44.0	32.5	36.5
	2	27.1	25.9	29.0	24.3
	3	8.6	6.9	9.8	9.5
	4	2.1	1.9	2.8	0.0
	5	0	0.0	0.0	0.0
Index of multiple deprivation (IMD Quintiles) Missing data n=15	1	17.8	12.0	21.7	26.4
	2	23.4	24.7	23.8	22.3
	3	18.4	17.1	22.8	9.7
	4	21.5	20.7	23.5	20.8
	5	16.5	25.5	8.2	20.8
Premorbid modified Rankin Score (Pre mRS)	0	52.7	61.0	43.7	58.1
	1	22.1	14.3	29.0	23.0
	2	14.7	17.4	12.4	14.9
	3	6.0	4.6	8.0	2.6
	4	3.9	2.3	5.9	1.4
	5	0.6	0.4	1.0	0.0
Discharge modified Rankin Score (DC mRS)	0	5.5	8.5	2.1	8.1
	1	11.0	10.4	11.2	12.2
	2	24.6	24.3	24.1	27.0
	3	32.6	36.3	30.8	27.0
	4	24.1	18.2	29.0	25.7
	5	2.3	2.3	2.8	0.0
National Institute of Health Stroke Score on arrival (NIHSS)	<5	55.9	56.4	57.0	50.0
	5-14	34.9	34.8	34.6	36.5
	15-20	6.6	6.9	5.6	9.5
	>20	2.6	1.9	2.8	4.0
Team	1	41.8			
	2	46.2			
	3	12.0			

6.6.2 Differences in the population characteristics between teams

Table 6-7 details the characteristics of those included in the analysis. These are provided for the total sample as well as for individual teams. Although the focus of analysis was on the total sample, detailing the teams separately highlighted the underlying differences in patient characteristics between teams. Descriptive statistics were used to compare the characteristics of patient populations from each team and are illustrated in Appendix 6-11.

In summary, Team One had a tendency to be older and from less deprived areas. Team Two had a tendency towards having more comorbidities, being less independent prior to stroke, more dependent on discharge and from more deprived areas. Team Three had a tendency to be younger and have fewer comorbidities but higher NIHSS on admission. These are similar to the distribution of characteristics of the ISDNs that each team came from as described in 6.4.2.

6.6.3 Missing data

NIHSS

Of the n=619 included in analysis, 31 (5%) had one or more missing NIHSS items, of which 12 (1.9%) had no items other than the mandatory loss of consciousness. Proportions of missing data and distribution of NIHSS scores were similar to that of the sample in question one for both SSNAP reported and adapted NIHSS.

Index of Multiple deprivation

Of the n=619 included in analysis for question two, 15 (2.4%) did not have IMD available. This is a slightly higher proportion than the 1.6% of the sample in question one.

EQ-VAS

As described earlier, it was possible for providers to submit the EQ5D-5L with a missing EQ-VAS score and enter 999 for this item. Therefore when data was scrutinised for question two, 87 (14.1%) of patients were found to have missing EQ-VAS. The distribution of this for binary characteristics is detailed later in Appendix 6-14. Except for three characteristics, the number of patients with missing EQ-VAS data is similarly distributed across different patient characteristics. These characteristics are dementia (35.7% missing for those with dementia compared to 13.6% for those without), CHF (25% missing for those with CHF, compared with 13.5 % for those without) and AF (21.2% missing for those with AF, compared with 12.9% for those without).

6.6.4 Distribution of outcomes

The following section describes the distribution of change in outcomes measured at domain level, EQIndex and EQ-VAS, from commencement of community rehabilitation (T_1) to approximately six-months post stroke (T_2).

i. Domains

The horizontal bar chart below illustrates the distribution of responses for each domain at both commencement of community rehabilitation (T_1) and six-months post stroke (T_2). (Figure 6-11).

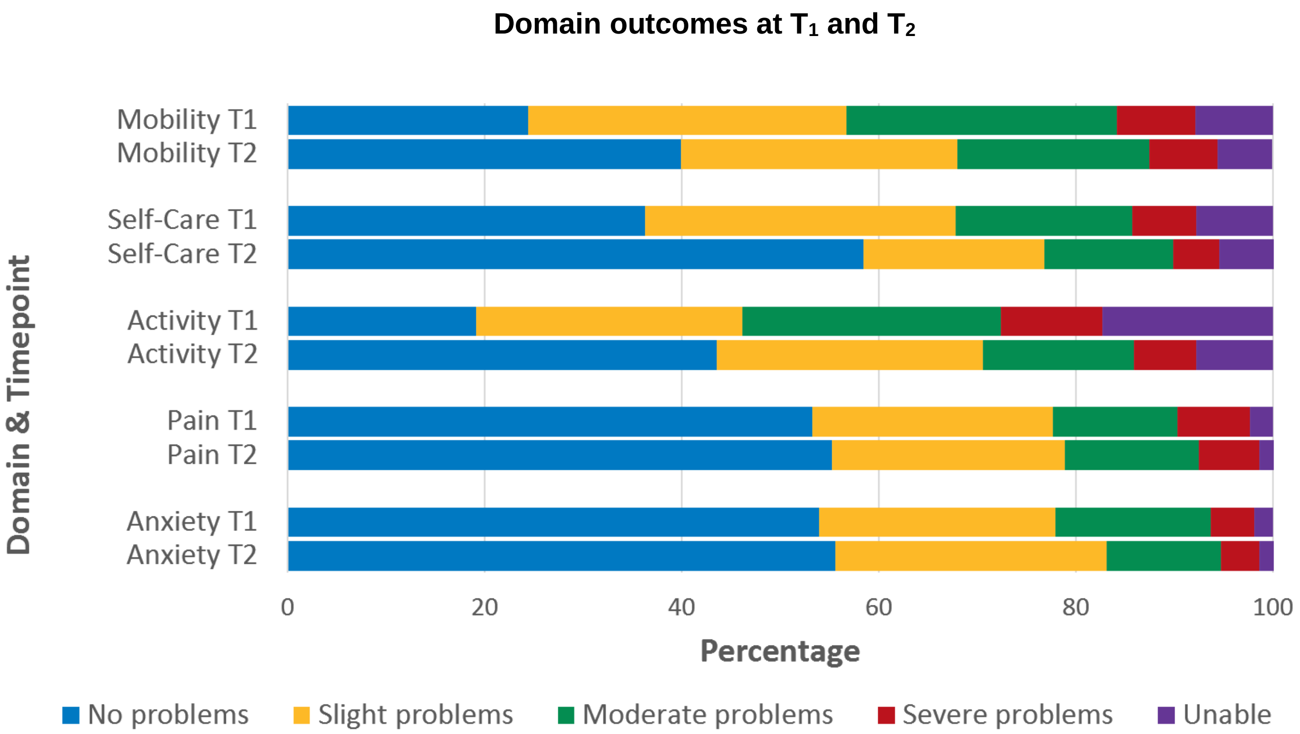


Figure 6-11: Bar chart illustrating distribution of responses at T_1 & T_2

For all domains there is a shift to the right between T_1 and T_2, which represents an increase in the proportions of patients reporting *no problems*, indicating an improvement in HRQoL.

The pain and anxiety domains both start with the largest proportion of patients reporting *no problems* (over half) and make the smallest improvement between T_1 and T_2. The activity domain starts with the smallest proportion of patients reporting *no problems* at T_1 and makes the largest proportional improvement at T_2.

Figure 6-12 illustrates the relative change (the difference between T_1 and T_2) for each domain. A reduction in score represents improvement.

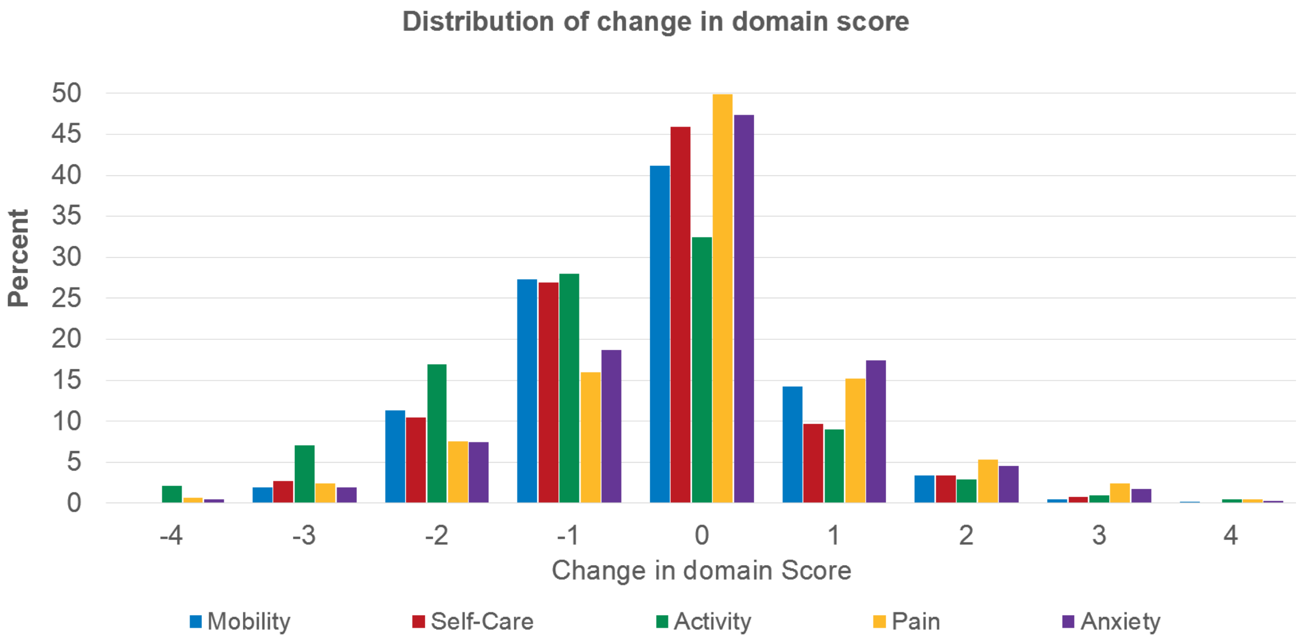


Figure 6-12: Bar chart illustrating change in domain scores between T_1 & T_2

All distributions are non-normally distributed (Kolmogorov-Smirnov and Shapiro-Wilk both <.001 for each domain). The largest proportion of patients reported no change for pain and anxiety domains. However, these two domains also had the largest proportion of increased scores, indicating a deterioration for 23.42% and 24.07% of patients in terms of pain and anxiety respectively. Mobility, self-care and activity have the largest reduction, indicating an improved health state for these domains. Table 6-8 summarises the distribution of change in domains.

Table 6-8: Statistics describing the distribution of change in domains

Statistic	Mobility	Self-Care	Activity	Pain	Anxiety
Median	0.00	0.00	-1.00	0.00	0.00
Interquartile range	1.00 (-1.00 to 0.00)	1.00 (-1.00 to 0.00)	2.00 (-2.00 to 0.00)	1.00 (-1.00 to 0.00)	1.00 (-1.00 to 0.00)
Skewness	.081	.019	.094	-.019	-.048
Kurtosis	.497	.764	.622	1.425	1.346
Range max	4.00	3.00	4.00	4.00	4.00
Range min	-3.00	-3.00	-4.00	-4.00	-4.00

ii. EQIndex

Figure 6-13 illustrates the change in EQIndex between T_1 and T_2. An increase in score represents improvement.

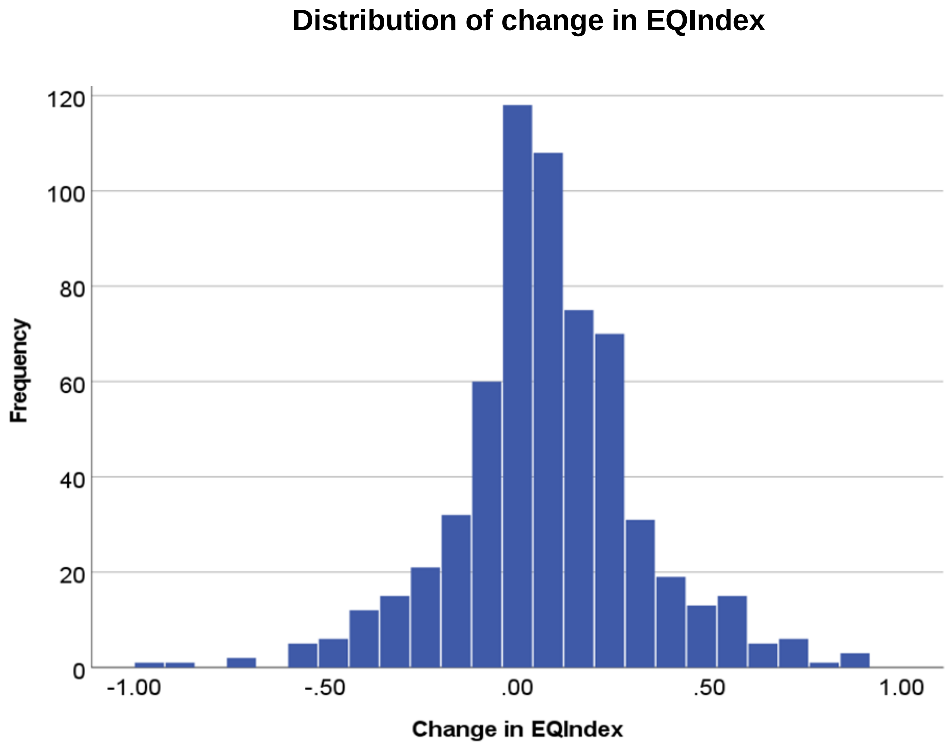


Figure 6-13: Histogram illustrating distribution of change in EQIndex

Change in EQIndex was non-normally distributed (Kolmogorov-Smirnov and Shapiro-Wilk both <.001) and negatively skewed towards a positive change in health state. A median change of .058 equates to a 5.8% improvement in HRQoL as measured by EQIndex. Table 6-9 summarises distributions of change in the EQIndex for the total sample (T_1 baseline included for reference).

Table 6-9: Statistics describing distribution of baseline & change in EQIndex

Statistic	**Total (n=619)**	
	T_1	**Change**
Median	0.758	0.058
Interquartile Range	0.275 (0.551 to 0.861)	0.250 (-0.041 to 0.210)
Skewness	-1.291	-.044
Kurtosis	1.672	1.729
Max	1.000	0.89
Min	-0.285	-0.93

iii. EQ-VAS

Figure 6-14 illustrates the change in EQ-VAS between T_1 and T_2. An increase in score represents improvement.

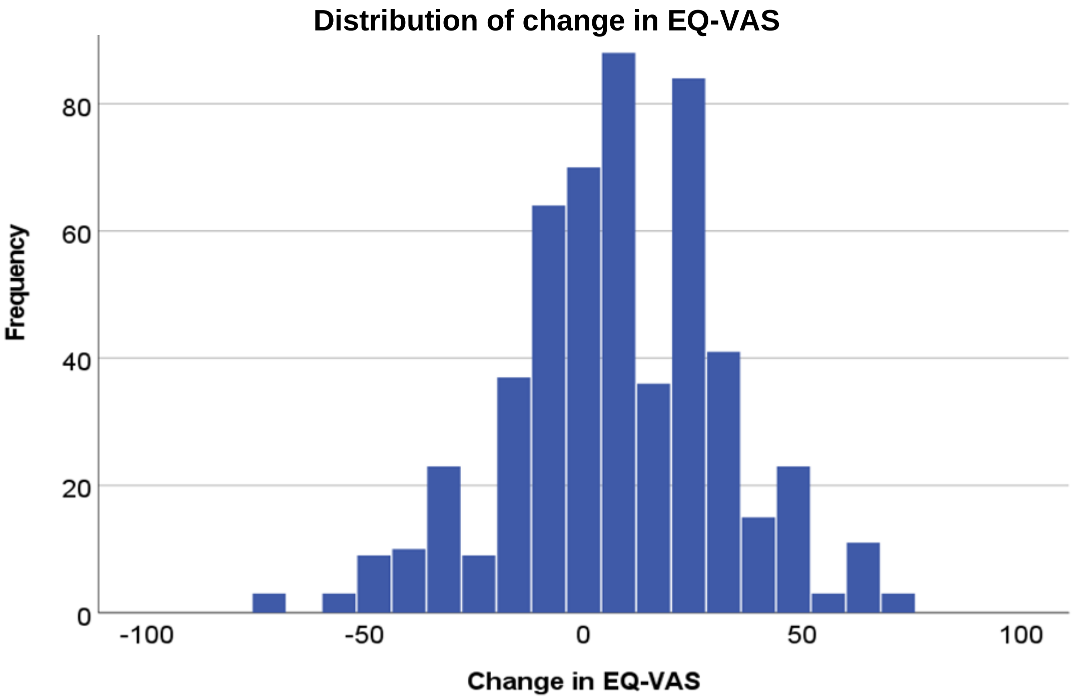


Figure 6-14: Histogram illustrating distribution of change in EQ-VAS

Change in EQ-VAS was non-normally distributed (Kolmogorov-Smirnov and Shapiro-Wilk both <.001) and negatively skewed towards a positive change in health state. A median change of 9 equates to a 9% improvement in HRQoL as measured by EQ-VAS. Table 6-10 summarises the distribution of change in EQ-VAS for the total sample (T$_1$ baseline included for reference).

Table 6-10: Statistics describing distribution of baseline & change in EQ-VAS

Statistic	**Total (n=532, 87 missing)**	
	T_1	**Change**
Median	60.00	9.00
Interquartile Range	30.00 (50.00 to 80.00)	25.00 (-5.00 to 20.00)
Skewness	-.376	-.201
Kurtosis	-.150	.391
Max	100.00	75.00
Min	0.00	-75.00

6.6.5 Univariate analysis of patient characteristics

This section describes the univariate analysis of patient characteristics with change in EQ5D-5L outcomes measured by domains, EQIndex and EQ-VAS.

Significance is based on *p* values from the statistical tests described in section 6.3.5. Descriptive data and outputs of statistical tests are detailed in Appendices 6-12 (domains), 6-13 (EQIndex) and 6-14 (EQ-VAS).

Table 6-11: Univariate analysis of characteristics with change in EQ5D-5L

Characteristic	**Domain**					**EQIndex**	**EQ-VAS**
	Mobility	**Self-Care**	**Activity**	**Pain**	**Anxiety**		
Gender (Male)	.674	.344	.928	.485	.233	.191	.444
CHF	.019	<.001	.004	.882	.253	.010	.306
Hypertension	.394	.592	.479	.418	.634	.563	.862
AF	.704	.537	.569	.945	.355	.402	.135
Diabetes	.769	.335	.381	.374	.059	.403	.346
Prior Stroke	.435	.181	.998	.398	.906	.784	.113
Dementia	.187	.508	.013	.148	.180	.363	.055
Age	.178	.032	.755	.567	.687	.843	.028
IMD (Higher = less deprived)	.025	.010	.573	.960	.209	.829	.784
Number of comorbidities	.760	.773	.429	.672	.469	.049	.405
NIHSS (Higher = more severe)	.319	.051	.558	.990	.141	.152	.319
Pre mRS (Higher = greater disability)	.497	.382	.551	.019	.735	.610	.322
DC mRS (Higher = greater disability)	.234	.006	.220	.210	.862	.220	.560
Team	.053	.003	.020	.205	.463	.100	.001

🟩	Outcome significantly improved with presence of binary predictor or increase in ordinal predictor	Significance $p<.05$
🟦	Outcome significantly worse with presence of binary predictor or increase in ordinal predictor	
🟨	Outcome differs significantly between categories (non-linear)	

i. Domains

There were few statistically significant associations with change in domain scores., compared with question one. Change in self-care had the greatest number of significant predictors, whilst changes in pain and anxiety had only one and none respectively. For binary characteristics, having CHF was associated with a worsening of outcome over time for mobility, self-care and activity domains. Similarly, dementia was associated with a deterioration in scores for the activity domain. For ordinal characteristics living in a less deprived area (mobility and self-care domains), greater premorbid disability (pain domain) greater disability on discharge from hospital and being older (both self-care domain) were associated with improvements in outcome.

There were significant differences between teams for self-care and activity, these are detailed in the following section 6.5.6. Univariate analysis of patient characteristics and change in domains are in Appendix 6-12.

ii. EQIndex

Compared with question one, fewer predictors were significantly associated with EQIndex. Having CHF at baseline was associated with having poorer outcomes. Greater number of comorbidities were associated with poorer outcomes, but this was non-linear. Univariate analysis of patient characteristics and change in EQIndex are in Appendix 6-13.

iii. EQ-VAS

Fewer predictors were significantly associated with EQ-VAS outcomes, compared with question one. Age was associated with changes in EQ-VAS, but this was non-linear as illustrated in Figure 6-15. Changes in EQ-VAS differed significantly between teams, this is detailed in the following section 6.5.6. Univariate analysis of patient characteristics and change in EQ-VAS are in Appendix 6-14.

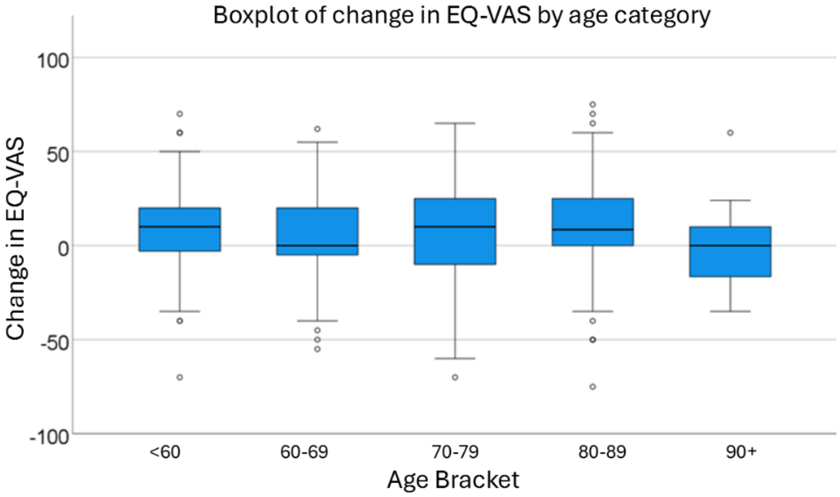


Figure 6-15: Boxplot of change in EQ-VAS by age category

6.6.6 Exploration of team differences

Table 6-11 identified three outcomes as significantly different between teams. These were self-care domain, activity domain and EQ-VAS. This section briefly explores these differences.

Variations between teams (population characteristics) are detailed in section 6.5.2. Based on results from question one, these variations contribute to the differences in baseline identified. However caution must be taken when interpreting these results as team sample sizes were much smaller compared with ISDNs, and not evenly distributed. In addition, there was a marked difference in the distribution of missing EQ-VAS data between teams and across binary characteristics (see Appendix 6-14).

Therefore, the following section does not seek to draw conclusions regarding differences between teams, rather to illustrate that these differences exist and how this data may be presented to support scrutiny.

i. Self-care domain

Figure 6-16 illustrates that between T_1 and T_2, smaller proportions of patients in Team Two reported improvements in the self-care domain. A reduction in score represents improvement.

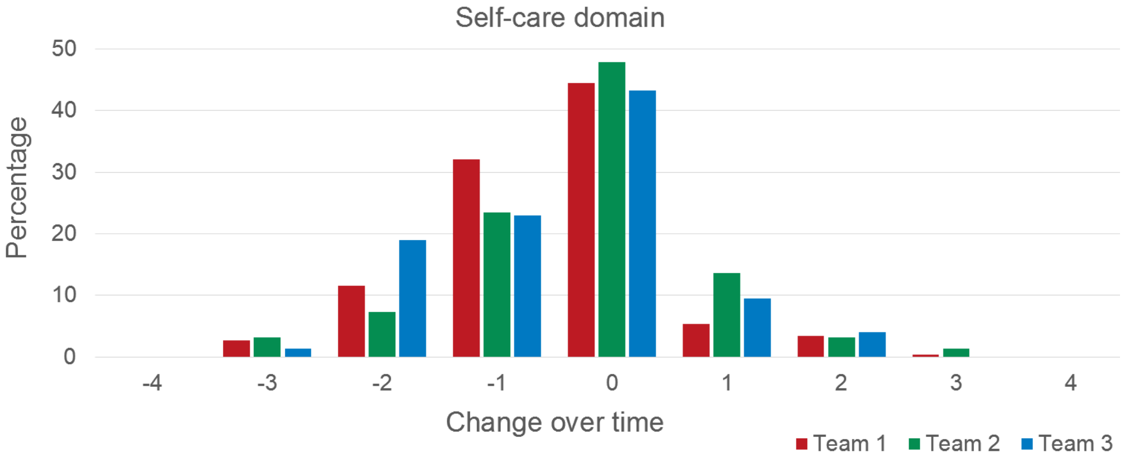


Figure 6-16:Bar chart illustrating change in self-care between T_1&T_2 (by team)

However, Team two also started with the largest proportion of patients reporting *no problems* in this domain (38.5%), therefore without potential to demonstrate improvement (ceiling effect).

ii. Activity domain

Figure 6-17 illustrates that between T_1 and T_2, Team Three reported the largest proportion of patients making improvements in the activity domain. A reduction in score represents improvement. Bar charts for the remaining domains are included in Appendix 6-15.

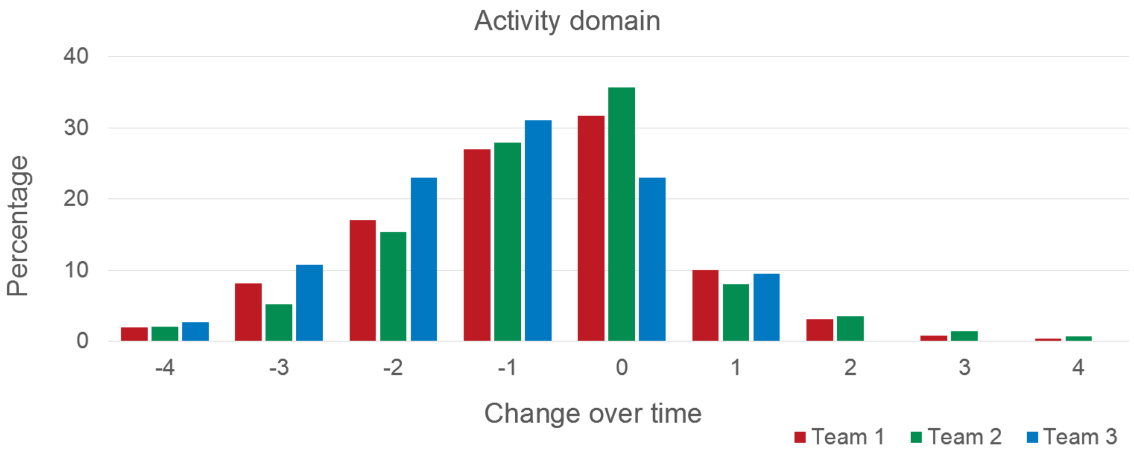


Figure 6-17: Bar chart illustrating change in activity between T_1 & T_2 (by team)

Figure 6-18 illustrates the activity domain scores at T_1 and T_2, providing information regarding the baseline scores.

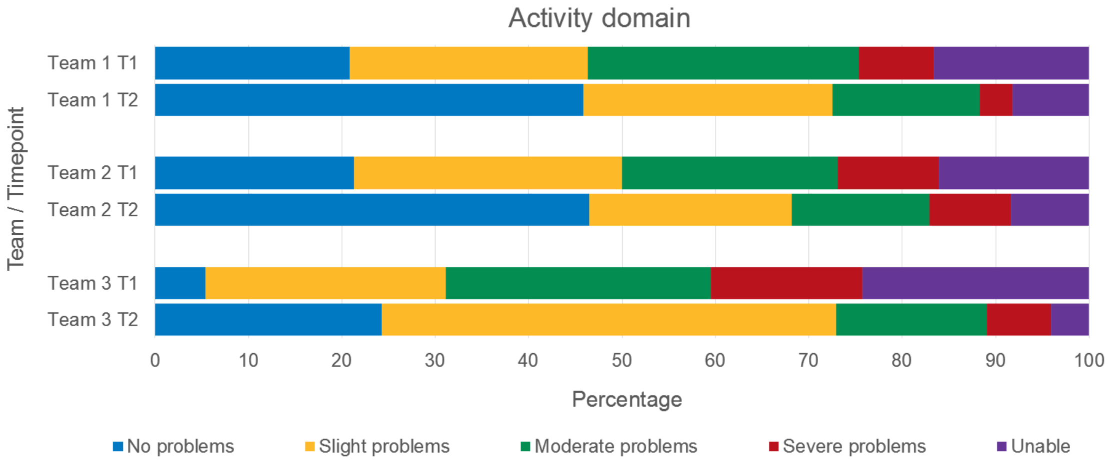


Figure 6-18: Bar chart illustrating activity domain scores at T_1 & T_2 (by team)

Together, Figures 6-17 and 6-18 suggest that patients in Team Three reported the largest improvement in activity but started with the least proportion of patients reporting *no problems* at T_1. Team Three therefore had the greatest potential to make improvements.

iii. EQ-VAS

There were differences in the proportions of patients within each team who reported improvements in their HRQoL as measured by an increase in the EQ-VAS. Figures 6-18, 6-19 and 6-20 illustrate the changes reported in EQ-VAS by patients in Team One, Two and Three respectively.

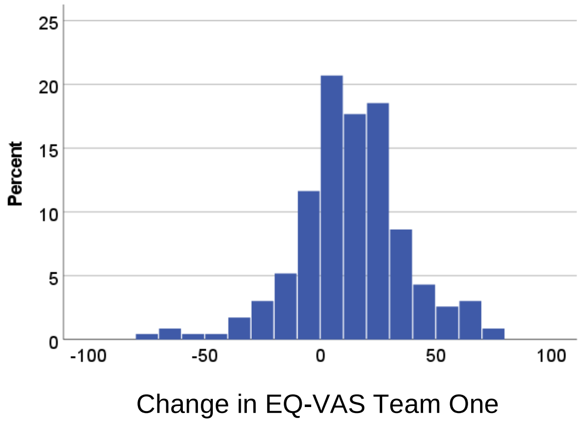


Figure 6-19: Histogram illustrating change in EQ-VAS for Team One

Team Two had the lowest proportion of patients reporting an increase in the EQ-VAS (48%), whilst Team One had the highest (66%). Team Two also had the highest median baseline EQ-VAS at T_1 (65) compared to Team One (60).

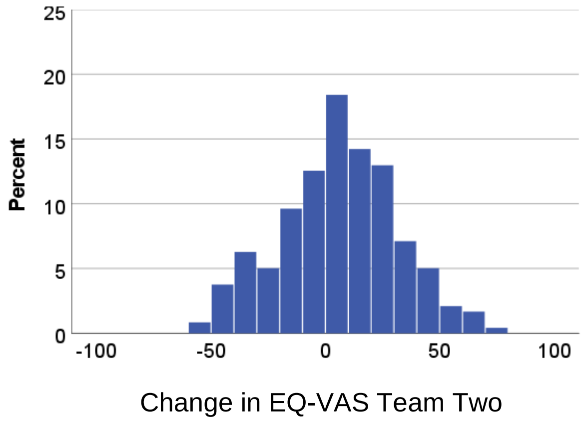


Figure 6-20: Histogram illustrating change in EQ-VAS for Team Two

This section has highlighted the challenges of exploring comparisons between teams and attempting to draw conclusions from this provider level data. These include the size (and variability between sizes) of the datasets, missing data, variability in baselines between populations and the distribution of outcomes.

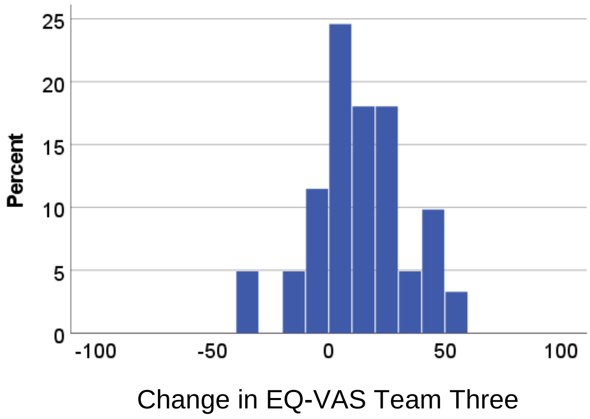


Figure 6-21: Histogram illustrating change in EQ-VAS for Team Three

6.7 Discussion

This study has explored the influence of established predictors on EQ5D-5L as reported by community dwelling stroke survivors in the first six-months after stroke. Findings concur with and add to the existing literature, as well as supporting the future interpretation of the EQ5D-5L in this population. Recommendations with regards to policy, practice and future research are made in the following chapter.

In question one, the highest proportion of patients reported problems in mobility and activity domains, with over half reporting no problems in the self-care, pain and anxiety domains. Both the EQIndex and EQ-VAS outcomes were skewed towards full health. The majority of predictors were significantly associated with outcomes, with fewer significant associations for pain and anxiety domains. In summary being female with comorbidities, a more severe stroke, greater premorbid and discharge disability and living in greater deprivation were associated with worse reported outcomes. Increasing age was associated with worse reported outcomes for mobility, self-care and activity domains, but better outcomes for pain and anxiety. There were significant differences between ISDNs for all outcomes.

With regards to change over time, gross improvements were evident across domains, EQIndex and EQ-VAS. Pain and anxiety domains started with the highest proportion of patients reporting no problems and made the smallest improvements over time. However, closer scrutiny exposed substantial underlying bidirectional change, representing a deterioration for almost a quarter of patients in these domains. Ceiling and floor effects were evident for both domains and EQIndex. Fewer predictors were significantly associated with a change in EQ5D-5L outcomes compared with the outcomes at a single timepoint, these are discussed in the following section. This was particularly evident for pain and anxiety domains.

6.7.1 Findings and their relation to the existing literature

Variation exists between the distribution of domain outcomes found in this and previous studies using the EQ5D-5L in Table 6-1. These are combined with study findings in Appendix 6-16 for ease of reference. However, the distribution of EQIndex and EQ-VAS outcomes found in this study fall within the range of the existing literature. This variation most likely reflects the influence of population-level differences such as societal norms and the health and social care infrastructure for stroke survivors across the world. Domains may be more sensitive to reflecting these broader cultural differences in comparison to the EQIndex or EQ-VAS. This study also found differences in population characteristics for both ISDNs and teams, which are discussed in section 6.6.3.

Findings from this study confirm that for community dwelling stroke survivors in England, the patient characteristics collected by SSNAP are significantly associated with the majority of EQ5D-5L outcomes at the level of domain, EQIndex and EQ-VAS. This is agreement with the wider literature presented earlier in section 6.1.4 [294,301,302]. However, differences in the number of significant associations for mobility, self-care and activity compared with pain and anxiety suggest the characteristics collected by SSNAP may be more applicable to the physical components of HRQoL.

In question two, pain and anxiety scores changed less over time than changes seen for other domains, with a higher proportion reporting deterioration in the scores. These changes were also unrelated to measured patient characteristics, suggesting that change in pain and anxiety may be influenced by other, unmeasured factors. Fewer characteristics were significant for change over time in domain, EQIndex and EQ-VAS, compared to a single time-point explored in question one. This was particularly evident for pain and anxiety domains as PremRS was the only significant association for pain, and none were significant for anxiety. A similar pattern of change across domains was reported in a longitudinal study of 152 German stroke survivors by Katona et al.[308]. They found no change in anxiety domain, a small deterioration in pain domain with larger improvements in mobility and activity domains over the first-year post stroke. The change in EQIndex found in this study (median 0.058) is comparable to the 0.06 reported over a similar time frame in UK stroke survivors by Luengo-Fernandez[288].

This study found changes over time in self-care domain score had the greatest number of significant predictors. Findings indicate that those who had more severe strokes, were older, discharged more disabled and lived in less deprived areas reported greater improvements in the self-care domain. Although this study did not explore associations with hospital length of stay, the recent HoRSSe study analysed larger samples of SSNAP data and found that stroke severity and discharge disability were both associated with longer hospital admissions [309]. This suggests that more elderly patients who have severe strokes may take longer to recover. Despite longer hospital admissions, these individuals continue to make improvements after discharge. This echoes findings of the Oxford Vascular study that found patients categorised as having had a severe stroke made smaller but more consistent improvements in their EQIndex over the subsequent 24 months. In contrast, those categorised as mild or moderate made larger improvements initially but had worse EQIndex scores by 24 months[288].

6.7.2 Psychological well-being after stroke

This study has explored changes in EQ5D-5L from shortly after discharge from hospital to six-months post stroke. This can be a difficult time for stroke survivors, who may have been sheltered from the impact of their stroke whilst in hospital. Adapting to life with the sequalae of stroke can be challenging. For many this time is characterised by uncertainty, anxiety and loss of autonomy[310,311]. In response, stroke survivors may undergo cycles of grief, fear and sense-making after discharge from hospital[312]. Almost a third of patients develop post-stroke depression in the first year[313]. Therefore, in the context of community stroke rehabilitation, it is essential that psychological outcomes are captured if services are to meet the needs of stroke survivors. The most consistently reported predictors of post-stroke depression include physical disability and stroke severity[313]. Consequently, an assumption has been made that improving physical health improves psychologically well-being. Findings from this study challenge this assumption for this population, as improvements in the physical domains of mobility, activity and self-care were not reflected in a substantial reduction in reported anxiety. Other predictors suggested in the literature may be more of a significant influence for stroke survivors in the first six-months. These include cognitive impairment [314], a lack of family or social support, pre-existing depression[315] and living alone[316].

6.7.3 Interpretation of EQ5D-5L in this population

Findings from this study offer insights to support the interpretation of the EQ5D-5L in the community dwelling stroke population. These have been summarised separately for domains, EQIndex, EQ-VAS and comparisons between providers.

Domains

Similar to many PROMs EQ5D-5L domains have acknowledged floor and ceiling effects[317]. Floor and ceiling effects are deemed present if more than 15% patients report the lowest or highest possible score[318]. Despite improvements in the EQ5D-5L in comparison with its predecessor EQ5D-3L[285], this study found clear floor effects. In question one, between 36% and 54% of patients reported "*no problems*" across the domains. Despite the obvious floor effect, this reflects a patient's perspective at a single time-point and as such is a valid representation. However, this strong floor effect influences the ability of domains to capture improvement and is acknowledged as a limitation. Therefore, caution must be taken when exploring longitudinal domain data, and baselines should always be included when considering this data.

Presenting aggregate before and after scores has the potential of masking underlying bidirectional change. In this study, almost a quarter of patients reported a deterioration in pain and anxiety between T_1 and T_2, not evident when aggregate scores were assessed in isolation. Therefore, it is imperative to visualise outcomes from a variety of perspectives as this study has, including tabulated descriptive statistics and baseline comparisons.

Døhl et al. suggested EQ5D-5L domains as an efficient method of identifying healthcare needs for stroke survivors[301]. Findings from this study would support this proposition, if floor effects are acknowledged and outcomes scrutinised from a variety of perspectives as described. Anxiety and pain domains may have particular utility as these components of HRQoL are rarely reflected elsewhere.

EQIndex

The EQIndex was designed primarily for economic evaluation and weighted towards health preferences established for a specific country[281]. Any weighting of responses has an associated value judgement. This includes the equal weighting of domains which would suggest an equal relative importance to the patient population[281]. Therefore, if weighting is to be used, the rationale for doing so must be clearly articulated. For example, using a set of values generated from a sample of a nation's general population. This supports decision-making regarding allocation of public tax-payer money to public services[319]. Guttaker et al. suggests there to be a distinction between this economic evaluation and clinical measurement of health. The authors caution against the use of aggregate PROMs data for purposes such as informing patient choice as this assumes patients hold the same relative values, which would be unlikely[292].

In the English value set, the EQIndex is weighted in favour of pain and anxiety domains[286]. In this study, these domains reported the lowest frequency of problems and the smallest (aggregate) change over time. Adjusting the EQIndex towards these domains may lead to an overestimation of baseline HRQoL, an underestimation of change over time and a lack of detail regarding the relative contribution of causal factors. Therefore, the use of EQ5D-5L domains and EQ-VAS to measure HRQoL may be more appropriate in this population.

EQ-VAS

This study found EQ-VAS at a single time-point to be significantly associated with most of the characteristics explored. However, these associations were not evident for change over time, suggesting that change may be influenced by other characteristics. The existing literature points to the influence of psychosocial factors on visual analogues scales. Hilari and Boreham explored associations between responses to a visual analogue scale and another multi-item scale-rated HRQoL tool (Stroke and Aphasia Quality of Life Scale). Despite a significant correlation between the two scales, they found stroke survivors predominantly considered psychosocial aspects when rating using the visual analogue scale[320]. This echoes other studies in stroke that report the EQ-VAS to have stronger correlations with outcomes measuring mood in comparison to disability or function[266,289].

In this study the EQ-VAS demonstrated a larger relative change in health outcome when compared with the EQIndex (median 9% and 5.8% respectively). In addition, the EQ-VAS had a smaller number of patients than the EQIndex reporting full health state at baseline (median 2.5 % and 16.8% respectively). Findings suggest the EQ-VAS is responsive to change in this population and may be influenced by psychosocial factors not captured by the other outcome measures used in SSNAP, such as mRS. However, if a measure is to be clinically useful it needs to be completed. This study found 12% of participants in question one and 14% of participants in question two did not have completed EQ-VAS. This is a consideration for national audits when considering mandating measures.

Comparison between populations

Explaining variation between providers is complex. Devlin and Appleby point to two main factors being responsible for variation in providers' outcomes, characteristics of their patient populations and characteristics of the provider themselves[202]. Before attempting to make comparisons, the influence of the population's characteristics must be fully understood, or the conclusions drawn may be misleading. Consequently, a number of authors caution against the use of PROMs for comparison between providers, instead using them to measure change in health status within patient groups and providers[276,292].

The populations analysed in question one and two varied. Participants in question one included patients within a specified ISDN, which represented a designated geographical area in which multiple teams may operate. Participants in question two were treated by a team from each ISDN, who collected an enhanced dataset as part of the pilot (see Figure 6-4). Comparisons between either ISDNs or teams were not the primary focus of this study. Data has been presented for each ISDN and individual teams to highlight that differences exist rather than drawing conclusions from this information. However the exploration of variation in these populations has illustrated two sources of potential differences. Firstly, differences were identified between the characteristics of populations. This would suggest differences in their casemixes, i.e. the proportions of those with specific characteristics vary between different populations. This is an acknowledged feature within the general population, influenced by a wide spectrum of social, environmental, health and economic determinants[321].

Secondly, differences were identified in the baseline EQ5D-5L outcomes between populations. Although this study found EQ5D-5L at six-months post stroke to be associated with a number of patient characteristics, other factors may also contribute to variations in baseline EQ5D-5L. These include differences in hospital length of stay, waiting times for community rehabilitation and the eligibility criteria used by community teams. These factors vary between region[37] and therefore have the potential to influence outcomes at a population level.

Based on findings from this study it is possible to see how population characteristics may have influenced outcomes at a single time-point. Differences were most evident between ISDN A and ISDN B. ISDN A had more favourable outcomes across domains, EQIndex and EQ-VAS. These may reflect the underlying differences in the characteristics of their populations which include ISDN A having fewer comorbidities, greater independence prior to and following stroke and less social deprivation. The relative contributions of these characteristics were not investigated. This would require statistical modelling with appropriate casemix adjustment before attempting to draw conclusions. Additional adjustment would be required to take into account baselines if changes over time were to be explored.

Prior to undertaking any such analysis, a number of additional factors need investigating such as the proportions of stroke survivors without EQ5D-5L data and the mode of EQ5D-5L collection. Both these factors are most likely dictated by provider-level differences, i.e. commissioning and models of service delivery. However, there may be differences in patient characteristics such as stroke severity, as this study found. Therefore, it is imperative that any data intended for comparison between providers be complete if it is to be representative.

The format of EQ5D-5L collection varies between providers. This is reflected in the SSNAP annual report for 2023 which stated 61% of stroke survivors answered EQ5D-5L questions over the telephone, 37% in person, 1% online and 1% received postal questionnaires[36]. Comparisons of screen, paper and phone based EQ5D-5L formats have suggested these variations have equivalence in terms of measurement[322,323]. However, these studies have been conducted within the general population and have not been replicated with stroke survivors. Stroke survivors are more likely to have communication or cognition impairments and a greater reliance on proxy responses all of which have the potential to introduce systematic bias when comparing responses from different formats.

6.7.4 Strengths and limitations

This study is the first to explore the influences of established predictors on the EQ5D-5L for community dwelling stroke survivors, both cross-sectionally and longitudinally and using such a large, complete dataset. The research question is clinically relevant and has been theory driven, with contributions from a variety of clinical stakeholders.

Limitations in the data have been clearly articulated in the discussion. However, two factors have not been explored. Firstly, no attempt has been made to separate out the effects of interrelated factors. Many of the predictors explored in this study have known correlations as they are indicators of medical complexity. Secondly, the influence of time since stroke on outcomes was not investigated. The potential for variation exists between stroke onset and both starting rehabilitation (T_1) and completing a six-month review (T_2). Future research should seek to explore these factors.

6.7.5 Conclusions

This study confirms that community dwelling stroke survivors report HRQoL that is associated with patient characteristics collected by SSNAP, but these are more sensitive to physical components of HRQoL. However, individual EQ5D-5L domains and the EQ-VAS provide additional information to that already offered by measures collected by SSNAP.

The collection of EQ5D-5L at both six-months and on commencement of rehabilitation offers an opportunity to gain insight into the needs of stroke survivors at what can be a challenging time in their recovery.

6.8 Chapter summary

This chapter has explored the use of EQ5D-5L in the context of community stroke rehabilitation. The evidence-base for EQ5D-5L in stroke has been detailed. National clinical audit data has been used to explore the influence of patient characteristics on EQ5D-5L outcomes. Findings have been used to support the interpretation of the EQ5D-5L for this population. Recommendations for policy, practice and future research (based on findings from this and earlier chapters) are discussed in the following chapter.

7 Discussion

7.1 Introduction

Chapter 7 reflects on the contribution made by this research and the subsequent implications for policy, practice and future research. There are three sections. Firstly, an overview of the thesis is provided, followed by considerations of the implications of this research. The chapter concludes with a reflection on the wider context of this research and the challenges experienced. This serves to provide the reader with an understanding of how the research and the researcher have been shaped by these experiences.

7.2 Overview of the research

7.2.1 Rationale

The Sentinel Stroke National Audit Programme (SSNAP) is an established quality improvement tool for hospital-based stroke care. It is the only national stroke audit that collects data detailing stroke care beyond hospital discharge. However, its role in driving quality improvement in the community setting was unexplored.

7.2.2 Aim

The aim of this study was:

To understand the role of national clinical audit in driving quality improvement in community stroke care.

This thesis consisted of four phases of study. Each phase used a distinct research method as part of a realist evaluation.

7.2.3 Exploration of the audit literature

A scoping review of the literature was undertaken to explore contextual features that influence the contribution of externally initiated, multidisciplinary clinical audits to quality improvement. The review identified important features pertinent to audits that are multidisciplinary and externally initiated. These focus on the challenges of engaging multiple disciplines and the utility of the data generated.

Findings suggested individual engagement to be influenced by not only their perception of the audit and its purpose, but also the perceived credibility of the audit and the culture of the organisation they are situated in. Resources were proposed as the main factor that influence audit participation, including dedicated time, information technology (IT) and expertise (IT and data analysis). A number of features were identified as influencing the ability of audit data to inform quality improvement. These included the perceived accuracy of data submitted, the accessibility and perceived utility of audit feedback. Findings were used to develop four Candidate Programme Theories. These theories sought to explore the role of national clinical audit in driving quality improvement in community stroke care.

7.2.4 Exploration of stakeholder experiences of SSNAP in the community

A mixed-methods online survey was used to refine the four Candidate Programme Theories. The survey captured the perspectives of a broad range of stakeholders in different roles from across England, including administrative, clinical, management and commissioning (n=206). Findings provided rich and candid insights into stakeholder experiences of the audit.

Community stakeholders reported being engaged in the audit and described using feedback to successfully inform a variety of quality improvements within their services. A number of challenges to audit participation were highlighted. These included the organisational culture, administrative support, online audit platform and ability of the audit to reflect the services delivered in this setting. This process generated four Initial Programme Theories exploring the role of national clinical audit in driving quality improvement in community stroke care.

7.2.5 Exploration of influences on SSNAP in community setting

Realist interviews were used to refine and test the four Initial Programme Theories. Interviews were undertaken with a broad variety of stakeholders in different roles from across England, including administrative, clinical, management and commissioning (n=20). Interviews offered an opportunity to collaboratively scrutinise theories with stakeholders, resulting in four refined Programme Theories.

Findings add to the existing literature, providing transferable insights into the role of national clinical audit in driving quality improvement in community services. These included the importance of organisational support for audit including dedicated administrative support, leadership interest and the fostering of audit champions. There was a recognition of the importance of accessible audit feedback to enable its strategic use and the role of collaboration-based approaches along the clinical pathway. Finally, the metrics collected must be perceived by stakeholders as reflecting both the service they deliver and the populations they serve.

7.2.6 Exploration of a PROM in community dwelling stroke survivors

Findings from earlier phases of this study suggested the collection of a patient reported outcome measure by SSNAP. It was proposed that the inclusion of the EQ5D-5L may capture the impact of community services on a patient's health-related quality of life. This final phase explored the evidence-base regarding the use the EQ5D-5L within stroke. National clinical audit data was used to explore the influence of patient characteristics on EQ5D-5L outcomes for community dwelling stroke survivors (n=3,813).

Findings confirmed the EQ5D-5L as reported by community dwelling stroke survivors in the sample, was associated with the patient characteristics collected by SSNAP. The EQ5D-5L was found to be more sensitive to physical components of health-related quality of life. However, individual EQ5D-5L domains provided additional information to that already offered by measures collected by SSNAP. The collection of EQ5D-5L at both six-months and on commencement of rehabilitation offers an opportunity to gain insight into the needs of stroke survivors at what can be a challenging time in their recovery.

7.3 Original contribution

7.3.1 Methodological

The use of mixed-methods survey as part of a realist evaluation in Chapter 4 was an original approach to refining candidate programme theories. A recent mapping review of realist methods identified 43 realist evaluations that included quantitative surveys[132], many of which used Likert scales to ascertain agreement with statements or satisfaction e.g. with healthcare interventions or interactions. To the author's knowledge no realist evaluations have reported the use of mixed methods survey. This method generated a broad sample of perspectives from across both England and the audit pathway. In addition, the online nature provided a level of anonymity which potentially encouraged greater candour when compared to face-to-face interviews. Although more challenging to synthesise, the mixed-methods survey generated rich causal insights into underlying mechanisms that would not have been evident based on quantitative results alone.

The investigation of change over time in EQ5D-5L domains was a novel approach to the analysis of this measure in stroke. As discussed in Chapter 6, relatively few studies use the latest five-level iteration of the EQ5D, instead favouring the EQ5D-3L. In addition the majority of published analyses of EQ5D (3 and 5L) have primarily used the EQIndex and not individual domains[291]. Where domains have been analysed, these have been dichotomised into *problems* and *no problems* and in the few studies exploring change over time, these have been comparison of the two time points and not an exploration of the underlying changes. The exploration of magnitude and direction of change within individual domains in this study has offered granular insights into the consequence of stroke for stroke survivors in the first six-months and the impact on their health-related quality of life.

7.3.2 Knowledge

The scoping review in Chapter 3 identified a gap in the literature regarding externally initiated multidisciplinary audits in the community setting. The majority of published audit and feedback literature relates to audits involving a single discipline in the hospital or clinic setting. Findings in Chapter 5 have provided insights into how community-based multidisciplinary teams use data for quality improvement and what contextual features influence their ability to do so. This is the first study to explore what community-based multidisciplinary teams require if they are to use audit to drive quality improvement.

There are a number of parallels between study findings and the wider audit and feedback literature, such as the burden of data collection as a barrier to audit participation. However the use of a realist evaluation has generated novel findings regarding the contextual features of community stroke care that influenced the ability of community multidisciplinary teams to use SSNAP for quality improvement. Key contextual features included a lack of perceived organisational support, the heterogenous nature of the services delivered and a lack of established infrastructure for either administrative or IT support. The complexity of the community setting has been explored and underlying mechanisms identified. For example, the importance of communicating across organisational boundaries and audit champions in the community setting. Cross-boundary communication provided opportunities for collaboration regarding the transfer of SSNAP records and ultimately led to the submission of more complete data. The role of champions may be specifically important in the community setting due to the dispersed models of service delivery and lack of physical crossover between team members.

Findings in Chapter 6 confirm that that community dwelling stroke survivors report health-related quality of life that is associated with patient characteristics collected by SSNAP. These were found to be more sensitive to physical components of health-related quality of life. This study showed that EQ5D-5L domains and EQ-VAS provided information regarding pain and mood, which would complement other measures in SSNAP if collected routinely.

This is the first study to explore change in individual EQ5D-5L domains over the first six-months post stroke. Although some associations with patient characteristics were evident, findings suggest that the established predictors of health-related quality of life, may not be key drivers for *change* in this outcome for stroke survivors in the first six-months. Further research is required to understand what factors may be associated with change in health-related quality of life in this population, this is discussed in the following section. In addition, a substantial proportion of patients reported a deterioration in their pain or mood over this period of time, suggesting this population may have needs that are not being met.

7.4 Implications of this research

7.4.1 Policy

Study findings suggest a number of policy-level considerations are required if community teams are to use SSNAP for quality improvement. These include the administrative support available to support participation, the challenges of collaborating across organisational boundaries and how to incentivise audit engagement.

In the longer-term, electronic health records have the potential to reduce the burden of data collection. However the NHS's vision for digitisation[43] is unlikely to be realised in the near future and data collection will likely remain a barrier to audit participation for teams without dedicated administrative support. This presents two considerations for policy makers at this point in time. Firstly, how to ensure that future digital health systems are designed to support the use of routine data for quality improvement. Study findings have identified the challenges of incompatible software between organisations along a clinical pathway. Decisive system leadership will be needed if the number of digital platforms are to be rationalised and the pathway streamlined for efficient data transfer along the clinical pathway.

Secondly, if participation in national clinical audits is mandated in the NHS Standard Contract[66], then clinical teams must be adequately resourced to do so. This study found teams unable to ring-fence administrative support and therefore diverting resources away from clinical activity to enable audit participation. As the centre of gravity for stroke rehabilitation moves out of acute hospitals and into the community setting, so should the resources necessary to monitor and improve the quality of care provided.

The current motivation for providers to populate and lock SSNAP records is linked to achieving their individual compliance and case ascertainment scores. This fails to incentivise a whole pathway approach whereby providers are motivated towards records being transferred efficiently and appropriately across the clinical pathway. Looking beyond findings from this study, stroke survivors describe a desire for greater continuity of care[324]. If stroke care is to be seamless as outlined in the National Stroke Service Model[41], the IT, quality assurance and quality improvement infrastructure must also be seamless. In the longer-term, such infrastructure must be tailored to the needs of stroke survivors rather than the convenience of existing piecemeal clinical pathways. In the short term, consideration should be given as to how best to work across existing organisational boundaries.

Study findings highlighted the importance of engaging individuals with SSNAP if it is to be used for quality improvement. A number of options exist for incentivising individuals, depending on their position in an organisation. For example, audit is mandated as part of post-graduate medical training[325]. Although few junior doctors work within the community setting, these teams do have large numbers of therapists and nurses. Health Education England have proposed a framework detailing four pillars of advanced clinical practice to support the career advancement of these healthcare professionals[326]. This framework includes clinical audit as part of the research pillar. Although not mandated, engagement and involvement in clinical audit could be incentivised for those clinicians wishing to progress professionally.

As discussed earlier, participation in national clinical audits is mandated at an organisational level in the NHS Standard Contract[66]. Consideration needs to be given as to how this is implemented strategically within organisations. For example, how is audit feedback routinely monitored, acknowledged and acted upon and where does responsibility for these actions lie? Although these components of the audit cycle were outside the scope of this PhD, findings suggested leadership interest in audit feedback to be a catalyst for team engagement. Therefore, in the same way that the infrastructure and resources to support IT, quality assurance and quality improvement should follow patients out into community services, so must the systems for accountability and governance.

7.4.2 Practice

Findings from this study highlighted the pivotal role of champions in clinical practice to facilitate team level engagement with SSNAP. These roles were described as unique to each team, a result of the needs of the service, the individuals and opportunities available. Participants described these roles as evolving over time for those demonstrating an interest in SSNAP which requires an opportunistic approach to identifying these individuals. This includes signposting to resources and support for those motivated to develop into this role, rather than the tokenistic nomination of an individual to whom SSNAP is allocated.

The mechanisms by which examples of good practice, such as those highlighted in this study are shared needs to be considered. Shared learning would enable teams to be more efficient, reduce barriers to participation and inspire confidence in the potential for SSNAP to bring about meaningful changes for patients. Examples could include experiences of success such as collaboration across organisational boundaries and increased staffing establishments based on business cases informed by audit feedback. Existing national clinical networks should be harnessed as well as tapping into more local systems through Integrated Stroke Delivery Networks (ISDNs), to support this knowledge exchange.

With regard to the use of EQ5D-5L, findings from this study would suggest the prioritisation of the EQ-VAS and individual domains for the following purposes. Firstly, collecting the measure on commencing rehabilitation in addition to six-months post stroke, would support teams in understanding the needs of their population at the outset and monitor the impact of their services upon different aspects of health-related quality of life. For example, this study found stroke survivors made the smallest improvements with regards to pain and anxiety, in fact almost a quarter of patients reported a deterioration in these domains. In these circumstances, teams should consider whether the interventions they are providing meet the needs of their patients. This information can support the planning and development of future needs-led services that are tailored to local populations.

In order to enable teams to interpret the EQ5D-5L, they should be supported to understand its limitations and the influence of patient characteristics. Without this investment, there is a risk that teams will perceive the extra data collection as an additional burden without benefit and fail to realise its potential for quality improvement. This concurs with a systematic review of the barriers and enablers of implementing PROMs by Foster et al. who proposed early investment in preparing organisations to use PROMs as fundamental to their success[201]. A recent study by Jolliffe et al. explored the implementation of the EQ5D-5L in MDT community stroke teams in Australia and found champions to be important enablers of the routine collection of PROMs in this setting[327]. Further analysis to understand the relative contribution of predictors is required before comparisons between teams should be explored. Attempts at making unadjusted service level comparisons without exploring the appropriate statistical modelling is not recommended as results may be misleading. This is discussed in the following section.

7.4.3 Future research

Historically, audit and feedback research has focussed on single-discipline activities in hospital or clinic settings. Despite this *relative* standardisation, substantial heterogeneity in study design has been identified as a limiting factor in many studies, as detailed in Chapter 1. This study has highlighted the additional complexities of audit in dispersed community settings with a wide range of professional contributors and diverse patient populations. The use of a theory-driven, mixed-methods approach has provided an opportunity to investigate these complexities and enabled a deeper scrutiny of mechanisms that influence the ability of audit to contribute to quality improvement. Future research into MDT audits must consider their wider context, building on findings of this study to better understand the influence of contextual features on outcomes rather than seeking to assess the success of an entire audit cycle in isolation. Failure to do so risks drawing inaccurate conclusions based on incomplete theoretical assumptions. This study has generated a number of clinically meaningful questions that would warrant further exploration. These include working across organisational data boundaries, the impact of digitisation on harvesting routine data for quality improvement in the community and the collection and interpretation of EQ5D-5L in this setting.

Future research should investigate how teams are enabled to collaborate across organisational boundaries. Examples of innovative practice should be explored to understand the mechanisms by which some teams are able to achieve collaboration and what contextual features facilitate this. As mentioned earlier, existing clinical and strategic networks should be exploited for sharing this knowledge. However, there needs to be a greater understanding of the role of these collaborative networks in driving change at scale if quality improvement opportunities are to be optimised.

Much work is being done to realise the vision of NHS digitisation in acute trusts and primary care. However, consideration must be given to the capture and efficient extraction of routine data to inform quality improvement in the context of services delivered in the community. This PhD has highlighted distinctions between the acute and community settings that influence the ability of teams to use data for quality improvement. Therefore, assumptions must not be made that digital health records can be rolled out across clinical pathways without due consideration of the context in which they are implemented.

Prior to undertaking further analysis on the EQ5D-5L, the equivalence of different modes of delivery in the stroke population must be established i.e. telephone / online / face to face. Reasons for this are two-fold. Firstly there may be potential systematic biases between the modes of delivery in a population with possible communication and cognitive impairments. Secondly, the use of digital platforms has the potential to reduce the burden of data collection and therefore may warrant further investigation or promotion.

Building on findings from this study, further analysis of the EQ5D-5L is required to establish the relative contribution of patient characteristics when statistical models are adjusted for other variables. In addition to the characteristics explored as part of this study, factors such as time since stroke, living alone, social support and cognitive impairment should also be considered. Adjusting for case-mix variation would be a step closer to enabling teams to compare patient outcomes between providers using audit feedback.

Further research is required to explore the factors driving *change* in EQ5D-5L over time. A deeper understanding of the influences on change in health-related quality of life in this population would inform the provision of services that better meet their needs. This should include not only exploring the impact of wider determinants of health and wellbeing such as social support and cognitive impairment, but also the intervention provided by community stroke rehabilitation teams. The latter requires much consideration. This study has highlighted a high degree of heterogeneity within community stroke services that could make attempts at comparison challenging. However, this may provide an opportunity to prioritise and explore the impact of key features of services. Potential factors include the provision of specific interventions e.g. well-being support, the skill mix of a team e.g. ratio of registered healthcare professionals to support workers, or process measures such as intensity of rehabilitation provided or duration of input. This would build on the work already undertaken by the WISE (What is the Impact of Stroke ESD?) study. This research investigated the adoption of evidence-based components of community stroke rehabilitation, but was unable to determine any association with patient outcome as measured by the modified Rankin Scale[54].

7.5 Reflexivity

Reflexivity has various definitions, depending on the epistemological stance taken. Malterud's (2001) definition best describes the approach taken within this study.

> "*Attending systematically to the context of knowledge construction, especially to the effect of the researcher at every step of the research process.*"[328]

Four main considerations have been made with regards to reflexivity in this research. These are the contribution of stroke survivors and their carers, the chosen methodology, the positionality of the researcher and the influence of the supervisory team. Additional reflections are offered regarding the challenges of using RE as a novice researcher and how this PhD has shaped the researcher.

7.5.1 Patient, Public Involvement and Engagement

This research has benefitted from the support of the Nottingham Stroke Research Partnership Group (NSRPG). The NSRPG is a group of stroke survivors and carers who provide feedback on and input into stroke research through the University of Nottingham. Their involvement included contributing to the wording of lay summaries and providing feedback on the study design and dissemination materials. However, there were challenges in engaging the group and garnering interest in what was deemed a "*dry*" topic described as more "*strategic than interesting to patients*". Therefore, efforts were made to share study findings in different arenas such as X (formerly Twitter) to reach a broader lay audience. This resulted in conversations with UK-based stroke survivors and carers regarding study purpose and findings, which have informed the format of subsequent dissemination.

7.5.2 Positionality

Researcher positionality includes their personal characteristics, experiences and beliefs, amongst other things[329]. A statement of positionality was made at the outset of this research, in Chapter 2. This was done not to bracket these experiences but instead to acknowledge and embrace them. Reflexivity is not an identification of study limitations, it is an appreciation of the value added[330]. The value added in this research included an understanding of the practical landscape of MDT stroke rehabilitation in the community, its constituent parts and how it is situated within the broader stroke pathway. Additional benefits included a working knowledge of the national audit under investigation (SSNAP) and credibility afforded by being in clinical practice.

External measures used to monitor positionality included sense-checking with collaborators, regular supervisory support, second reviewer and use of established quality criteria e.g. CHERRIES and COREQ (both included in appendices). Tools exploited to enhance rigour include a reflexive diary during data collection, notes of collaborator discussions, summaries and reflections on supervision.

7.5.3 Supervisory team

Although strategic, the choice of a supervisory team consisting of the SSNAP Clinical Director (MJ) and Associate Director (RF), had the potential to generate tension within this research. Candour has been demonstrated in the contributions made by each member of the supervisory team throughout. At no point did either individual influence the interpretation of data or study findings, nor was it expected they would attempt to do so. In addition to their expertise, the value of their positionality allowed for a bird's-eye view of this research in the context of national clinical policy, and introductions to collaborators who may otherwise have been difficult to engage. These included individuals from SSNAP and HQIP. Great care has been taken to be transparent regarding any potential conflict of interest e.g. in publications. In the same way this was intended to reassure the reader of the distinction between SSNAP and this research, this was clarified for benefit of all stakeholders. All participant information clearly stated that the research was independent of SSNAP and that SSNAP were not obliged to act upon any findings.

7.5.4 Chosen methodology

The choice of scientific realism as a methodology within which to situate this research has had clear implications for its design and therefore outcomes. The guidelines provided by the RAMESES organisation provide explicit expectations of the steps to follow. This includes transparent reporting of the origin and influence of any data included in the study (e.g. literature, interviews), contributions of stakeholders and decisions made regarding the shape or direction of the study.

Despite the risk for iterative and collaborative studies to be messy, the transparency demanded by RAMESES offers assurance to the reader that the research has been conducted in a rigorous manner. On reflection, there is a balance to strike between attempting to convey the “messy complexity” of lived experiences, and artificial simplification for the ease of presenting bold findings.

This was a lesson learnt after almost three years of taking a supervisor (new to RE) on a realist journey of exploration. Together we learned to sit (un)comfortably with contingent, approximate and evolving findings. In the final supervision, in an attempt to summarise, the entire RE was presented as a single flowchart. The messy complexity that previously provided authenticity was lost and supervisor feedback was clear, these neat findings failed to convey study insights.

7.5.5 Challenges of RE

On commencement of this PhD there were personal reservations regarding the choice of scientific realism as chosen methodology. Ray Pawson has himself suggested that realist research "*is not for novices*"[123] and its ontological foundations are commonly acknowledged as challenging for early career researchers[104]. In fact, when first encountered in a previous research degree the confusion generated by trying to grapple with realism guaranteed it was not on the short list for this study. Initial conversations with peer post-graduate students and early career researchers revealed a number of different orthodoxies within realism, most commonly dictated by where a researcher received training. There were jokes regarding the "*realist police*" who may scrutinise the legitimacy or critique work presented as realist, however no evidence of this was ever offered. Despite these initial concerns, realism was deemed the most appropriate methodology to investigate the role of SSNAP, as clinical experience pointed to context being a crucial factor.

These initial fears are in stark contrast to the experiences of the last three years. Scientific realism has proved to be an open and catholic church, with international collaboration via a strong online presence. Leaders in the field such as Ray Pawson, Nick Tilley, Geoff Wong, Andrew Booth, Sonia Dalkin and Justin Jagosh regularly contribute and respond to questions in the online forum, from which this PhD has benefitted. Involvement in NottsRealism resulted in running webinars, engaging with international researchers such as Ferdi Mukumbang and Maura MacPhee and presenting early findings to an international audience. Despite the fear of bruising critiques, these opportunities were constructive and always resulted in a deeper understanding of the research at hand. The involvement of key collaborators enabled the contribution and guidance from individuals with a wealth of expertise in stroke rehabilitation, policy, audit and realism. This PhD is undoubtedly richer, more robust and clinically meaningful as a result of their involvement.

7.5.6 What have I learnt?

From the outset this PhD has been viewed as an opportunity for professional development and personal growth. As such, every available resource and opportunity has been embraced. In addition to the early investment in extensive methodological training from the Centre for Advancement in Realist Evaluation and Synthesis (CARES), formal training was purposely sought from a variety of providers to inform the methods used. These included online survey design (University of Southampton), advanced qualitative interviewing (University of Birmingham), mixed methods, writing for publication and ethics in healthcare research (University of Nottingham). A variety of software has been used such as survey design (Jisc^{TM}) organisation of qualitative data (NVivo^{TM}) and statistical analysis (SPSS^{TM} and STATA^{TM}).

As discussed earlier, efforts have been made to engage with a variety of networks. These have been crucial in not only the study development, but also the dissemination of findings, an overview is detailed on the following page. Dissemination has required overcoming personal challenges such as a fear of public speaking and a persistent sense of imposter syndrome.

Despite the substantial amount of research training undertaken, perhaps the most significant learning is a more personal discovery that nothing is insurmountable, given some effort and the right support.

Health Services Research UK Birmingham in-person July 2022

Oral presentation: The contribution of online surveys in the development of theory in realist research. https://hsruk.org/conferences/conference-2022/presentations/community-based-care

Nottingham Realist Group Online June 2022

Presentation and discussion: Use of surveys within the realist paradigm.

World Stroke Congress Singapore in-person October 2022

Poster presentation: How is the post-acute national stroke registry perceived by stakeholders in England and how is data currently used? (Findings from a national survey) https://journals.sagepub.com/toc/wsoa/17/3_suppl

UK Stroke Forum Liverpool in-person December 2022

Poster presentation: How do stakeholders perceive and engage with the national stroke audit? (Findings from a national survey) https://journals.sagepub.com/doi/epub/10.1177/17474930221142512

European Stroke Conference Munich in-person May 2023

Poster: How can the UK's National Stroke Audit drive quality improvement in post-hospital care? https://journals.sagepub.com/doi/epub/10.1177/23969873231169660

Sentinel Stroke National Audit Programme Online June 2023

Overview of PhD findings for strategic SSNAP stakeholders.

Publication in Synapse Magazine (not peer reviewed) July 2023

Exploring quality improvement in community services using a national survey.

Sentinel Stroke National Audit Programme Online July 2023

Granular & technical feedback to SSNAP operational team.

BMC Health Services Research September 2023

Novel use of a survey as part of a realist evaluation of national clinical audit

(submitted and minor amendments made – awaiting editorial decision).

International Audit & Feedback Meta-Lab Toronto in-person October 2023

Oral presentation (15 mins): How can the national stroke audit in England drive quality improvement in the evolving post-acute setting? https://www.ohri.ca/auditfeedback/af-metalab-meeting-2023

UK Stroke Forum Birmingham in-person December 2023

Poster presentation: How can prospective national audit drive quality improvement in the community setting? https://europe.nxtbook.com/nxteu/sageuk/ukstrokeforum_202402_supp/index.php#/p/56

Policy, Practice and Research Nottingham in-person March 2024

Policy implication of PhD findings, open debate with NHS England Stroke Programme leads and leading academic in stroke.

East Midlands Stroke Delivery Network Nottingham in-person March 2024

Quality Improvement in Stroke Rehabilitation: How can routine data be leveraged to drive change?

References

1. Oxford English Dictionary. Audit (*v.*) Oxford University Press. Accessed Nov 13, 2023. https://doi.org/10.1093/OED/1169582901.
2. Packwood T, Kerrison S, Buxton M. The Implementation of Medical Audit. *Soc Policy Admin*. 1994;28(4)299-316.
3. *Power M. The audit explosion. Demos; 1994. Accessed Jan 16, 2022. https://demos.co.uk/wp-content/uploads/files/theauditexplosion.pdf*.
4. Matthews D. *A history of auditing: the changing audit process in Britain from the nineteenth century to the present day*. Routledge; 2006.
5. Hood C. A public management for all seasons? *Public Adm*. 1991;69(1):3-19.
6. Power M. The audit society—Second thoughts. *Int J Audit*. 2000;4(1):111-119.
7. Steer P. OCR Policy Briefing. *Policy Bulletin.* 2019;16. Accessed Jan 16, 2022. https://www.ocr.org.uk/Images/520296-ocr-policy-briefing-march-2019.pdf.
8. Maltby J. There is no such thing as audit society. Working Paper 39. Department of Management Studies, University of York. 2008. Accessed Jan 16, 2022. https://eprints.whiterose.ac.uk/3749/1/wp39maltby.pdf.
9. Catlow J, Bhardwaj-Gosling R, Sharp L, Rutter MD, Sniehotta FF. Using a dark logic model to explore adverse effects in audit and feedback: a qualitative study of gaming in colonoscopy. *BMJ Quality & Safety*. 2022;31(10):704-715.
10. Bowerman M, Raby H, Humphrey C. In search of the audit society: some evidence from health care, police and schools. *Int J Audit*. 2000;4(1):71-100.
11. The Health Foundation. Working for patients'- White Paper. 2021. Accessed Jan 31, 2022. https://navigator.health.org.uk/theme/working-patients-white-paper.
12. NHS. The National Health Service and Community Care Act. 1990. Accessed Jan12, 2022. https://www.legislation.gov.uk/ukpga/1990/19/introduction/enacted.
13. Taylor E, Jones F, McKevitt C. How is the audit of therapy intensity influencing rehabilitation in inpatient stroke units in the UK? An ethnographic study. *BMJ Open.* 2018; Accessed May 27, 2021. https://doi:10.1136/bmjopen-2018-023676.
14. Dixon N. What is clinical audit's purpose: quality assurance or quality improvement? *Fac Dent J*. 2011;2(2):79-83.
15. Skrypak, M, Duffy, E, Rezel, K. Best Practice in Clinical Audit. London: Healthcare Quality Improvement Partnership; 2020.
16. Hut-Mossel L, Ahaus K, Welker G, Gans R. Understanding how and why audits work in improving the quality of hospital care: A systematic realist review. *PLoS One*. 2021;16(3):25-38.
17. Bowie P, Bradley NA, Rushmer R. Clinical Audit and quality improvement - time for a rethink? *J Eval Clin Pract*. 2010;18(1):42-8.
18. Stewart K, Bray B, Buckingham R. Improving quality of care through national clinical audit. *Future Hosp J*. 2016;3(3):203-206.
19. Ivers N, Jamtvedt G, Flottorp S, et al. Audit and feedback: effects on professional practice and healthcare outcomes. *Cochrane Database Syst Rev*. 2012;(7):CD000259.
20. Lee P, Chin K, Liew D, et al. Economic evaluation of clinical quality registries: a systematic review. *BMJ Open*. 2019;9(12):984-991.
21. Flottorp S, Jamtvedt G, Gibis B, McKee M. Using audit and feedback to health professionals to improve the quality and safety of health care. *World Health Organization: Policy Summary.* 2010.
22. Ivers NM, Sales A, Colquhoun H, et al. No more 'business as usual' with audit and feedback interventions: Towards an agenda for a reinvigorated intervention. *Implement Sci*. 2014;9(1):14-14.
23. Taylor A, Neuburger J, Walker K, Cromwell D, Groene O. How is feedback from national clinical audits used? Views from English National Health Service trust audit leads. *J Health Serv Res Policy*. 2016;21(2):91-100.
24. Boyle A, Keep J. Clinical audit does not work, is quality improvement any better? *Br J Hosp Med*. 2018;79(9):508-510.
25. Foy R, Eccles MP, Jamtvedt G, Young J, Grimshaw JM, Baker R. What do we know about how to do audit and feedback? Pitfalls in applying evidence from a systematic review. *BMC Health Serv Res*. 2005;5:50-58.

26. Brehaut JC, Colquhoun HL, Eva KW, et al. Practice Feedback Interventions: 15 Suggestions for Optimizing Effectiveness. *Ann Intern Med*. 2016;164(6):435-443.
27. Brehaut JC, Eva KW. Building theories of knowledge translation interventions: use the entire menu of constructs. *Implement Sci*. 2012;7:1-10.
28. Colquhoun HL, Brehaut JC, Sales A, et al. A systematic review of the use of theory in randomized controlled trials of audit and feedback. *Implement Sci*. 2013;8(1):1-8.
29. Colquhoun HL, Carroll K, Eva KW, et al. Advancing the literature on designing audit and feedback interventions: identifying theory-informed hypotheses. *Implement Sci*. 2017;12:10-14.
30. Brown B, Gude WT, Blakeman T, et al. Clinical Performance Feedback Intervention Theory (CP-FIT): a new theory for designing, implementing, and evaluating feedback in health care based on a systematic review and meta-synthesis of qualitative research. *Implement Sci*. 2019;14:25-38.
31. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby J. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ*. 2021;374:2061-2069.
32. Antonacci G, Whitney J, Harris M, Reed JE. How do healthcare providers use national audit data for improvement? *BMC Health Serv Res*. 2023;23(1):393-402.
33. McVey L, Alvarado N, Keen J, et al. Institutional use of National Clinical Audits by healthcare providers. *J Eval Clin Prac*. 2020;27(1):143-150.
34. Alvarado N, McVey L, Greenhalgh J, et al. Exploring variation in the use of feedback from national clinical audits: A realist investigation. *BMC Health Serv Res*. 2020;20(1):859-868.
35. National Institute for Health and Care Excellence (NICE) What are strokes and TIAs? 2023. Accessed Nov 15, 2023. https://cks.nice.org.uk/topics/stroke-tia/background-information/definition/.
36. Sentinel Stroke National Audit Programme (SSNAP). Annual Report: 2023. Accessed Nov 15, 2023. https://www.strokeaudit.org/Documents/National/Clinical/Apr2022Mar2023/Apr2022Mar2023-AnnualReport.aspx.
37. Sentinel Stroke National Audit Programme (SSNAP). National Clinical Audit Results: 2023. Accessed Aug 28, 2023. https://www.strokeaudit.org/Results2/Clinical-audit/National-Results.aspx.
38. Intercollegiate Stroke Working Party. National Clinical Guidelines for Stroke for the UK and Ireland. 2023. Accessed Oct 20, 2023. https://www.strokeguideline.org.
39. National Institute for Health and Care Excellence (NICE). Stroke rehabilitation in adults: Guideline NG236. 2023. Accessed Nov 15, 2023. https://www.nice.org.uk/guidance/ng236.
40. National Institute for Health and Care Excellence (NICE). Stroke in adults. 2016. Accessed Nov 15, 2023. https://www.nice.org.uk/guidance/qs2.
41. NHS England National Stroke Programme. National Stroke Service Model: Integrated Stroke Delivery Networks (ISDNs). 2021. Accessed Nov 16, 2023. https://www.england.nhs.uk/wp-content/uploads/2021/05/stroke-service-model-may-2021.pdf.
42. NHS England. A National service model for an integrated community stroke service. 2021. Accessed Feb 4, 2023. https://www.england.nhs.uk/publication/national-service-model-for-an-integrated-community-stroke-service/.
43. NHS England. The NHS long term plan. 2019. Accessed Oct 20, 2023. https://www.longtermplan.nhs.uk/.
44. Langhorne P, Ramachandra S, Collaboration SUT. Organised inpatient (stroke unit) care for stroke: network meta-analysis. *Cochrane Database Syst Rev*. 2020;4:CD000197.
45. NHS England. Principle Five: "Home first" approach. Accessed April 25, 2024. https://www.england.nhs.uk/urgent-emergency-care/reducing-length-of-stay/reducing-long-term-stays/home-first/.
46. Sentinel Stroke National Audit Programme (SSNAP). National Results: Acute Organisational Audit 2021. Accessed Nov 16, 2023. https://www.strokeaudit.org/Results2/Organisational/National-Organisational.aspx.

47. Sentinel Stroke National Audit Programme (SSNAP). National Results: Post-Acute Organisational Audit 2021. Accessed Nov 16, 2023. https://www.strokeaudit.org/Results2/PostAcute2021/National.aspx.
48. Department of Health. National Stroke Strategy. 2007. Accessed Dec 28, 2023. https://nsnf.org.uk/assets/documents/dh_081059.pdf.
49. Sentinel Stroke National Audit Programme (SSNAP). Clinical Audit April 2013 - March 2018 Annual Public Report Accessed April 26, 2024. https://www.strokeaudit.org/Results2/Clinical-audit/National-Results.aspx.
50. Early Supported Discharge Trialists. Services for reducing duration of hospital care for acute stroke patients. Cochrane Database Syst Rev. 2001. Accessed April 26, 2024. https://doi.org/10.1002/14651858.CD000443.
51. Langhorne P, Baylan S, Early Supported Discharge Trialists. Early supported discharge services for people with acute stroke. Cochrane Database Syst Rev. 2017. Accessed May 11, 2021. https://dx.doi.org/10.1002/14651858.CD000443.pub4.
52. Fisher RJ, Gaynor C, Kerr M, et al. A consensus on stroke: early supported discharge. *Stroke*. 2011;42(5):1392-7.
53. Chouliara N, Fisher RJ, Kerr M, Walker MF. Implementing evidence-based stroke Early Supported Discharge services: a qualitative study of challenges, facilitators and impact. *Clin Rehabil*. 2014;28(4):370-377.
54. Fisher RJ, Chouliara N, Byrne A, et al. Large-scale implementation of stroke early supported discharge: the WISE realist mixed-methods study. *Health Serv Deliv Res*. 2021;9(22)
55. Scobie S, Kumpunen S. The state of community health services in England. Evidence for better health care. *Nuffield Trust*. 2023. Accessed Dec 19,2024. https://www.nuffieldtrust.org.uk/resource/the-state-of-community-health-services-in-england-0-02023.
56. Bailey N. Key Messages for Successful Implementation of a Specialist Community Rehabilitation Service. *J Integr Care*. 2005;13(2):22-27.
57. Foot C, Sonola L, Bennett L, Fitzsimons B, Raleigh V, Gregory S. *Managing quality in community health care services. Kings Fund. 2014. Accessed Jan 16, 2022. https://assets.kingsfund.org.uk/f/256914/x/1854e77a22/managing_quality_community_services_2014.pdf*.
58. *World Health Organization. Regional Office for Europe & European Stroke Council. Pan European consensus meeting on stroke management : report, Helsingborg. 1995. Accessed April 25, 2024. https://iris.who.int/handle/10665/107573*.
59. Riksstroke: The Swedish Stroke Register. National Board of Health and Welfare. Accessed Jan 1, 2024. https://www.riksstroke.org/sve/.
60. Public Health Scotland. Scottish Stroke Care Audit. Accessed Jan 1, 2024. https://www.strokeaudit.scot.nhs.uk/index.html.
61. The Australian Stroke Clinical Registry (AuSCR). Accessed Jan 25, 2022. https://auscr.com.au/.
62. Cadilhac DA, Kim J, Lannin NA, et al. National stroke registries for monitoring and improving the quality of hospital care: A systematic review. *Int J Stroke*. 2016;11(1):28-40.
63. Sentinel Stroke National Audit Programme (SSNAP). King's College London. Accessed Jan 1, 2024. https://www.strokeaudit.org/.
64. Rudd AG, Hoffman A, Paley L, Bray B. 20 years of researching stroke through audit. *Clin Rehab*. 2018;32(8):997-1006.
65. Sentinel Stroke National Audit Programme (SSNAP). National Clinical Audit Results. April 2016 - March 2017 Annual Public Report. Accessed Dec 22, 2023. https://www.strokeaudit.org/Documents/National/Clinical/Apr2016Mar2017/Apr2016Mar2017-AnnualReport.aspx.
66. NHS England. The NHS Standard Contract. Accessed Jan 1, 2024. https://www.england.nhs.uk/nhs-standard-contract/.
67. Bray BD, Cloud GC, James MA, et al. Weekly variation in health-care quality by day and time of admission: a nationwide, registry-based, prospective cohort study of acute stroke care. *Lancet*. 2016;388(10040):170-177.

68. Bray BD, Ayis S, Campbell J, et al. Associations between the organisation of stroke services, process of care, and mortality in England: prospective cohort study. *BMJ*. 2013;346:2827-2834.

69. Scottish Stroke Improvement Programme. National Report: 2023. Public Health Scotland. Accessed April 27, 2024. https://www.publichealthscotland.scot/media/20499/ssip-june2023-english.pdf.

70. Miall N, Fergie G, Pearce A. Health Inequalities in Scotland: trends in deaths, health and wellbeing, health behaviours, and health services since 2000. Project Report. University of Glasgow. Accessed April 2, 2024. https://doi.org/10.36399/gla.pubs.282637.

71. Finch D, Wilson H, Bibby J. Leave no one behind: the state of health and health inequalities in Scotland. The Health Foundation. 2023. Accessed April 26, 2024. https://www.health.org.uk/sites/default/files/upload/publications/2023/HF_Health_Scotland_Web_Final.pdf.

72. Cadilhac D, Kilkenny M, Lannin N, et al. Weekend versus weekday hospital discharge: Experience from the Australian stroke clinical registry. Conference Abstract. *Eur Stroke J*. May 2016;1 (1 Supplement 1):214-215.

73. World Health Organisation. Quality of Care. 2021. Accessed Jan 1, 2022. https://www.who.int/health-topics/quality-of-care#tab=tab_3.

74. Jones B, Kwong E, Will W. Quality Improvement Made Simple. The Health Foundation. 2021. Accessed Jan 31, 2022. https://doi.org/10.37829/HF-2021-I05.

75. Yates M, Bechman K, Dennison EM, et al. Data quality predicts care quality: findings from a national clinical audit. *Arthritis Res Ther*. 2020;22(1):1-8.

76. Donabedian A. Evaluating the quality of medical care. *The Milbank memorial fund quarterly*. 1966;44(3):166-206.

77. Walsh K, Gompertz PH, Rudd AG. Stroke care: How do we measure quality? *Postgrad Med J*. 2002;78(920):322-326.

78. Stroke Unit Trialists Collaboration: Organised inpatient (stroke unit) care for stroke. *Cochrane Database Syst Rev*. 2013;(9):CD000197.

79. Pohl J, Held JPO, Verheyden G, et al. Consensus-based core set of outcome measures for clinical motor rehabilitation after stroke—a Delphi study. *Front Neurol*. 2020;11:875- 883.

80. Reeves M, Lisabeth L, Williams L, et al. Patient-reported outcome measures (PROMs) for acute stroke: rationale, methods and future directions. *Stroke*. 2018;49(6):1549-1556.

81. Katzan IL, Thompson NR, Lapin B, Uchino K. Added value of patient-reported outcome measures in stroke clinical practice. *J Am Heart Assoc*. 2017;6(7):e005356.

82. Smith S, Cano S, Browne J. Patient reported outcome measurement: drawbacks of existing methods. *BMJ*. 2019;364

83. Rymer MM, Anderson CS, Harada M, et al. Stroke service: how can we improve and measure outcomes? Consensus summary from a global stroke forum. *Acta Neurol Scand*. 2014;130(2):73-80.

84. Kwakkel G, Lannin NA, Borschmann K, et al. Standardized measurement of sensorimotor recovery in stroke trials: consensus-based core recommendations from the stroke recovery and rehabilitation roundtable. *Int J Stroke*. 2017;12(5):451-461.

85. Wallace SJ, Worrall L, Rose T, et al. A core outcome set for aphasia treatment research: The ROMA consensus statement. *Int J Stroke*. 2019;14(2):180-185.

86. Millar JD, Van Wijck F, Pollock A, Ali M. International consensus recommendations for outcome measurement in post-stroke arm rehabilitation trials. *Eur J Phys Rehabil Med*. 2021;57(1):61-68.

87. English C, Simpson DB, Billinger SA, et al. A roadmap for research in post-stroke fatigue: Consensus-based core recommendations from the third Stroke Recovery and Rehabilitation Roundtable. *Neurorehabil Neural Repair*. 2024;38(1):7-18.

88. Van Criekinge T, Heremans C, Burridge J, et al. Standardized measurement of balance and mobility post-stroke: Consensus-based core recommendations from the third Stroke Recovery and Rehabilitation Roundtable. *Neurorehabil Neural Repair*. 2024;38(1):41-51.

89. Crombie IK, Davies HTO. Beyond health outcomes: the advantages of measuring process. *J Eval Clin Prac*. 1998;4(1):31-38.

90. Kasner SE. Clinical interpretation and use of stroke scales. *Lancet Neurol*. 2006;5(7):603-612.
91. Quinn TJ, Dawson J, Walters MR, Lees KR. Reliability of the modified Rankin Scale: a systematic review. *Stroke*. 2009;40(10):3393-3395.
92. Ali M, Fulton R, Quinn T, et al. How well do standard stroke outcome measures reflect quality of life? A retrospective analysis of clinical trial data. *Stroke*. 2013;44(11):3161-3165.
93. Banks JL, Marotta CA. Outcomes validity and reliability of the modified Rankin scale: implications for stroke clinical trials: a literature review and synthesis. *Stroke*. 2007;38(3):1091-1096.
94. Pożarowszczyk N, Kurkowska-Jastrzębska I, Sarzyńska-Długosz I, Nowak M, Karliński M. Reliability of the modified Rankin Scale in clinical practice of stroke units and rehabilitation wards. *Front Neurol*. 2023;14:1064642.
95. Bruno A, Akinwuntan AE, Lin C, et al. Simplified modified rankin scale questionnaire: reproducibility over the telephone and validation with quality of life. *Stroke*. 2011;42(8):2276-2279.
96. Saposnik G, Hill MD, O'Donnell M, Fang J, Hachinski V, Kapral MK. Variables associated with 7-day, 30-day, and 1-year fatality after ischemic stroke. *Stroke*. 2008;39(8):2318-2324.
97. EuroQol Research Foundation. EQ-5D User guide. 2019. Accessed Jan 11, 2023. https://euroqol.org/publications/user-guides.
98. Mayan M. *Essentials of qualitative inquiry*. 2nd ed. Routledge; 2023.
99. Allsop J, Saks M. *Researching health: Qualitative, quantitative and mixed methods*. 3rd ed. SAGE Publications Ltd; 2019.
100. Crotty M. *Foundations of Social Research: Meaning and perspective in the research process*. 2nd ed. Routledge; 2020.
101. Guba EG, Lincoln YS. *Handbook of qualitative research: Competing paradigms in qualitative research*. California, Sage Publications; 1994.
102. Djulbegovic B, Guyatt GH. Progress in evidence-based medicine: a quarter century on. *Lancet*. 2017;390(10092):415-423.
103. Griffiths P, Norman I. Qualitative or quantitative? Developing and evaluating complex interventions: time to end the paradigm wars. *Int J Nurs St*. 2013;50(5):583-584.
104. Mukumbang FC, De Souza DE, Eastwood JG. The contributions of scientific realism and critical realism to realist evaluation. *J Crit Realism*. 2023:1-21.
105. Mukumbang FC. Retroductive theorizing: a contribution of critical realism to mixed methods research. *J Mix Methods Res*. 2023;17(1):93-114.
106. Wynn Jr D, Williams CK. Principles for conducting critical realist case study research in information systems. *MIS quarterly*. 2012:787-810.
107. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review – a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy*. 2005;10:21-34.
108. Pawson R, Tilley N. *Realistic Evaluation*. SAGE Publications Ltd; 1997.
109. Collier A. *Critical realism: an introduction to Roy Bhaskar's philosophy*. Verso Books; 1994.
110. Archer M, Bhaskar R, Collier A, Lawson T, Norrie A. *Critical realism: Essential readings*. Routledge; 2013.
111. Sayer A. Critical realism and the limits to critical social science. *J Theory Soc Behav*. 1997;27(4):473-488.
112. Pawson R, Tilley N. *An introduction to scientific realist evaluation*. Sage; 1997.
113. Greenhalgh T, Pawson R, Greenhalgh J, et al. The RAMESES Projects. Accessed Dec 1, 2023. https://www.ramesesproject.org/Home_Page.php.
114. Brekke J, Anastas J, Floersch J, Longhofer J. "The realist frame: Scientific realism and critical realism", in Brekke J, Anastas J, eds. Shaping a Science of Social Work. Oxford University Press; 2018:22-40.
115. Dalkin SM, Greenhalgh J, Jones D, Cunningham B, Lhussier M. What's in a mechanism? Development of a key concept in realist evaluation. *Implement Sci*. 2015;10(1):1-7.
116. Pawson R. *The science of evaluation: a realist manifesto*. Sage; 2013.

117. Ivers NM, Grimshaw JM, Jamtvedt G, et al. Growing Literature, Stagnant Science? Systematic Review, Meta-Regression and Cumulative Analysis of Audit and Feedback Interventions in Health Care. *J Gen Intern Med*. 2014;29(11):1534-1541.
118. Foy R, Skrypak M, Alderson S, et al. Revitalising audit and feedback to improve patient care. *BMJ*. 2020;368:213-218.
119. Clarke DJ, Burton L-J, Tyson SF, et al. Why do stroke survivors not receive recommended amounts of active therapy? Findings from the ReAcT study, a mixed-methods case-study evaluation in eight stroke units. *Clin rehabil*. 2018;32(8):1119-1132.
120. Public Health England. A brief introduction to realist evaluation. 2021. Accessed Jan 18, 2022. https://assets.publishing.service.gov.uk/media/60f7fdf7d3bf7f56824cc634/Brief_introduction_to_realist_evaluation.pdf.
121. Pawson R, Manzano-Santaella A. A realist diagnostic workshop. *Evaluation*. 2012;18(2):176-191.
122. Nielsen SB, Lemire S, Tangsig S. Unpacking context in realist evaluations: Findings from a comprehensive review. *Evaluation*. 2022;28(1):91-112.
123. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist synthesis: An introduction. ESRC Research Methods Programme 2004. Accessed Jan 18, 2022. https://www.betterevaluation.org/sites/default/files/RMPmethods2.pdf.
124. Astbury B, Leeuw FL. Unpacking black boxes: mechanisms and theory building in evaluation. 2010;31:363-381.
125. De Weger E, Van Vooren NJE, Wong G, et al. What's in a realist configuration? Deciding which causal configurations to use, how, and why. *Int J Qual Methods*. 2020;19:1609-1612.
126. Davidoff F, Dixon-Woods M, Leviton L, Michie S. Demystifying theory and its use in improvement. *BMJ Qual Saf*. 2015;24:228-238.
127. Shearn K, Allmark P, Piercy H, Hirst J. Building realist program theory for large complex and messy interventions. *Int J Qual Methods*. 2017;16:1-11.
128. Gilmore B, McAuliffe E, Power J, Vallières F. Data analysis and synthesis within a realist evaluation: toward more transparent methodological approaches. *Int J Qual Methods*. 2019;18:1-19.
129. Pawson R. Middle Range Theory and Programme Theory Evaluation: Draft Chapter. 2008. Accessed Dec 31, 2023. https://eprints.ncrm.ac.uk/id/eprint/242/1/MRTPTEfinal.doc.
130. Jagosh J. Introduction to Realist Methodology - Teaching resources. Centre for Advancement in Realist Evaluation and Synthesis (CARES); 2021.
131. Greenhalgh T, Pawson R, Wong G, et al. Quality standards for realist evaluation for evaluators and peer-reviewers: The RAMESES II project. University of Oxford. 2017. Accessed Dec 12, 2023. https://ramesesproject.org/media/RE_Quality_Standards_for_evaluators_and_peer_reviewers.pdf.
132. Renmans D, Pleguezuelo VC. Methods in realist evaluation: A mapping review. *Eval Program Plan*. 2023;97:209-218.
133. Wong G, Westhorp G, Greenhalgh J, Manzano A, Jagosh J, Greenhalgh T. Quality and reporting standards, resources, training materials and information for realist evaluation: the RAMESES II project. *Health Serv Deliv Res*. 2017;5(28):1-108.
134. Emmel N. *Sampling and choosing cases in qualitative research: A realist approach*. SAGE Publications Ltd; 2013.
135. Wiltshire G, Ronkainen N. A realist approach to thematic analysis: making sense of qualitative data through experiential, inferential and dispositional themes. *J Crit Realism*. 2021;20(2):159-180.
136. Byng R, Norman I, Redfern S. Using realistic evaluation to evaluate a practice-level intervention to improve primary healthcare for patients with long-term mental illness. *Evaluation*. 2005;11(1):69-93.
137. Kazi MF. *Realist evaluation in practice: Health and social work*. Sage; 2003.
138. Wong G, Westhorp G, Manzano A, Greenhalgh J, Jagosh J, Greenhalgh T. RAMESES II reporting standards for realist evaluations. *BMC Med*. 2016;14:96-112.

139. Haynes A, Gilchrist H, Oliveira JS, Tiedemann A. Using realist evaluation to understand process outcomes in a COVID-19-impacted yoga intervention trial: a worked example. *Int J Environ Res Public Health*. 2021;18(17):965-972.
140. Jagosh J. Coding, Configuring and Conveying in Realist Analysis: Training Module A. Centre for Advancement of Realist Evaluation and Synthesis (CARES); 2022.
141. Mukumbang FC, Kabongo EM, Eastwood JG. Examining the application of retroductive theorizing in realist-informed studies. *Int J Qual Method*. 2021;20:516-524.
142. Thagard P, Shelley C. Abductive reasoning: Logic, visual thinking, and coherence. Tenth International Congress of Logic, Methodology and Philosophy of Science, Florence, August 1995. Springer; 413-427.
143. Jagosh J, Bush PL, Salsberg J, et al. A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC Pub Health*. 2015;15(1):1-11.
144. Rycroft-Malone J, McCormack B, Hutchinson AM, et al. Realist synthesis: illustrating the method for implementation research. *Implement Sci*. 2012;7(1):1-10.
145. Johnston G, Crombie IK, Alder EM, Davies HTO, Millard A. Reviewing audit: barriers and facilitating factors for effective clinical audit. *J Qual Healthc*. 2000;9(1):23-36.
146. International Monetary Fund (IMF). World Economic and Financial Surveys Economic Outlook Database. Accessed Oct 20, 2021. https://www.imf.org/en/Data.
147. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Method*. 2005;8(1):19-32.
148. Colquhoun HL, Levac D, O'Brien KK, et al. Scoping reviews: time for clarity in definition, methods, and reporting. *J Clin Epidemiol*. 2014;67(12):1291-1294.
149. Eriksen MB, Frandsen TF. The impact of patient, intervention, comparison, outcome (PICO) as a search strategy tool on literature search quality: a systematic review. *J Med Library Assoc*. 2018;106(4):420-428.
150. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci*. 2010;5:1-9.
151. Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Ann Intern Med*. 2018;169(7):467-473.
152. Pawson R. Digging for nuggets: how ‘bad’research can yield ‘good’evidence. *Int J Soc Res Method*. 2006;9(2):127-142.
153. Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMESES publication standards: realist syntheses. *J Adv Nurs*. 2013;69:1005-1022.
154. Dada S, Dalkin S, Gilmore B, Hunter R, Mukumbang FC. Applying and reporting relevance, richness and rigour in realist evidence appraisals: advancing key concepts in realist reviews. *Res Synth Methods*. 2023;14(3):504-514.
155. Batty GM, Grant R, Aggarwal R, et al. National Clinical Sentinel Audit of Evidence-based Prescribing for Older People. *J Eval Clin Prac*. May 2004;10(2):273-279.
156. Bodansky D, Oskrochi Y, Judah G, Lewis M, Fischer B, Narayan B. Change the habit to change the practice: Do audits really ever change anything? *Injury*. 01 Sep 2017;48(9):1999-2002.
157. Cameron M, Penney G, MacLennan G, McLeer S, Walker A. Impact on maternity professionals of novel approaches to clinical audit feedback. *Eval Health Prof*. 2007;30(1):75-95.
158. Cornish JA, Tilney HS, Tan E, Thompson MR, Smith JJ, Tekkis PP. The National Bowel Cancer Audit Project: what do trusts think of the National Bowel Cancer Audit and how can it be improved? *Tech Coloproctol*. 2011;15(1):53-9.
159. Currie K, Laidlaw R, Ness V, et al. Mechanisms affecting the implementation of a national antimicrobial stewardship programme; multi-professional perspectives explained using normalisation process theory. *Antimicrob Resist Infect Control*. 2020;9:1-12.
160. Dixon-Woods M, Campbell A, Aveling E-L, Martin G. An ethnographic study of improving data collection and completeness in large-scale data exercises. *Wellcome Open Res*. 2019;4:203-211.
161. Dunne D, Lal N, Pranesh N, Spry M, McFaul C, Rooney P. Surgical audit: are we not closing the loop? Multicenter Study. *Int J Health Care Qual Assur*. 2018;31(8):966-972.

162. Gould NJ, Lorencatto F, During C, et al. How do hospitals respond to feedback about blood transfusion practice? A multiple case study investigation. 2018. PloS One. 13 (11):e0206676. Accessed July 23, 2021. https://doi.org/10.1371/journal.pone.0206676.

163. Mannion R, Goddard M. Impact of published clinical outcomes data: case study in NHS hospital trusts. *BMJ*. 2001;323(7307):260-263.

164. Phekoo K, Clements J, Bell D. *The Healthcare Quality Improvement Partnership (HQIP). National Clinical Audit Quality Assessment Overview of the self-assessment survey. 2014. Accessed Sept 13, 2021. https://www.hqip.org.uk/wp-content/uploads/2018/02/audit-of-clinical-audits-national-report.pdf*.

165. Randell R, Alvarado N, McVey L, et al. Requirements for a quality dashboard: Lessons from National Clinical Audits. *AMIA Annual Symposium Proceedings*. 2019;2019:735-744.

166. Stevenson K, Baker R, Farooqi A, Sorrie R, Khunti K. Features of primary health care teams associated with successful quality improvement of diabetes care: a qualitative study. *Fam Pract*. 2001;18(1):21-6.

167. Sykes M, Thomson R, Kolehmainen N, Allan L, Finch T. Impetus to change: a multi-site qualitative exploration of the national audit of dementia. *Implement Sci*. 2020;15(1):45.

168. Arvidsson E, Dahlin S, Anell A. Conditions and barriers for quality improvement work: a qualitative study of how professionals and health centre managers experience audit and feedback practices in Swedish primary care. *Fam Pract*. 2021;22(1):113.

169. Asprang AF, Frich JC, Braut GS. Organizational impact of governmental audit of blood transfusion services in Norway: A qualitative study. *Transfus Apher Sci*. 01 Oct 2015;53(2):228-232.

170. Botje D, Klazinga NS, Sunol R, et al. Is having quality as an item on the executive board agenda associated with the implementation of quality management systems in European hospitals: a quantitative analysis. *Int J Qual Health Care*. 2014;26 Suppl 1:92-9.

171. Dupont C, Deneux-Tharaux C, Touzet S, et al. Clinical audit: a useful tool for reducing severe postpartum haemorrhages? *Int J Qual Health Care*. 2011;23(5):583-9.

172. Egholm C, Helmark C, Christensen J, et al. Facilitators for using data from a quality registry in local quality improvement work: a cross-sectional survey of the Danish Cardiac Rehabilitation Database. *BMJ Open*. 2019;9(6):e028291. Accessed July 23, 2021. https://bmjopen.bmj.com/content/9/6/e028291.

173. Egholm C, Helmark C, Doherty P, Nilsen P, Zwisler A-D, Bunkenborg G. "Struggling with practices" - A qualitative study of factors influencing the implementation of clinical quality registries for cardiac rehabilitation in England and Denmark. *BMC Health Serv Res*. 2019;19(1):102-102.

174. Eldh AC, Wallin L, Fredriksson M, et al. Factors facilitating a national quality registry to aid clinical quality improvement: findings of a national survey. *BMJ Open*. 2016;6(11):e011562. Accessed July 23, 2021. https://bmjopen.bmj.com/content/6/11/e011562.

175. Eldh AC, Fredriksson M, Halford C, et al. Facilitators and barriers to applying a national quality registry for quality improvement in stroke care. *BMC Health Serv Res*. 2014;14:354-361.

176. Fredriksson M, Eldh A, Vengberg S, et al. Local politico-administrative perspectives on quality improvement based on national registry data in Sweden: a qualitative study using the Consolidated Framework for Implementation Research. *Implement Sci*. 2014;9(1):189-189.

177. Gude WT, Roos-Blom MJ, van der Veer SN, et al. Facilitating Action planning within audit and feedback interventions: a mixed-methods process evaluation of an action implementation toolbox in intensive care. Article. *Implement Sci*. Sep 2019;14(1):11. 90.

178. Hanskamp-Sebregts M, Zegers M, Boeijen W, Wollersheim H, van Gurp PJ, Westert GP. Process evaluation of the effects of patient safety auditing in hospital care (part 2). *Int J Quality Health Care*. Jul 2019;31(6):433-441.

179. Numan RC, Klomp HM, Li W, et al. A clinical audit in a multidisciplinary care path for thoracic surgery: An instrument for continuous quality improvement. *Lung Cancer*. December 2012;78(3):270-275.

180. Pedersen MS, Landheim A, Moller M, Lien L. First-line managers' experience of the use of audit and feedback cycle in specialist mental health care: A qualitative case study. *Arch Psychiatr Nurs*. 2019;33(6):103-109.

181. Sparring V, Granstrom E, Andreen Sachs M, Brommels M, Nystrom ME. One size fits none - a qualitative study investigating nine national quality registries' conditions for use in quality improvement, research and interaction with patients. *BMC Health Serv Res*. 20 Oct 2018;18(1):802-809.

182. Sinuff T, Muscedere J, Rozmovits L, Dale CM, Scales DC. A qualitative study of the variable effects of audit and feedback in the ICU. *BMJ Qual Saf*. 2015;24(6):393-399.

183. Wagner DJ, Durbin J, Barnsley J, Ivers NM. Beyond quality improvement: exploring why primary care teams engage in a voluntary audit and feedback program. *BMC Health Serv Res*. 2017;17(1):803 -810.

184. Wagner DJ, Durbin J, Barnsley J, Ivers NM. Measurement without management: qualitative evaluation of a voluntary audit & feedback intervention for primary care teams. *BMC Health Serv Res*. 2019;19:13-21. 419.

185. Wooller KR, Backman C, Gupta S, Jennings A, Hasimja-Saraqini D, Forster AJ. A pre and post intervention study to reduce unnecessary urinary catheter use on general internal medicine wards of a large academic health science center. *BMC Health Serv Res*. 2018;18(1):1-9.

186. Jolliffe L, Morarty J, Hoffmann T, et al. Using audit and feedback to increase clinician adherence to clinical practice guidelines in brain injury rehabilitation: A before and after study. *PLoS One*. 2019. Accessed Sept 10, 2021. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0213525.

187. Stephenson M, McArthur A, Giles K, Lockwood C, Aromataris E, Pearson A. Prevention of falls in acute hospital settings: a multi-site audit and implementation project. *Int J Qual Health Care*. 2016;28(1):92-8.

188. Langston M. Effects of peer monitoring and peer feedback on hand hygiene in surgical intensive care unit and step-down units. *J Nurs Care Qual*. 2011;26(1):49-53.

189. Freeman J, Dawson L, Jowitt D, et al. The impact of the Hand Hygiene New Zealand programme on hand hygiene practices in New Zealand's public hospitals. *N Z Med J*. 2016;129(1443):67-76.

190. Hoque DME, Kumari V, Hoque M, Ruseckaite R, Romero L, Evans SM. Impact of clinical registries on quality of patient care and clinical outcomes: a systematic review. *PLoS One*. 2017;12(9):e0183667. Accessed Jan 16, 2022. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0183667.

191. van der Veer SN, de Keizer NF, Ravelli ACJ, Tenkink S, Jager KJ. Improving quality of care. A systematic review on how medical registries provide information feedback to health care providers. *Int J Med Inform*. 2010;79(5):305-323.

192. Bonawitz K, Wetmore M, Heisler M, et al. Champions in context: which attributes matter for change efforts in healthcare? *Imp Sci*. 2020;15:1-10.

193. Miech EJ, Rattray NA, Flanagan ME, Damschroder L, Schmid AA, Damush TM. Inside help: an integrative review of champions in healthcare-related implementation. *SAGE Open Med*. 2018;6:e3261. Accessed Jan 16, 2024. https://doi.org/10.1177/20503121187732.

194. Dowding DW, Alvarado N, McVey L, Mamas MA, Randell R. Variation in National Clinical Audit Data Capture: Is Using Routine Data the Answer? *Stud Health Technol Inform*. 2019;264:1658-1659.

195. Berwick D. A promise to learn - a commitment to act. Improving the safety of patients in England. National Advisory Group 2013. Accessed Jan 31, 2022. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf.

196. Allwood D. Healthcare Quality Improvement (HQIP). Engaging clinicians in quality improvement through national clinical audit. 2014. Accessed Jan 16, 2022. https://www.hqip.org.uk/wp-content/uploads/2018/02/engaging-clinicians-in-qi-through-national-clinical-audit.pdf.

197. Desveaux L, Ivers NM, Devotta K, Ramji N, Weyman K, Kiran T. Unpacking the intention to action gap: a qualitative study understanding how physicians engage with audit and feedback. *Implement Sci*. 2021;16(1):9. 19.

198. Cadilhac DA, Kilkenny M, Churilov L, Harris D, Lalor E. Identification of a reliable subset of process indicators for clinical audit in stroke care: an example from Australia. *Clin Audit*. 2010:67-77.

199. Keenan D. Blog published by Healthcare Quality Improvement Partnership (HQIP): The Future for National Clinical Audit. Accessed Jan 10, 2022. https://www.hqip.org.uk/news/blog-the-future-for-national-clinical-audit/#.YeZ-p_7P2Ul.

200. Hysong SJ, Francis J, Petersen LA. Motivating and engaging frontline providers in measuring and improving team clinical performance. *BMJ Qual Saf*. 2019;28(5):405-411.

201. Foster A, Croot L, Brazier J, Harris J, O'Cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. *J Patient Rep Outcomes*. 2018;2(1):1-16.

202. Devlin NJ, Appleby J. Getting the most out of PROMs. Putting health outcomes at the heart of NHS decision-making. The King's Fund. 2010. Accessed Jan 16, 2024. https://www.kingsfund.org.uk/insight-and-analysis/reports/getting-the-most-out-of-proms.

203. Meyer GS, Nelson EC, Pryor DB, et al. More quality measures versus measuring what matters: a call for balance and parsimony. *BMJ Qual Saf*. 2012;21(11):964-968.

204. Springer MV, Sales AE, Islam N, et al. A step toward understanding the mechanism of action of audit and feedback: a qualitative study of implementation strategies. *Implement Sci*. 2021;16(1):e11609. Accessed May 27, 2021. https://doi.org/10.1186/s13012-021-01102-6. 35.

205. Hibbard JH, Stockard J, Tusler M. Hospital performance reports: impact on quality, market share, and reputation. *Health Aff*. 2005;24(4):1150-1160.

206. Propper C. Competition in health care: lessons from the English experience. *Health Econ Pol Law*. 2018;13(3-4):492-508.

207. Bloom N, Propper C, Seiler S, Van Reenen J. The impact of competition on management quality: evidence from public hospitals. *Rev Econ St*. 2015;82(2):457-489.

208. Wong G. Special invited editorial: getting started with realist research. *Int J Qual Methods*. 2015;14(5):1609406915621428. Accessed Jan 22, 2024. https://doi.org/10.1177/1609406915621428.

209. Jagosh J. Constructing Excellent Initial Programme Theories: Training Module D. Centre for Advancement of Realist Evaluation and Synthesis (CARES); 2022.

210. Jagosh J. Constructing Excellent Initial Programme Theories: Training Module A. Centre for Advancement of Realist Evaluation and Synthesis (CARES); 2022.

211. Jagosh J. Constructing Excellent Initial Programme Theories: Training Module B. Centre for Advancement in Realist Evaluation and Synthesis (CARES); 2022.

212. Jagosh J. Constructing Excellent Initial Programme Theories: Training Module C. Centre for Advancement of Realist Evaluation and Synthesis (CARES); 2022.

213. Wong G. Tackling complexity and generalisability using realist research. Webinar hosted by The Laboratory for Interdisciplinary Evaluation of Public Policies (LIEPP) 2023. Accessed May 7, 2024. https://www.sciencespo.fr/liepp/fr/content/cycle-de-seminaires-methodes-et-approches-en-evaluation-metheval.html#_ga=2.145671408.538614223.1681738106-288868795.1677251352.

214. Creswell JW, Clark VLP. *Designing and Conducting Mixed Methods Research*. SAGE Publications Ltd; 2017.

215. Spitzer-Shohat S, Shadmi E, Goldfracht M, Key C, Hoshen M, Balicer RD. Evaluating an organization-wide disparity reduction program: understanding what works for whom and why. *PLos One*. 2018;13(3):Accessed Feb 9, 2024. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0193179.

216. Desveaux L, Shaw J, Saragosa M, et al. A mobile app to improve self-management of individuals with type 2 diabetes: qualitative realist evaluation. *J Med Internet Res*. 2018;20(3):e81.

217. Martin P, Tannenbaum C. A realist evaluation of patients' decisions to deprescribe in the EMPOWER trial. *BMJ Open*. 2017;7(4):e476. Accessed Feb 9, 2024. https://bmjopen.bmj.com/content/7/4/e015959.

218. RAMESES Archives. Conversation between Ray Pawson, Sonia Dalkin, Justin Jagosh and Gill Westhorp regarding use of surveys in realist evaluation. 2016. Accessed

Feb 9, 2024. https://www.jiscmail.ac.uk/cgi-bin/wa-jisc.exe?A2=ind1605&L=RAMESES&P=R3576.
219. O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. *J Health Serv Res Pol*. 2008;13(2):92-98.
220. Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs—principles and practices. *Health Serv Res*. 2013;48(2):2134-2156.
221. Clark VLP. Meaningful integration within mixed methods studies: Identifying why, what, when, and how. *Contemp Educ Psychol*. 2019;57:106-111.
222. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *J Med Internet Res*. 2004:e34. Accessed June 9, 2023. https://www.jmir.org/2004/3/e34/.
223. Williams M. The problem of representation: Realism and operationalism in survey research. *Sociol Res Online*. 2003;8(1):81-91.
224. Dillman DA, Smyth JD, Christian LM. *Internet, phone, mail, and mixed-mode surveys: The tailored design method*. John Wiley & Sons; 2014.
225. NIHR Centre for Engagement and Dissemination. UK Standards for public involvement. 2019. Accessed Jan 16, 2022. https://sites.google.com/nihr.ac.uk/pi-standards/standards.
226. Regmi PR, Waithaka E, Paudyal A, Simkhada P, van Teijlingen E. Guide to the design and application of online questionnaire surveys. *Nepal J Epidemiol*. 2016;6(4):640-644.
227. Dalkin S, Forster N, Hodgson P, Lhussier M, Carr SM. Using computer assisted qualitative data analysis software (CAQDAS; NVivo) to assist in the complex process of realist theory generation, refinement and testing. *Int J Soc Res Methodol*. 2021;24(1):123-134.
228. Jagosh J. Coding, Configuring and Conveying in Realist Analysis: Training Module C. Centre for Advancement in Realist Evaluation and Synthesis (CARES); 2022.
229. Jagosh J. Coding, Configuring and Conveying in Realist Analysis: Training Module B. Centre for Advancement in Realist Evaluation and Synthesis (CARES); 2022.
230. Mannion R, Davies H. Understanding organisational culture for healthcare quality improvement. *BMJ*. 2018;363:e112. Accessed Sept 12, 2023. https://www.bmj.com/content/363/bmj.k4907.
231. Cappadona I, Corallo F, Cardile D, et al. Audit as a Tool for Improving the Quality of Stroke Care: A Review. *Int J Environ Res Pub Health*. 2023;20(5):4490-4498.
232. Sarkies M, Francis-Auton E, Long J, et al. Audit and feedback to reduce unwarranted clinical variation at scale: a realist study of implementation strategy mechanisms. *Implement Sci*. 2023;18(71):e224. Accessed Dec 13, 2023. https://doi.org/10.1186/s13012-023-01324-w.
233. Greenhalgh T, Papoutsi C. Studying complexity in health services research: desperately seeking an overdue paradigm shift. Springer; 2018. p. 1-6.
234. Wolpert M, Rutter H. Using flawed, uncertain, proximate and sparse (FUPS) data in the context of complexity: learning from the case of child mental health. *BMC Med*. 2018;16(1):1-11.
235. Pawson R. Theorizing the interview. *British J Sociol*. 1996;3:295-314.
236. Manzano A. The craft of interviewing in realist evaluation. *Evaluation*. 2016;22(3):342-360.
237. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.
238. Edwards R, Holland J. *What is qualitative interviewing?* Bloomsbury Academic; 2013.
239. Archibald MM, Ambagtsheer RC, Casey MG, Lawless M. Using zoom videoconferencing for qualitative data collection: perceptions and experiences of researchers and participants. *Int J Qual Methods*. 2019;18:e96. Accessed March 27, 2023. https://doi.org/10.1177/1609406919874596.
240. Greenhalgh T, Pawson R, Wong G, et al. The Realist Interview: The RAMESES II Project. 2017. Accessed March 24, 2023. https://www.ramesesproject.org/media/RAMESES_II_Realist_interviewing.pdf.

241. Jagosh J. Realist Interviewing. Training Material: Module A&B. Centre for Advancement of Realist Evaluation and Synthesis (CARES); 2022.
242. Bergeron DA, Gaboury I. Challenges related to the analytical process in realist evaluation and latest developments on the use of NVivo from a realist perspective. *Int J Soc Res Methodol*. 2020;23(3):355-365.
243. Staley K, Buckland SA, Hayes H, Tarpey M. 'The missing links': understanding how context and mechanism influence the impact of public involvement in research. *Health Expectations*. 2014;17(6):755-764.
244. Jagosh J. Realist Qualitative Interviewing: Training Module D. Centre for Advancement of Realist Evaluation and Synthesis; 2022.
245. Jagosh J. Realist Qualitative Interviewing: Training Module C. Centre for Advancement of Realist Evaluation and Synthesis (CARES); 2022.
246. Greenhalgh T, Pawson R, Wong G, et al. Retroduction in Realist Evaluation: The RAMESES II Project. 2017. Accessed March 24, 2023. https://www.ramesesproject.org/media/RAMESES_II_Retroduction.pdf.
247. Jagosh J. Coding, Configuring and Conveying in Realist Analysis: Training Module D. Centre for Advancement in Realist Evaluation and Synthesis (CARES); 2022.
248. Jackson SF, Kolla G. A new realistic evaluation analysis method: linked coding of context, mechanism, and outcome relationships. *Am J Eval*. 2012;33(3):339-349.
249. Kringos DS, Sunol R, Wagner C, et al. The influence of context on the effectiveness of hospital quality improvement strategies: a review of systematic reviews. *BMC Health Serv Res*. 2015;15:1-13.
250. Shea CM. A conceptual model to guide research on the activities and effects of innovation champions. *Implement Res Pract*. 2021;2:e443. Accessed Feb 27, 2024. https://doi.org/10.1177/2633489521990443.
251. Soo SD. The role of champions in the implementation of patient safety practice change. *Health Q*. 2009:e129. Accessed Feb 27, 2024. https://pubmed.ncbi.nlm.nih.gov/19667789/.
252. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci*. 2009;4:50 - 58.
253. Keith J, Grimm F, Steventon A. How better use of data can help address key challenges facing the NHS. The Health foundation. 2022. Accessed Sept 5, 2022. https://www.health.org.uk/publications/long-reads/how-better-use-of-data-can-help-address-key-challenges-facing-the-nhs.
254. Goldacre B, Morley J. Better, Broader, Safer: Using health data for research and analysis. A review commissioned by the Secretary of State for Health and Social Care. Department of Health and Social Care. 2022. Accessed Feb 26, 2024. https://assets.publishing.service.gov.uk/media/624ea0ade90e072a014d508a/goldacre-review-using-health-data-for-research-and-analysis.pdf.
255. Willis TA, Wright-Hughes A, Weller A, et al. Interventions to optimise the outputs of national clinical audits to improve the quality of health care: a multi-method study including RCT. National Institute for Health and Care Research. 2022. Accessed Feb 26, 2024. https://pubmed.ncbi.nlm.nih.gov/35767668/.
256. Yu AYX, Bravata DM, Norrving B, Reeves MJ, Liu L, Kilkenny MF. Measuring stroke quality: methodological considerations in selecting, defining, and analyzing quality measures. *Stroke*. 2022;53(10):3214-3221.
257. Martin G, Dixon-Woods M. Collaboration-based approaches. Elements of Improving Quality and Safety in Healthcare. Cambridge University Press. 2022.
258. Powell W. *Neither market nor hierarchy*. The sociology of organizations: classic, contemporary, and critical readings. 2003.
259. Power M, Tyrrell PJ, Rudd AG, et al. Did a quality improvement collaborative make stroke care better? A cluster randomized trial. *Implement Sci*. 2014;9:1-9.
260. Kilbride C, Perry L, Flatley M, Turner E, Meyer J. Developing theory and practice: creation of a community of practice through action research produced excellence in stroke care. *J Interprof Care*. 2011;25(2):91-97.
261. Lynch E, Laver K, Levy T, Schultz T. 'The way that we are collecting and using data has evolved' evaluating the Australian National Stroke Audit programme to inform

strategic direction. *BMJ Open Qual*. 2023;12(1):e002136. Accessed March 2, 2024. https://bmjopenquality.bmj.com/content/12/1/e002136.
262. Hopman WM, Verner J. Quality of life during and after inpatient stroke rehabilitation. *Stroke*. 2003;34(3):801-805.
263. Schindel D, Schneider A, Grittner U, Jöbges M, Schenk L. Quality of life after stroke rehabilitation discharge: a 12-month longitudinal study. *Disabil Rehabil*. 2021;43(16):2332-2341.
264. Bergen N, Labonté R. “Everything is perfect, and we have no problems”: detecting and limiting social desirability bias in qualitative research. *Qual health Res*. 2020;30(5):783-792.
265. Krumpal I. Determinants of social desirability bias in sensitive surveys: a literature review. *Qual Quant*. 2013;47(4):2025-2047.
266. Söderblom L. Health-related quality of life three months after stroke: Degree project. Institute of Neuroscience and Physiology, Department of Clinical Neuroscience. Gothenburg, Sweden. 2018. https://gupea.ub.gu.se/bitstream/handle/2077/55907/gupea_2077_55907_1.pdf?sequence=1&isAllowed=y.
267. Bowling A. Current state of the art in quality of life measurement. In: Carr AJ, Higginson IJR, P G, eds. *Quality of Life*. BMJ Books; 2003.
268. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. *Health Technol Assess*. 1998;2(14)
269. Brazier J, Ratcliffe J, Saloman J, Tsuchiya A. *Measuring and valuing health benefits for economic evaluation*. Oxford university press; 2017.
270. Buck D, Jacoby A, Massey A, Ford G. Evaluation of measures used to assess quality of life after stroke. *Stroke*. 2000;31(8):2004-2010.
271. Hilari K, Owen S, Farrelly SJ. Proxy and self-report agreement on the Stroke and Aphasia Quality of Life Scale-39. *J Neurol Neurosurg & Psychiatry*. 2007;78(10):1072-1075.
272. Williams LS, Bakas T, Brizendine E, et al. How valid are family proxy assessments of stroke patients’ health-related quality of life? *Stroke*. 2006;37(8):2081-2085.
273. Duncan PW, Lai SM, Tyler D, Perera S, Reker DM, Studenski S. Evaluation of proxy responses to the Stroke Impact Scale. *Stroke*. 2002;33(11):2593-9.
274. Carod-Artal FJ, Egido JA. Quality of life after stroke: the importance of a good recovery. *Cerebrovascular diseases*. 2009;27(Suppl. 1):204-214.
275. Lapin BR, Thompson NR, Schuster A, Honomichl R, Katzan IL. The validity of proxy responses on patient-reported outcome measures: Are proxies a reliable alternative to stroke patients’ self-report? *Qual Life Res*. 2021;30:1735-1745.
276. Browne JP, Cano SJ, Smith S. Using patient-reported outcome measures to improve health care: time for a new approach. *Med Care*. 2017;55(10):901-904.
277. (NICE) NIfHaCE. Position statement on the use of EQ5D-5L value set for England. 2019. Accessed March 12, 2024. https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/technology-appraisal-guidance/eq-5d-5l. 2019.
278. Varagunam M, Hutchings A, Neuburger J, Black N. Impact on hospital performance of introducing routine patient reported outcome measures in surgery. *J Health Serv Res Policy*. 2014;19(2):77-84.
279. Kyte D, Cockwell P, Lencioni M, et al. Reflections on the national patient-reported outcome measures (PROMs) programme: Where do we go from here? *J Roy Soc Med*. 2016;109(12):441-445.
280. Garratt AM, Engen K, Kjeldberg IR, et al. Use of EQ-5D-5L for assessing patient-reported outcomes in a National Register for specialized rehabilitation. *Arch Phys Med Rehabil*. 2024;105(1):40-48.
281. Devlin N, Parkin D, Janssen B. *Methods for analysing and reporting EQ-5D data*. Springer Nature; 2020.
282. Cameron LJ, Wales K, Casey A, et al. Self-reported quality of life following stroke: A systematic review of instruments with a focus on their psychometric properties. *Qual Life Res*. 2021:1-14.
283. Shah K, Mulhern B, Longworth L, Janssen B. Important aspects of health not captured by EQ-5D: views of the UK general public. *Office of Health Economics*. 2016;

284. Golicki D, Niewada M, Buczek J, et al. Validity of the EQ5D-5L in stroke patients. *Value Health*. 2014;17(7):570-579.
285. Janssen MF, Pickard AS, Golicki D, et al. Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study. *Qual Life Res*. 2013;22:1717-1727.
286. Devlin N. Computing EQ-5D-5L index values with SPSS using the English (ENG) Devlin value set. 2022. Accessed Nov 22, 2023. https://euroqol.org/wp-content/uploads/2020/12/ENG_value-set_SPSS.txt.
287. Devlin NJ, Shah KK, Feng Y, Mulhern B, van Hout B. Valuing health-related quality of life: An EQ-5 D-5 L value set for England. *Health Econom*. 2018;27(1):7-22.
288. Luengo-Fernandez R, Gray AM, Bull L, et al. Quality of life after TIA and stroke: ten-year results of the Oxford Vascular Study. *Neurology*. 2013;81(18):1588-1595.
289. Pickard SA, Johnson JA, Feeny DH. Responsiveness of generic health-related quality of life measures in stroke. *Qual Life Res*. 2005;14(1):207-219.
290. Hunger M, Sabariego C, Stollenwerk B, Cieza A, Leidl R. Validity, reliability and responsiveness of the EQ-5D in German stroke patients undergoing rehabilitation. *Qual Life Res*. 2012;21(7):1205-1216.
291. Yan J, Xie R, Yin Z, et al. A systematic literature review on statistical methods applied to analyse EQ5D data in randomized clinical trials. presented at: EuroQol Plenary; 2022; Chicago.
292. Gutacker N, Bojke C, Daidone S, Devlin N, Street A. Analysing hospital variation in health outcome at the level of EQ-5D dimensions. Centre for Health economics, University of York. 2012. Accessed Jan 11, 2023. https://eprints.whiterose.ac.uk/136620/1/CHERP74_analysing_hospital_variation_health_outcome_EQ_5D.pdf. Centre for Health Economics, University of York; 2012.
293. Mei Y-x, Zhang Z-x, Wu H, et al. EQ-5D results in stroke survivors: What are they suffering from? Results from the Henan Rural Cohort Study. *Res Square*. 2020:e89. Accessed Dec 19, 2023. https://doi.org/10.21203/rs.3.rs-59671/v1.
294. Garzón Hernández JP, López-Romero LA, Mendoza JA, Gómez R, Silva Sieger FA. Corrélation of EQ-5D and mRS in ischémie stroke: a multicenter cross-sectional study. *Revista de la Universidad Industrial de Santander Salud*. 2023;55:37-45.
295. Wong HJ, Lua PL, Harith S, Ibrahim KA. Health-related quality of life profiles and their dimension-specific associated factors among Malaysian stroke survivors: a cross sectional study. *Health Qual Life Outcomes*. 2021;19:1-14.
296. Liang Y, Lin J, Hou Y, et al. Health-related quality of life in cervical dystonia using EQ-5D-5L: a large cross-sectional study in China. *Front Neurol*. 2022;13:272-278.
297. Wang A, Rand K, Yang Z, Brooks R, Busschbach J. The remarkably frequent use of EQ-5D in non-economic research. *Europ J Health Econ*. 2022:1-8.
298. Lu W-S, Huang S-L, Yang J-F, Chen M-H, Hsieh C-L, Chou C-Y. Convergent validity and responsiveness of the EQ-5D utility weights for stroke survivors. *J Rehabil Med*. 2016;48(4):346-351.
299. Xie J, Wu EQ, Zheng Z-J, et al. Impact of stroke on health-related quality of life in the noninstitutionalized population in the United States. *Stroke*. 2006;37(10):2567-2572.
300. Oppe M, Devlin NJ, Szende A. *EQ-5D value sets: inventory, comparative review and user guide*. Springer; 2007.
301. Døhl Ø, Halsteinli V, Askim T, et al. Factors contributing to post-stroke health care utilization and costs, secondary results from the life after stroke (LAST) study. *BMC Health Serv Res*. 2020;20:1-10.
302. Oemrawsingh A, van Leeuwen N, Venema E, et al. Value-based healthcare in ischemic stroke care: case-mix adjustment models for clinical and patient-reported outcomes. *BMC Med Res Method*. 2019;19(1):1-9.
303. Kwah LK, Diong J. National institutes of health stroke scale (NIHSS). *Physiotherapy*. 2014;60(1):12-16.
304. Teale EA, Forster A, Munyombwe T, Young JB. A systematic review of case-mix adjustment models for stroke. *Clin Rehabil*. 2012;26(9):771-786.
305. NHS England. Stroke Rehabilitation Pilot Sites. Accessed January 11, 2023. https://www.england.nhs.uk/ourwork/clinical-policy/stroke/rehabilitation-pilot-sites/.

306. The English Indices of Deprivation 2019. Ministry of Housing Communities and Local Government. Accessed Jan 22, 2023. https://assets.publishing.service.gov.uk/media/5dfb3d7ce5274a3432700cf3/IoD2019_FAQ_v4.pdf.

307. Gittins M, Lugo-Palacios D, Vail A, et al. Delivery, dose, outcomes and resource use of stroke therapy: the SSNAPIEST observational study. *Health Serv Del Res*. 2020:e478. Accessed March 15, 2023. https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr08170#/abstract.

308. Katona M, Schmidt R, Schupp W, Graessel E. Predictors of health-related quality of life in stroke patients after neurological inpatient rehabilitation: a prospective study. *Health Qual Life Outcomes*. 2015;13:1-7.

309. Riley-Bennett F, Russell L, Byrne A, Fisher R. What factors are associated with severe disability following stroke on discharge from hospital? Analysis from the UK Sentinel Stroke National Audit Programme (SSNAP) data [Manuscript submitted for publication March 2024].

310. Mendes Pereira C, Greenwood N, Jones F. “A proof of life” through transition from hospital to home after a stroke in a Portuguese setting-a multi-perspective, longitudinal qualitative study. *Int J Qual Stud Health Well-being*. 2023;18(1):986-993.

311. Chen L, Xiao LD, Chamberlain D, Newman P. Enablers and barriers in hospital-to-home transitional care for stroke survivors and caregivers: A systematic review. *J Clin Nurs*. 2021;30(19-20):2786-2807.

312. Theadom A, Rutherford S, Kent B, McPherson K, Group AI. The process of adjustment over time following stroke: A longitudinal qualitative study. *Neuropsychol Rehabil*. 2018;29(9):1464–1474.

313. Towfighi A, Ovbiagele B, El Husseini N, et al. Poststroke depression: a scientific statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2017;48(2):e30-e43.

314. Ayerbe L, Ayis S, Wolfe CDA, Rudd AG. Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. *Br J Psychiatry*. 2013;202(1):14-21.

315. De Ryck A, Brouns R, Geurden M, Elseviers M, De Deyn PP, Engelborghs S. Risk factors for poststroke depression: identification of inconsistencies based on a systematic review. *J Geriatr psychiatry Neurol*. 2014;27(3):147-158.

316. Damsbo AG, Kraglund KL, Buttenschøn HN, Johnsen SP, Andersen G, Mortensen JK. Predictors for wellbeing and characteristics of mental health after stroke. *J Affect Disord*. 2020;264:358-364.

317. Konnopka A, Koenig H-H. The “no problems”-problem: an empirical analysis of ceiling effects on the EQ-5D 5L. *Qual Life Re*. 2017;26:2079-2084.

318. Terwee CB, Bot SDM, de Boer MR, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol*. 2007;60(1):34-42.

319. Neumann PJ, Sanders GD, Russell LB, Siegel JE, Ganiats TG. *Cost-effectiveness in health and medicine*. Oxford University Press; 2016.

320. Hilari K, Boreham L-D. Visual analogue scales in stroke: what can they tell us about health-related quality of life? *BMJ Open*. 2013;3(9):e003309. Accessed Feb 12, 2024. https://bmjopen.bmj.com/content/3/9/e003309.

321. NHS Digital (2022) The Casemix Companion. Accessed Jan 27, 2024. https://digital.nhs.uk/services/national-casemix-office/the-why-what-and-how-of-casemix/the-casemix-companion.

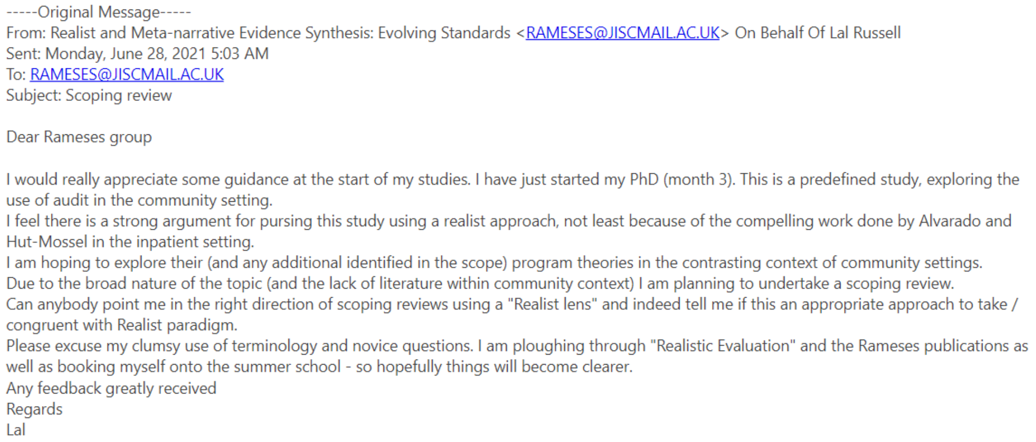
322. Lundy JJ, Coons SJ, Flood E, Patel MJ, e PROC. Agreement among paper and electronic modes of the EQ-5D-5L. *Patient-Centred Outcomes Res*. 2020;13:435-443.

323. Mulhern B, O’Gorman H, Rotherham N, Brazier J. Comparing the measurement equivalence of EQ-5D-5L across different modes of administration. *Health Qual Life Outcomes*. 2015;13:1-9.

324. Pindus DM, Mullis R, Lim L, et al. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services–a systematic review and meta-ethnography. *PloS One*. 2018;13(2):e0192533. Accessed Feb 9, 2024. https://doi.org/10.1371/journal.pone.0192533.

325. Allwood D, Fisher R, Warburton W, Dixon J. Creating space for quality improvement. *BMJ*. 2018;361:e45. Accessed April 2, 2024. https://www.bmj.com/content/361/bmj.k1924.
326. NHS England. Multi-professional framework for advanced clinical practice in England. Health Education England. 2017.
327. Jolliffe L, Andrew NE, Srikanth V, Beare R, Noeske KE, Snowdon DA. Development of an implementation strategy for routine collection of generic patient reported outcome measures: a qualitative study in multidisciplinary community rehabilitation. *Disabil Rehabil*. 2023;3:1-10.
328. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet*. 2001;358(9280):483-488.
329. Berger R. Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualit Res*. 2015;15(2):219-234.
330. Olmos-Vega FM, Stalmeijer RE, Varpio L, Kahlke R. A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Med Teacher*. 2023;45(3):241-251.

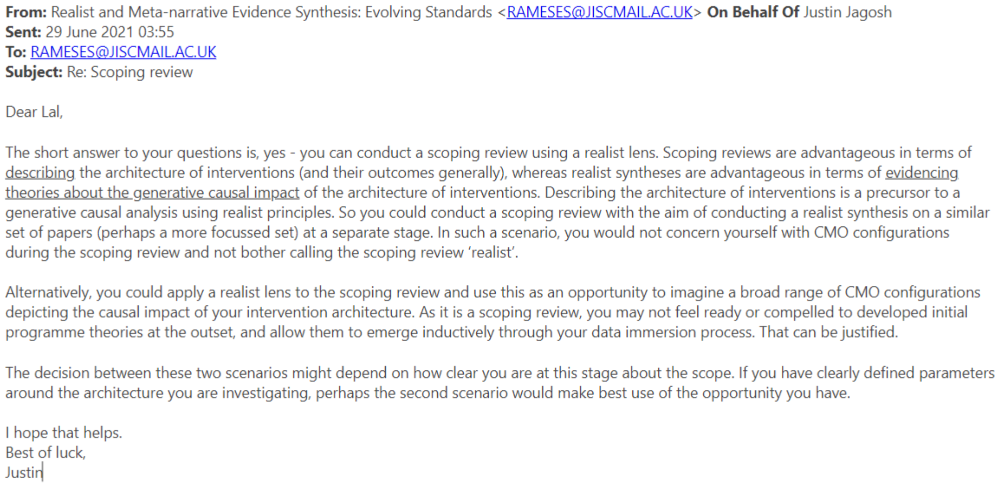
Appendix 3-1: Excerpt of email discussion with realist community



-----Original Message-----
From: Realist and Meta-narrative Evidence Synthesis: Evolving Standards <RAMESES@JISCMAIL.AC.UK> On Behalf Of Lal Russell
Sent: Monday, June 28, 2021 5:03 AM
To: RAMESES@JISCMAIL.AC.UK
Subject: Scoping review

Dear Rameses group

I would really appreciate some guidance at the start of my studies. I have just started my PhD (month 3). This is a predefined study, exploring the use of audit in the community setting.
I feel there is a strong argument for pursing this study using a realist approach, not least because of the compelling work done by Alvarado and Hut-Mossel in the inpatient setting.
I am hoping to explore their (and any additional identified in the scope) program theories in the contrasting context of community settings.
Due to the broad nature of the topic (and the lack of literature within community context) I am planning to undertake a scoping review.
Can anybody point me in the right direction of scoping reviews using a "Realist lens" and indeed tell me if this an appropriate approach to take / congruent with Realist paradigm.
Please excuse my clumsy use of terminology and novice questions. I am ploughing through "Realistic Evaluation" and the Rameses publications as well as booking myself onto the summer school - so hopefully things will become clearer.
Any feedback greatly received
Regards
Lal



From: Realist and Meta-narrative Evidence Synthesis: Evolving Standards <RAMESES@JISCMAIL.AC.UK> **On Behalf Of** Justin Jagosh
Sent: 29 June 2021 03:55
To: RAMESES@JISCMAIL.AC.UK
Subject: Re: Scoping review

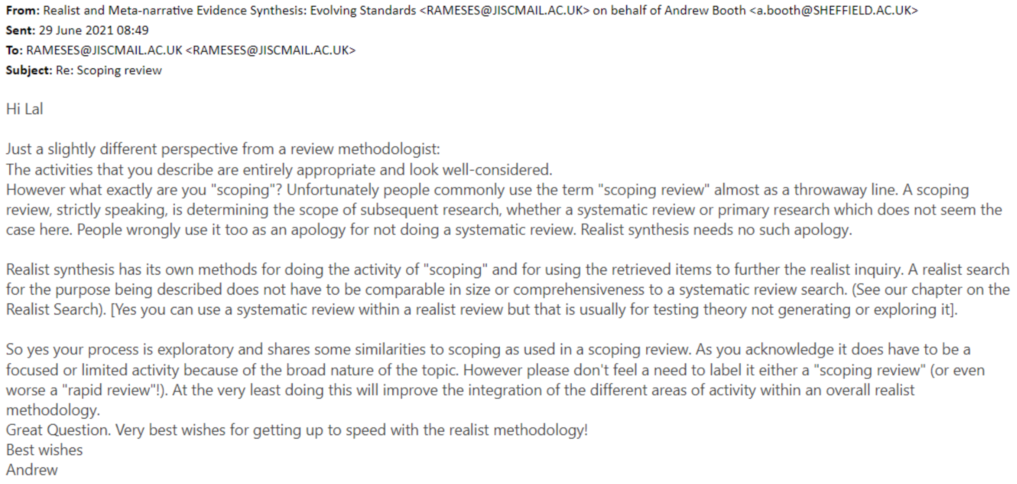
Dear Lal,

The short answer to your questions is, yes - you can conduct a scoping review using a realist lens. Scoping reviews are advantageous in terms of describing the architecture of interventions (and their outcomes generally), whereas realist syntheses are advantageous in terms of evidencing theories about the generative causal impact of the architecture of interventions. Describing the architecture of interventions is a precursor to a generative causal analysis using realist principles. So you could conduct a scoping review with the aim of conducting a realist synthesis on a similar set of papers (perhaps a more focussed set) at a separate stage. In such a scenario, you would not concern yourself with CMO configurations during the scoping review and not bother calling the scoping review 'realist'.

Alternatively, you could apply a realist lens to the scoping review and use this as an opportunity to imagine a broad range of CMO configurations depicting the causal impact of your intervention architecture. As it is a scoping review, you may not feel ready or compelled to developed initial programme theories at the outset, and allow them to emerge inductively through your data immersion process. That can be justified.

The decision between these two scenarios might depend on how clear you are at this stage about the scope. If you have clearly defined parameters around the architecture you are investigating, perhaps the second scenario would make best use of the opportunity you have.

I hope that helps.
Best of luck,
Justin



From: Realist and Meta-narrative Evidence Synthesis: Evolving Standards <RAMESES@JISCMAIL.AC.UK> on behalf of Andrew Booth <a.booth@SHEFFIELD.AC.UK>
Sent: 29 June 2021 08:49
To: RAMESES@JISCMAIL.AC.UK <RAMESES@JISCMAIL.AC.UK>
Subject: Re: Scoping review

Hi Lal

Just a slightly different perspective from a review methodologist:
The activities that you describe are entirely appropriate and look well-considered.
However what exactly are you "scoping"? Unfortunately people commonly use the term "scoping review" almost as a throwaway line. A scoping review, strictly speaking, is determining the scope of subsequent research, whether a systematic review or primary research which does not seem the case here. People wrongly use it too as an apology for not doing a systematic review. Realist synthesis needs no such apology.

Realist synthesis has its own methods for doing the activity of "scoping" and for using the retrieved items to further the realist inquiry. A realist search for the purpose being described does not have to be comparable in size or comprehensiveness to a systematic review search. (See our chapter on the Realist Search). [Yes you can use a systematic review within a realist review but that is usually for testing theory not generating or exploring it].

So yes your process is exploratory and shares some similarities to scoping as used in a scoping review. As you acknowledge it does have to be a focused or limited activity because of the broad nature of the topic. However please don't feel a need to label it either a "scoping review" (or even worse a "rapid review"!). At the very least doing this will improve the integration of the different areas of activity within an overall realist methodology.
Great Question. Very best wishes for getting up to speed with the realist methodology!
Best wishes
Andrew

Appendix 3-2: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	SECTION
TITLE			
Title	1	Identify the report as a scoping review.	3.2.2
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	N/A
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3.2
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualise the review questions and/or objectives.	3.3.2
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	3.4.1
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	3.4.2
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	3.4.3
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	3.4.4.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	3.4.5
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	3.4.3
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how	3.4.4

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	SECTION
sources of evidence§		this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	3.4.6
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	3.5.1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	3.5.2
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	N/A
Synthesis of results	18	Summarise and/or present the charting results as they relate to the review questions and objectives.	3.6 & 3.7
DISCUSSION			
Summary of evidence	19	Summarise the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	3.8
Limitations	20	Discuss the limitations of the scoping review process.	3.8.1
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	3.8.2

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* are compiled from

† A more inclusive term used to account for the different types of evidence or data sources

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision.

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473.

Appendix 3-3: Data extraction chart

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Alvarado, McVey, Greenhalgh, Dowding, Mamas, Gale, Doherty & Randell **2020** (England)[34]	Exploring variation in the use of feedback from national clinical audits: A realist investigation	Realist evaluation using semi-structured interviews	To explore the reasons behind variation in the extent to which national clinical audit feedback stimulates quality improvement	Variety of inpatient hospital areas (Cardiac, Urology & Paediatric Intensive Care)	Doctors, Nurses, Audit Clerks Trust Bord members and Audit staff from five NHS Trusts	Variety of national clinical audits	•High relevance •Conceptually rich •No reservations re: rigour	“The resources allocated to support audit participation (which impacted data quality and timeliness) and access to resources to enact change in response to this feedback were reported to constrain its use as a tool for stimulating QI” “Challenges accessing supplier held data ...constrained the perceived usefulness of this feedback” Participant discussing incentives: “Accreditation from NACR, which requires meeting certain standards of care, as a driver for engagement with NCA feedback” “In this context of competition, the primary use of NCA feedback was to attract patient referrals to the service” “Data in the public reports could be up to 2 years old and was not, therefore, perceived as a reliable basis for practice change” “Annual report - that did not offer a level of detail that enabled them to ‘pick out subtler changes’ where quality improvement might be delivered”
Arvidsson, Dahlin & Anell **2021** (Sweden)[168]	Conditions and barriers for QI: Professionals and health centre managers experience audit and feedback in primary care	Explorative qualitative design: Focus Group	To explore how professionals and health centre managers in primary care experience existing forms of audit and feedback	Primary Care Health Centre	Health Centre Managers, Physicians, nurses and allied healthcare professionals from six health centres	Variety of health and financial measures	•Med relevance •Conceptually thick •Acknowledged self-selection bias of HC	“The dominance of non-clinical measures and a focus on external accountability were perceived as barriers to QI by health professionals” “An unbalanced practice of A&F, focussing on revenues, expenditures and non-clinical measures is likely to suppress A&F based on clinical data and may reduce professionals’ interest in A&F activities in general” “Previous experiences of lack of resources (time and staff) during attempts to perform QI projects can also cause change fatigue and decrease motivation”
Asprang, Frich & Braut **2015** (Norway)[169]	Organizational impact of governmental audit of blood transfusion services in Norway	Explorative qualitative design: Focus Group	To explore the organisational effects of a governmental audit of blood transfusion services	National blood transfusion service (Hospital and blood bank)	Doctors, healthcare practitioners and managers from three regions	Blood transfusion national audit	•Med relevance •Conceptually thin •Conflict of researcher’s role	“Professionals and senior managers struggled to understand the content of the supervisory report…auditors should ensure a common understanding of the findings and the possible deviations. Using words and concepts that professionals are able to understand could facilitate understanding and organisational change”
Batty, Grant, Aggarwal, Lowe, Potter,& Jackson **2004** (England)[155]	National Clinical Sentinel Audit of Evidence-based Prescribing for Older People	Case study	To audit performance of hospitals evidence-based prescribing	Inpatient hospital (mixed)	Pharmacist, physician, nurse & audit staff from NHS Trusts	Adherence to prescribing guidelines for 65+	•Med relevance •Conceptually thin •Assumptions & speculation in findings	“[Benchmarking] could also have led hospitals to become complacent with their performance when they discovered other hospitals were also performing poorly”

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Bodansky, Oskrochi, Judah, Lewis, Fischer & Narayan **2017** (England)[156]	Change the habit to change the practice: Do audits really ever change anything?	Pre and post audit review of medical records	To assess adherence to local MRSA guidelines for emergency hip fracture surgery	Surgery	Surgeons, Nurses and Healthcare Assistants at a single hospital	Adherence to clinical guidelines	•Low relevance •Conceptually thin •Required quals triangulation to explore causation	"Providing education is not sufficient to change clinical practice" "Consideration of the principles of behaviour change, including habit and memory, may help in the design of more effective interventions"
Botje, Klazinga, Sunol, Groene, Pfaff, Mannion, Depaigne-Loth, Arah, Dersarkissian & Wagner **2014** (Europe)[170]	Is having quality as an item on the executive board agenda associated with implementation of quality management systems: A quantitative analysis	Mixed method, cross-sectional study surveying CEOs & quality managers and data from onsite audits	To assess whether there is a relationship between having quality as an item on the board's agenda and implementation of quality management	Acute inpatient hospitals	CEOs and Quality Managers from seven European countries	Various - Multidisciplinary	•Med relevance •Conceptually thin •Lacked quals to explore mechanisms	"Having quality as an item on the executive board's agenda is also important symbolically as it signals their quality orientation to the rest of the hospital, and ultimately obtain more resources than those who do not"
Bowie, Bradley & Rushmer **2010** (Scotland)[17]	Clinical audit and quality improvement – time for a rethink?	Qualitative study using semi-structured and focus group interviews.	To explore the views and experiences of audit advisors regarding their role in supporting health care teams in the audit process.	Multiple pathology mainly inpatient hospital	Audit advisors in two regions	Various – Multidisciplinary	•Med relevance •Conceptually thick •Acknowledged self-selection limitations	"This 'lack of protected time' was identified as a smoke-screen by participants, hiding a multitude of other reasons" "Doctors often had dedicated contractual time for audit…..viewed by participants as 'very audit active' as they chased career opportunities" "Management failure to support and resource changes fuels low motivation and disillusionment"
Cameron, Penney, MacLennan, McLeer & Walker **2007** (Scotland)[157]	Impact on Maternity Professionals of Novel Approaches to Clinical Audit Feedback	Mixed methods evaluation of feedback interventions	To evaluate the feasibility, acceptability, and impact of two interventions that were designed to increase the intensity of clinical audit feedback	Inpatient hospital	Physicians Midwives Nurses Sonographers	Obstetrics	•High relevance •Conceptually rich •No reservations re: rigour	"Specific themes that emerged as contributing to the positive aspects of participation included …. providing leverage or ammunition in making a case to management for additional resources." "Participants felt that they had been demoralised and that the feedback had not given due credit. A recurring theme, regardless of the style of feedback received, was a sense of frustration and lack of capacity to implement desired changes." "All participants expressed generally positive views on the content and style of the report, and several specifically commented on the value of comparing performance with others." "Despite overall positive perceptions of the audit report, some participants expressed reservations about the accuracy and validity of some findings."

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Cornish, Tilney, Tan, Thompson, Smith & Tekkis **2011** (UK)[158]	The National Bowel Cancer Audit Project (NBOCAP): what do trusts think of the NBOCAP and how can it be improved?	Prospective e-survey	To understand why trusts were/were not participating in the NBOCAP and how to improve the quality of data collected and feedback	Inpatient hospital	Colorectal surgeons (Surgical team contribute to audit)	Surgical outcomes and quality of care for bowel cancer in UK	•Low relevance •Conceptually thin •Selection bias and low response rate	Reason reported for non-submission of data to NBOCAP: • Lack of IT support (23.6%) • Pressure from peers / professional bodies (24.3%) • Compare unit data with national data (56.8%) • Because national audit improves outcomes (45.9%) • To generate information for use at local level (42.6%) • To compare trends over time (38.5%)
Currie, Laidlaw, Ness, Gosdzielewska, Malcom, Sneddon, Seaton & Flowers **2020** (Scotland)[159]	Mechanisms affecting the implementation of a national antimicrobial stewardship programme; multi-professional perspectives explained using NPT	In-depth qualitative interviews	To explain mechanisms affecting the implementation of a national antimicrobial stewardship programme, from multi-professional perspectives	Inpatient hospital	Doctors, Nurses and Clinical Pharmacists	Antimicrobial stewardship	•Med relevance •Conceptually thick •No reservations re: rigour	“To have a national body behind you saying, look, this is what everyone in Scotland is doing, this is what’s appropriate, this is what everyone else thinks is correct, and if you want to have a variance from it then we need to have a pretty good reason behind it. It’s really useful to have that authority behind you.” “Whilst a few AMTs use audit data to target quality improvement projects, most report no capacity for quality improvement work and therefore opportunities for the reflexive component of monitoring are lost.”
Dixon-Woods, Campbell, Aveling & Martin **2019** (UK)[160]	An ethnographic study of improving data collection and completeness in large-scale data exercises	Ethnography	To explore how improved data submission and completion rates were achieved during a crucial period of the evolution of two large-scale data exercises	Inpatient hospital	Audit programme personnel	National Lung Cancer Audit and the Vascular Registry	•High relevance •Conceptually rich •No reservations re: rigour	“Data entry was very rarely built into job specifications or organisational charts in the clinical centres, and rarely was it an activity that was directly funded or resourced by organisations.” “These mundane obstacles [data collection] had a powerful impact on clinicians' ability and willingness to complete data entry” “Professional leaders’ strategies to promote the collective professional responsibility and value of data collection as an important form of self-governance” “Critical to establishing this cultural account of clinical audit was the legitimacy that the professional leadership “breathed” into the enterprise” “The realisation grew that pushing the task of data entry too far down could have negative consequences for physicians and others in the hierarchy: their performance (and that of their centre) might be misrepresented by poor quality data, and accordingly the quality of their care could easily be underestimated by external authorities and peers” “a policy context that seemed increasingly inclined to weaponise data as a means of blaming and shaming”

Author, Year (Country)	Document Title	Study Design	Aim	Setting	Participants	Audit focus	Relevance, Richness & Rigour	Key extract
Dunne, Lal, Pranesh, Spry, Mcfaul & Rooney **2018** (UK)[161]	Surgical audit: are we not closing the loop?	Multi-centre descriptive evaluation	To assess rates of audit activity and completion across surgical directorates, and explore the barriers to successful audit completion	Surgery	3 surgical directorates	Variety of aspects of surgical care	• Med relevance • Conceptually thin • No attempt to dig deeper than broad survey	"Completion of an audit is a compulsory part of both foundation doctor and surgical training due to the importance on improving both clinical and professional outcomes" "The commonest reason cited [for not completing audit] was that the prime audit driver was a junior doctor and that these junior doctors either completed their objective (presentation/publication) or moved hospital trusts leading to a lack of audit momentum"
Dupont, Deneux-Tharaux, Touzet, Colin, Bouvier-Colle, Lansac, Thevenet, Boberie-Moyrand, Piccin & Rudigoz **2011** (France)[171]	Clinical audit: a useful tool for reducing severe postpartum haemorrhages?	Quasi-experimental before-and-after survey	To assess the impact of regular criteria-based audits on the prevalence of severe post-partum haemorrhage	Inpatient maternity	All ward staff	Post-partum haemorrhage prevalence in maternity units	• Low relevance • Conceptually thin • Quants only, no attempt to understand causation	"A major strength of regular clinical audits is that they bring practitioners together frequently to discuss the management of severe cases and to define relevant improvement objectives appropriate to the local context and based on the audit's findings"
Egholm, Helmark, Christensen, Eldh, Winblad, Bunkenborg, Zwisler & Nilsen **2019** (Denmark) [172]	Facilitators for using data from a quality registry in local quality improvement work	Cross-sectional nationwide survey study	To investigate use of data from a clinical quality registry for cardiac rehabilitation	Hospital	Front line staff, mid managers and heads of departments	Cardiac rehabilitation standards	• Med relevance • Conceptually thick • Despite quants only, explored granular details	"Roles and responsibilities for acting on data are unclear and there is a general lack of time and understanding regarding the use of CQRs" "Feedback data may not reach the frontline staff because it fails to pass through complex delivery pathways, staff may not know that local feedback data exists"
Egholm, Helmark, Doherty, Nilsen, Zwisler & Bunkenborg **2019** (England & Denmark) [173]	"Struggling with practices" – a qualitative study of factors influencing the implementation of clinical quality registries for cardiac rehab in England and Denmark	Qualitative interview	To explore barriers and facilitators for registry implementation by exploring how staff perceive the implementation process	Hospital	Nurse, Physiotherapist Dietician, Administrator	Cardiac rehabilitation standards	• Med relevance • Conceptually thick • No reservations re: rigour	"Facilitators for registry implementation: • Local registry advocates/ champions. • Management interest in output data (results) • The prospect of improving patient care"

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Eldh, Fredriksson, Halford, Wallin, Dahlstrom, Vengberg & Winblad **2014** (Sweden)[175]	Facilitators and barriers to applying a national quality registry for quality improvement in stroke care	Semi-structured telephone interviews	To describe the experiences of stakeholders to determine elements that facilitate and hinder clinical quality improvement	Inpatient stroke	Nurses' managers & Physicians	Adherence to national stroke standards	•High relevance •Conceptually thick •No concerns re: rigour	"There were aspects connected to Riks-Stroke which supposedly hindered quality improvement, primarily the burden of data registration. With time being one of the constraints in clinical health care, data registration may occupy resources which could possibly be spent on improvement efforts" "Relationship between NQRs and quality improvement was found to be complex, suggesting that an NQR can contribute to quality improvement but does not automatically do so. Rather, the local context determines if and how the NQR induces quality improvement" "Quality improvement appeared where there was 1) collaboration among the local NQR stakeholders and the collaboration included managers and 2) contextual factors present such as an active and purposeful management system supporting planning performing, follow up and action on quality"
Eldh, Wallin, Fredriksson, Vengberg, Winblad, Halford & Dahlström **2016** (Sweden)[174]	Factors facilitating a national quality registry to aid clinical quality improvement: findings of a national survey	Quantitative survey	To explore what aspects of the registry and healthcare organisations facilitate or hinder the use of registry data in quality improvement	Inpatient stroke	Managers Physicians & Nurses	Adherence to national stroke standards	•Med relevance •Conceptually thin •Although quants, survey items detailed	"One of the limitations of registries such as Riksstroke is evidently the burden of registering data. This is most likely reflected in that merely 65% of the Riksstroke respondents considered the gain from partaking in the registry justified the resources spent working with it"
Fredriksson, Eldh, Vengberg, Dahlström, Halford, Wallin & Winblad **2014** (Sweden)[176]	Local politico-administrative perspectives on quality improvement based on national registry data in Sweden: a qualitative study using CIFR	Qualitative interview	To investigate the perspectives of politicians and administrators on quality improvement based on national registry data	Various	Politicians and administrators	Various including stroke (Riksstroke)	•Med relevance •Conceptually thick •Participants may not have had the required understanding	"Lagging data access at the politico-administrative level makes it difficult for the politico-administrative leaderships to initiate, monitor, and support timely QI efforts" "Regarding available resources, the politico-administrative representatives pointed out that the meso-level often lacks resources to analyse NQR-data, not least personnel resources"
Freeman, Dawson, Jowitt, White, Callard, Sieczkowski, Kuriyan & Roberts **2016** (NZ)[189]	The impact of the Hand Hygiene New Zealand programme on hand hygiene practices in New Zealand's public hospitals	Multimodal programme report	To detail the progress made by Hand Hygiene since 2011 and describe the challenges experienced along the way	Variety of inpatient areas	Ward-based multi-disciplinary teams	Hand hygiene	•Low relevance •Conceptually thin •Lacked qualitative depth	"While public reporting has resulted in at least one DHB being singled out for negative media attention, this was used as an opportunity by local proponents of the programme to generate greater support from staff and senior management. Ultimately this helped to drive considerable improvement in that DHB [District Health Board]"

Author, Year (Country)	Document Title	Study Design	Aim	Setting	Participants	Audit focus	Relevance, Richness & Rigour	Key extract
Gould, Lorencatto, During, Rowley, Michie, Foy, Stanworth, Grimshaw & Francis **2018** (England)[162]	How do hospitals respond to feedback about blood transfusion practice? A multiple case study investigation	Multiple case study design	To investigate which hospital staff receive feedback and formulate a response, how feedback is disseminated within hospitals, and how responses are enacted	Inpatient hospital	Hospital transfusion committee and various clinical roles within transfusion	Blood transfusion service	•Med relevance •Conceptually rich •No concerns re: rigour	"Key enablers of action across all cases included clear lines of responsibility and strategies to remind staff about recommendations" "Appropriate responses by hospital staff to feedback about blood transfusion practice depend upon supportive infrastructures and role clarity" "If the feedback was not reaching the staff whose behaviour is being audited, it would not lead to a change in behaviour, and therefore have little impact on patient safety or outcomes."
Gude, Roos-Blom, van der Veer, Dongelmans, de Jonge, Peek & Keizer **2019** (Netherlands)[177]	Facilitating action planning in audit and feedback interventions: an evaluation of an action implementation toolbox in intensive care	Mixed methods process evaluation - documentary analysis and semi-structured interviews	To understand the mechanisms through which audit and feedback facilitates action planning	Intensive Care Units	Doctors and Nurses	Pain management	•High relevance •Conceptually rich •No concerns re: rigour	"ICUs had one or two people responsible for implementing the intervention locally (Champion). They would typically review the feedback in the dashboard, discuss it with the wider team and update their action plan accordingly" "The data collection and analysis methods were questioned by some ICUs as they suspected missing pain measurements in the data underlying the feedback, differences in how pain was determined and mismatching shift times (Accuracy). This hampered the feedback's credibility and inhibited ICUs' acceptance of the feedback"
Hanskamp-Sebregts, Zegers, Boeijen, Wollersheim, Van Gurp & Westert **2018** (Netherlands)[178]	Process evaluation of the effects of patient safety auditing in hospital care	Process evaluation	To identify factors that explain the observed effects of internal auditing on improving patient safety	Variety of inpatient setting	Healthcare providers and managers	Patient safety. Externally initiated as imposed at an organisational level.	•Med relevance •Conceptually thin •No concerns re: rigour	"Factors that hindered implementation were … time-consuming and labour-intensive implementation of improvement actions; and limited organisational support for quality improvement (e.g. insufficient staff capacity and time, no available quality improvement data and information and communication technological (ICT) support)."
Jolliffe, Mararty, Hoffman, Crotty, Hunter, Cameron, Li & Lanin **2019** (Australia)[186]	Using audit and feedback to increase clinician adherence to clinical practice guidelines in brain injury rehabilitation	Before and after study	To explore whether frequent audit and feedback cycles over a sustained period of time increased clinician adherence to guidelines	Inpatient brain injury	Allied Healthcare Professionals, Medical & Nursing	Adherence to guideline indicators	•Med relevance •Conceptually thick •No concerns re: rigour	"a sustained fortnightly audit and feedback program led to a significant increase in adherence to clinical practice guideline recommendations" "The adherence improvements following intervention were likely due to a combination of the following attributes of our program: a) high level of managerial support, b) feedback delivered using a non-aversive and clinician-led approach, c) high frequency of audit and feedback cycles"

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Langston 2011 USA [188]	Effects of Peer Monitoring and Feedback on Hand Hygiene in Surgical Intensive Care Unit	Cohort Study	To increase compliance to hand hygiene through non-personal and personal staff feedback	Inpatient hospital	Physicians and Nurses	Hand hygiene	•Low relevance •Conceptually thin •Sampling limitations	"The audit tool was straightforward and easy for the staff to complete. Managers appreciated the ease and speed with which it could be implemented"
Manion & Goddard **2001** (Scotland) [163]	Impact of published clinical outcomes data: case study in NHS hospital trusts	Case study	To examine the impact of the publication of clinical outcomes data on NHS Trusts in Scotland to inform the development of similar schemes elsewhere	Inpatient hospital	Chief Executives, Medical Directors, Doctors and Nurse Managers	Cancer surgery and Stroke	•Med relevance • Conceptually thin •No concerns re: rigour	"The indicators were mainly used to support applications for further funding and service development." "Causes of poor effect: **Timeliness**—The elapsed time between collection and publication of data was a major drawback to the indicators being used in a meaningful way for continuous quality improvement. **Process or outcome indicators**—Many members of staff preferred process rather than outcome indicators as they were thought to be more reliable, up to date, and easier to measure and to provide better guidance on what specific actions are needed to improve the quality of care"
McVey, Alvarado, Keen, Greenhalgh, Mamas, Gale, Doherty, Feltblower, Elshehaly, Dowding & Randell **2020** (England)[33]	Institutional use of National Clinical Audits (NCA) by healthcare providers	Semi-structured interviews	To explore the potential for national clinical audits to contribute to quality improvements, from the perspective of hospital boards and their quality committees	Inpatient	Hospital board, divisional managers, Doctor, Nurse and non-clinical support staff.	Various national clinical audits	•High relevance •Conceptually rich •No concerns re: rigour	"Clinicians submitted business cases for QI projects, based on NCA data, to divisional and then institutional committees" "Some clinicians in our study saw little point in seeking institutional resource approval for QI arising from NCAs, causing them to question the value of audit participation altogether" "Importance of legitimacy as a motivating factor for organisations and their managers, encouraging them to respond to demands. We found this to be the case with boards and their quality committees, which engaged with those NCAs for which participation was mandated by NHS England and when NCA performance was associated with financial or reputational gain or penalties" "The retrospective nature of data within public NCA reports limited their usefulness for institutional staff… The time lag was regarded as unhelpful, given the need to respond rapidly to problems with care quality and for business cases to be evidenced using recent information. This limitation could generate additional work for committees and staff, leading to frustration and disengagement with the audits" "Institutional staff were motivated to monitor their hospital's performance in these reports because of their public nature, and the risk to their reputations for safe and effective care if they appeared as "negative outliers" in the reports"

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Numan, Klomp, Li, Buitelaar, Burgers, Van Sandick & Wouters **2012** (Netherlands)[179]	A clinical audit in multidisciplinary care path for thoracic surgery: An instrument for continuous quality improvement	Prospective cohort study	To assess the results of a multidisciplinary care path for patients undergoing thoracic cancer surgery	Cardiothoracic surgery	Anaesthetist, Surgeon, Nurse & therapists	Pathway standards	•Low relevance •Conceptually thin • Limited exploration of alternate causality to support claims	“This [the audit] provides the opportunity for thoracic surgeons to compare their results with those of other thoracic surgeons with similar patient groups”
Pedersen, Lanheim, Møller & Lien **2019** (Norway)[180]	First-line managers' experience of the use of audit and feedback cycle in specialist mental health care	Qualitative case study	To explore how first-line managers in a District Psychiatric Centre experienced using audit and feedback cycle	District psychiatric centre	First-line managers and clinicians	Implement-ation of national guidelines	•Med relevance •Conceptually thin •Sample limited to single institution (n=5)	“The potential impact of the use of audit and feedback may thus not be fully realised, in part, because of limited organisational support”
Phekoo, Clements & Bell **2014** (UK)[164]	Overview of the self-assessment survey: “audit of audits” Report to the Healthcare Quality Improvement Partnership	Report including survey findings	To assess progress over time to inform and support the on-going development of existing clinical audits	Various	National clinical audit leads	National clinical audit and patient outcome programmes in UK	•Med relevance •Conceptually thin •No concerns re: rigour	“For NCAs [National clinical audits] to benefit patients it is important the findings are disseminated widely, not merely in annual reports”
Randell, Alvarado, McVey, Ruddle, Doherty, Gale, Mamas & Dowding **2019** (England) [165]	Requirements for a quality dashboard: Lessons from National Clinical Audits	Semi structured interviews	To understand how national clinical audit data are used for quality improvement and factors that support or constrain use	Inpatient Hospitals	Hospital board, divisional managers, Dr, Nurse and non-clinical support staff.	Various	•Med relevance •Conceptually thick •No concerns re: rigour	“Trust in the quality of national comparator data is also important for clinical teams. Inconsistent or inaccurate coding was reported to have a negative impact on interviewees’ trust in MINAP data and on their ability to make meaningful comparisons with other organisations”

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Sinuff, Muscedere, Rozmovits, Dale & Scales **2015** (Canada)[182]	A qualitative study of the variable effects of audit and feedback in the ICU	Interviews	To understand the individual and organisational barriers to implementing audit and feedback and preferences for the types of audit and feedback interventions to support behaviour change from the perspectives of ICU clinicians and leaders.	Intensive Care Units (ICU)	Physicians, Nurses, respiratory therapists, Pharmacists and ICU Administrators	Implementation of various guidelines used e.g. to reduce central line infections and ventilator-associated pneumonia.	•High relevance •Conceptually thin •No concerns re: rigour	"The audit process was perceived as being insufficiently transparent." "Suggestions for improvement included improving information sharing about the rationale for change and the audit process, tools and metrics…delivering timely feedback and increasing engagement by senior management" "Staff felt disenfranchised: their opinions about the process were not sought nor were they informed of the process" "Feedback was often perceived to be irrelevant because of delayed reporting" "Clinicians who were not research oriented, in particular, could not relate to the volumes of data presented" "Engagement of leadership on levels, from nursing and physician to senior administration, was perceived to be a very important aspect of successful audit and feedback" "Being well supported and having recognition of achievements by hospital senior management were seen as imperative to increase clinicians' confidence in, and willingness to engage with the audit and feedback process"
Sparring, Granström, Sachs, Brommels & Nyström **2018** (Sweden)[181]	One size fits none – a qualitative study investigating nine national quality registries' conditions for use in quality improvement	Multiple case study design	To investigate the perceived barriers and facilitators for the use of national quality registers (NQR) in quality improvement	Various	Representatives from each NQR	Various	•High relevance •Conceptually thin •Limited to 2 participants from each NQR	Barriers to using NQR's identified as: "Double administration due to technical constraints. Low data quality due to incorrect data and low coverage" "Lack of time, money, and personnel. Problems with incompatible IT-systems" Facilitators to using NQR's identified as: "Increasing number of enthusiasts with a strong belief in the value of NQRs" "Public benchmarking" "Paradigm shift towards value-based health care, which fits perfectly with the introduction of PROMs and PREMs… information we can use for important research."
Stephenson, McArthur, Giles, Lockwood, Aromataris & Pearson **2016** (Australia)[187]	Prevention of falls in acute hospital settings: multi-site audit and best practice implementation project	Multi-site audit	To identify barriers to best practice and to implement and assess the effects of strategies to promote best practice in falls prevention	Medical and surgical wards	A nominated Clinical leader from each site inputted data regarding ward activity	Falls	•Low relevance •Conceptually thin •Lack of quals data to understand variation in practice	"Despite sustained practice improvement, reported fall rates remained unchanged. The focus on staff education possibly led to improved reporting of falls, which may explain the apparent lack of effect on fall rates"

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Stevenson, Baker, Farooqi, Sorrie & Khunti **2001** (England)[166]	Features of primary health care teams associated with successful quality improvement of diabetes care	Semi structured interviews	To identify features of primary health care teams associated with successful quality improvement during audit	Primary care	GP's and practice nurses	Diabetes care	•Low relevance •Conceptually thin •Unusual quantification of quals data	“Some teams clearly regarding audit as a mechanism to help identify what needed to be changed, and to be followed by the development of systematic plans to implement change” “Some responders felt more confident about their audit experiences and accepted it as a quality improvement mechanism”
Sykes, Thomson, Kolehmainen, Allan & Finch **2020** (England)[167]	Impetus to change: a multi-site qualitative exploration of national audit of dementia	Multi-method qualitative exploration	To explore the national audit to identify opportunities to enhance impact on quality improvement	Inpatient	Directors, governance team, ward managers, nurses, medics & healthcare professionals	Dementia	•Med relevance •Conceptually thick •No concerns re: rigour	“The role of the national audit [acted] as a lever for gaining internal improvement resources” “However, comparison can also lead to complacency” “I don’t know how valuable the benchmarking is, apart from that it brings it to the attention of the board. If you’re somewhere near the bottom then they want something done about it, it’s a useful lever sometimes in that way”
Taylor, Neuburger, Walker, Cromwell & Groene **2016** (England)[23]	How is feedback from national clinical audits used? Views from English National Health Service trust audit leads	Mixed methods (Survey & interview)	To explore how the output of national clinical audits in England is used by professionals and whether and how their impact could be enhanced.	Inpatient	Variety of Surgeon, Oncologist, Specialist Nurse	Cancer Care (4 national audits: Bowel, Head & neck, lung and gastric)	•Med relevance •Conceptually thick •No concerns re: rigour	“According to interviewees, this is due to the credibility of the established professional societies and authoritative bodies associated with the reports, rather than the content of the reports themselves” “Most interviewees specifically detailed that they [reports] are useful for presenting an overview of current clinical practice, enabling local teams to identify areas for improvement, providing reassurance about current practice or reinforce what is already known, and for use as evidence for service planning and for making business cases“ “Some described how comparative Trust results motivated them to improve, driven by a competitive spirit”
Taylor, Jones & McKevitt **2018** (England)[13]	How is the audit of therapy intensity influencing rehabilitation in inpatient stroke units in the UK?	Ethnography	To understand how the introduction of timed therapy targets has influenced delivery of stroke unit therapy	Inpatient Stroke	Multi-disciplinary team	Stroke Care	•High relevance •Conceptually rich •No concerns re: rigour	“Therapists associated the SSNAP audit and the monitoring of therapy time with the commissioning of their services. They expressed mistrust about auditing practices in other services, and they worried about commissioners taking these results at face value” “Their specific roles differed, but in each site, there was someone influential who clinicians respected due to their clinical experience” “They questioned the quality of the national audit data for therapy, and they used language such as ‘bending the rules’, ‘playing the numbers game’ or ‘lying’ when discussing the practices of other teams” “Rivalry and mistrust were observed to go hand in hand with discussion of the audit ratings”“ Whether the improvements in their audit results reflected ‘real life’ improvement, she and her colleagues consistently responded with a clear ‘no’, explaining that most of their changes had been in their audit processes.”

Author, Year (Country)	**Document Title**	**Study Design**	**Aim**	**Setting**	**Participants**	**Audit focus**	**Relevance, Richness & Rigour**	**Key extract**
Wagner, Durbin, Barnsley & Ivers **2017** (Canada)[183]	Beyond quality improvement: exploring why primary care teams engage in voluntary audit and feedback	Qualitative interview	To explore the motivating factors that drive primary care teams to participate in a voluntary audit and feedback initiative	Primary Care	Directors / physician leaders and Quality Improvement support staff	Family Health	•Low relevance •Conceptually thick •Sample predominantly executive directors	"Practices were interested in an A & F [Audit and Feedback] initiative that presented recent data, of measures perceived to be meaningful to their practices, and that captured the full scope of primary care practice"
Wagner, Durbin, Barnsley & Ivers **2019** (Canada)[184]	Measurement without management: qualitative evaluation of a voluntary audit & feedback for primary care teams	Semi-structured interviews	To identify barriers or facilitators to implementation in a team-based primary care context	Primary Care	Directors, physician leaders and healthcare professionals	Family Health	•High relevance •Conceptually rich •No concerns re: rigour	"In the absence of such documentation, participants were concerned about methodological consistency between practices, limiting the utility of peer comparison" "Participants cited the frequency of audit cycles as a barrier to implementation. It was specifically noted that the six-month gap between … was insufficient to observe the effect of any change. Some participants further expressed feedback fatigue" "Visualizations were difficult to interpret; the website was hard to navigate and lacked functionality to print or share the feedback report"
Wooller, Backman, Gupta, Jennings, Hasimja-Saraqini & Forster **2018** (Canada) [185]	A pre and post intervention study to reduce unnecessary urinary catheter use on general medicine wards of a large academic health science centre	Pre-post programme evaluation	To describe the use of a program to drive improvement efforts, and specifically to reduce the use of urinary catheters on general internal medicine wards.	Inpatient hospital	Physicians & Nurses	Urinary Catheter use	•Low relevance •Conceptually thick •No concerns re: rigour	"It seems likely the excellent uptake was a function of physician leadership buy-in as well as evidence-based standard post-catheter care orders, both of which were regarded favourably by physicians and nurses alike"

Appendix 3-4: Examples of “*If…then*” statements

Articulated as context, mechanism and outcome

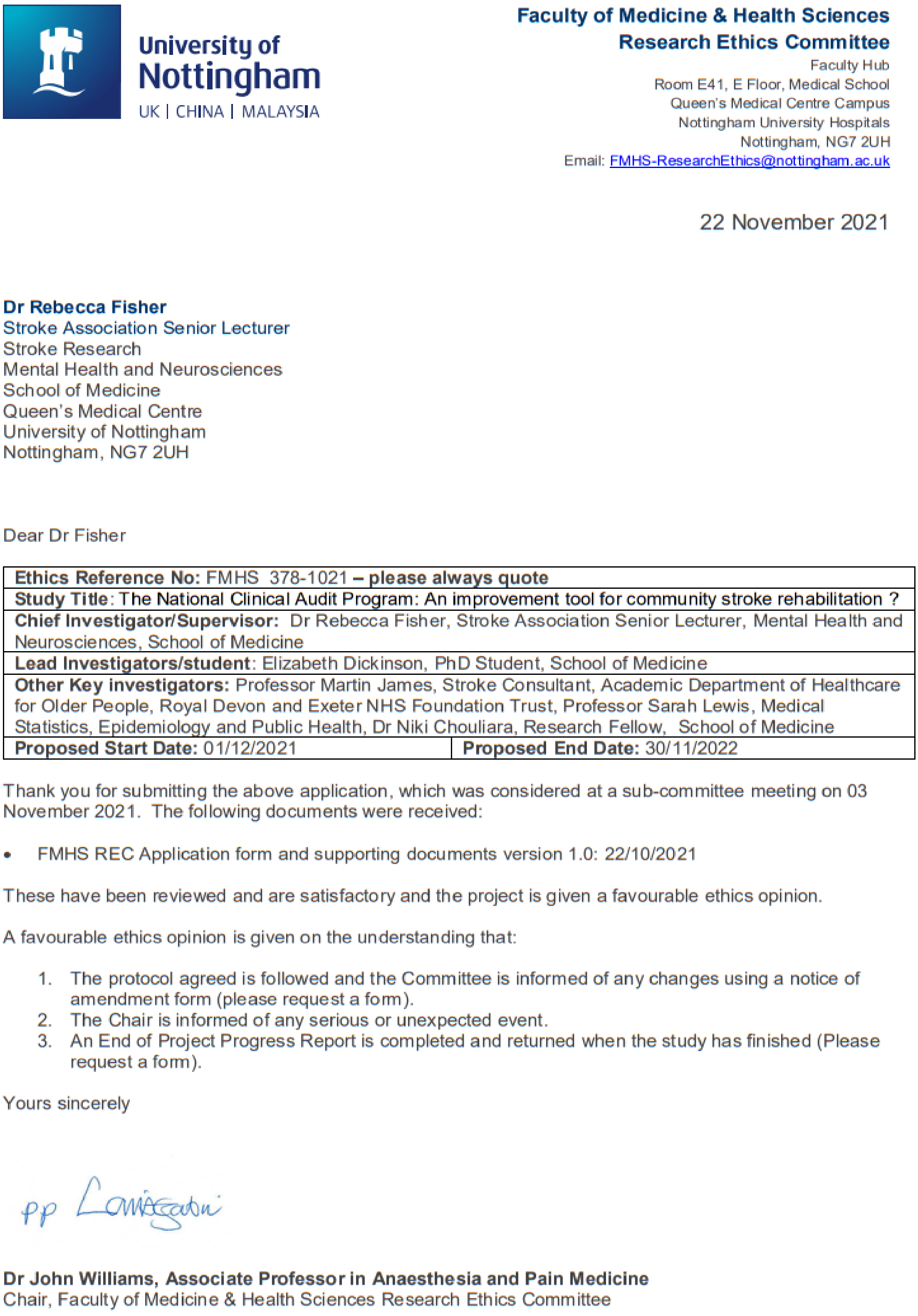
	Context	Mechanism	Outcome
Engagement and participation	If there is an organisational culture that suggests audit is a worthwhile activity, because of the positive role modelling of behaviour and attitudes	Then stakeholders are encouraged and motivated to be involved in the process	Stakeholders will engage with the audit and access the available resources
	If individuals have previous negative experiences of audit	Then fear of repeating these experiences puts them off	Stakeholders will not engage with the audit or access the available resources
	If stakeholders can access information about audit purpose, roles are clearly articulated, and they have insight into what is expected of them	Then they are empowered / enabled to participate in audit	Stakeholders will participate in the audit and audit tasks will be completed
	If stakeholders can access information about audit purpose, roles are clearly articulated, and they have insight into what is expected of them	Then they feel they have no choice, and they are obliged to participate	Stakeholders will participate in the audit and audit tasks will be completed
	If individuals perceive audit to be a worthwhile activity and have busy caseloads	Then they choose to prioritise audit activity against the competing demands on their time	Stakeholders will participate in the audit activities are completed
	If individuals perceive audit to be a worthwhile activity and have busy caseloads	Then they do not choose to prioritise audit activity against the competing demands on their time	Stakeholders will participate in the audit activities are not completed
	If stakeholders have sufficient time to complete activities	Then they will be able to prioritise them routinely	Stakeholders will participate in the audit and audit tasks will be completed
	If stakeholders have access to resources such as laptops to complete activities, they feel it is an important and legitimate activity	Then they will perceive audit activities as valued and important to the organisation and be motivated	Data inputted will be complete and therefore reflect the service delivered
	If stakeholders perceive audit as a burden that compromises clinical work	Then they don’t perceive the relative benefit of audit activities, and they won’t be motivated	Data inputted will be incomplete and therefore not reflect the service delivered

	Context	Mechanism	Outcome
Feedback use	If the audit is run by a reputable organisation	Then they perceive feedback reports as trustworthy and are confident to use the report to compare services	Stakeholders will use the report to inform quality improvement
	If data isn't perceived as timely	Then stakeholders will feel it doesn't reflect relevant caseloads	Stakeholders will be less confident in using feedback for quality improvement
	If stakeholders doubt the accuracy of the data inputted	Then they will mistrust the feedback report and not act upon it	Stakeholders will not use the report to inform quality improvement
	If stakeholders have access to training resources to support scrutinising audit reports	Then they will be confident in utilising feedback reports to support in the planning of service improvements	Quality improvements will be planned or informed by audit feedback reports
	If there is insufficient support for service improvements	Then they will be reluctant to engage in scrutinising audit reports as they don't perceive it a worthwhile use of time	Quality improvements will not be planned or informed by audit feedback reports

Appendix 3-5: Five theories prioritised by collaborators

Proposed Candidate Theory	Context	Mechanism	Outcome
1. Individual perception of audit influences motivation to engage	If individuals perceive audit to be a worthwhile activity	Then they are motivated by the potential benefits	Individuals will engage with the audit
2. If information regarding the audit is available, individuals are empowered to participate	If the purpose and process of audit is explained and roles articulated	Then individuals understand the audit and have insight what is expected of them. Consequently, they are empowered to participate	Individuals will complete the audit tasks appropriate for their role
3. If stakeholders have resources to support participation, data will be inputted completely and reflect the caseload	If resources such as laptops are available to complete audit activities	Then individuals are enabled by the resources and motivated by the perceived value placed on the audit by their organisation	Data inputted will be complete for the caseload
4. If data is perceived as accurate then it will be used to inform quality improvement	If data contained in feedback report is perceived as accurate	Then the report will be perceived as trustworthy, and individuals will have the confidence to act upon it	Audit feedback is used to inform the quality improvement
5. If stakeholders have the skills to scrutinise data, they will be more confident using it	If stakeholders have access to training resources to support the scrutinising of audit reports	Then they will be confident in utilising feedback reports to support in the planning of service improvements	Feedback reports are used to inform the planning of quality improvement

Appendix 4-1: Ethical Approval



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Faculty of Medicine & Health Sciences
Research Ethics Committee
Faculty Hub
Room E41, E Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH
Email: FMHS-ResearchEthics@nottingham.ac.uk

22 November 2021

Dr Rebecca Fisher
Stroke Association Senior Lecturer
Stroke Research
Mental Health and Neurosciences
School of Medicine
Queen's Medical Centre
University of Nottingham
Nottingham, NG7 2UH

Dear Dr Fisher

Ethics Reference No: FMHS 378-1021 **– please always quote**	
Study Title: The National Clinical Audit Program: An improvement tool for community stroke rehabilitation ?	
Chief Investigator/Supervisor: Dr Rebecca Fisher, Stroke Association Senior Lecturer, Mental Health and Neurosciences, School of Medicine	
Lead Investigators/student: Elizabeth Dickinson, PhD Student, School of Medicine	
Other Key investigators: Professor Martin James, Stroke Consultant, Academic Department of Healthcare for Older People, Royal Devon and Exeter NHS Foundation Trust, Professor Sarah Lewis, Medical Statistics, Epidemiology and Public Health, Dr Niki Chouliara, Research Fellow, School of Medicine	
Proposed Start Date: 01/12/2021	**Proposed End Date:** 30/11/2022

Thank you for submitting the above application, which was considered at a sub-committee meeting on 03 November 2021. The following documents were received:

- FMHS REC Application form and supporting documents version 1.0: 22/10/2021

These have been reviewed and are satisfactory and the project is given a favourable ethics opinion.

A favourable ethics opinion is given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

pp

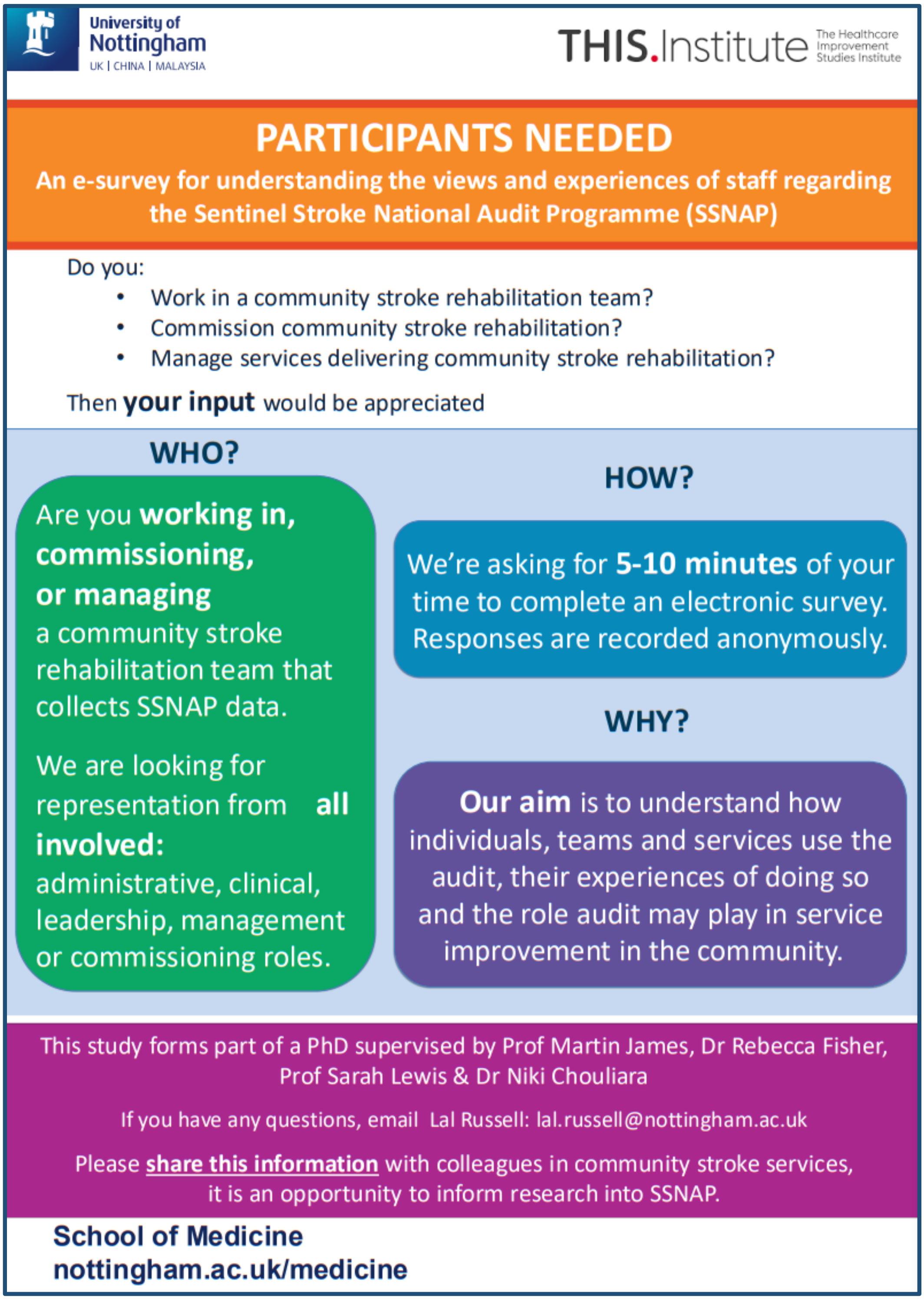
Dr John Williams, Associate Professor in Anaesthesia and Pain Medicine
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix 4-2: Checklist for Reporting Results of Internet E-Surveys

Category	Item	Details or section no.
Design	Describe target population, sample frame	See section 4.2.2 and 4.2.3
Processes	Institutional approval	Appendix 4-1: Faculty ethics approval
	Informed consent	Appendix 4-4: Participant Information sheet
	Data protection	No personal information collected
Development	Development and testing	See section 4.2.2
Recruitment	Open or closed	Open
	Mode of contact	See section 4.2.3
	Advertising	Appendix 4-3: Survey advert
Administration	Web or email	Automatic capture from Jisc Online™ web platform
	Context	Potential participants directed to specific survey portal
	Mandatory / voluntary	Voluntary survey. However, all questions mandated for submission.
	Incentives	No incentives offered
	Date / Time	01.12.2021 to 01.04.2022
	Randomisation	No randomisation, all items presented in standard order
	Adaptive questioning	Yes. If participants reported receiving audit feedback (item 14) 4 additional items were displayed. If participants selected “other” from categorical responses (items 6, 10, 13a, 14a, 15a & 16a) free text responses were mandated.
	Number of items	18 items (first item participant consent) & 7 sub items
	Number of screens	5 potential pages of survey items
	Completeness check	All items mandated
	Review step	Participants able to use back / forwards buttons to review and update responses prior to submission.

Response rate	Unique visitor site	Unique visitor numbers not recorded
	View rate	3300 views in total (may include duplicate views by same individual)
	Participation rate	There were 3004 visits to 1st page alone (information sheet). An additional 86 progressed to page 2, and 4 to the final page without submitting a completed survey. 206 submitted completed surveys.
	Completion rate	206 /(86+4+206) x 100 = 70%
Multiple entries	Cookies	Not used
	IP check	Not used
	Log file analysis	Not used
	Registration	Not used
Analysis	Handling of incomplete surveys	Not applicable – all questions mandated
	Atypical timestamps	Not used
	Statistical correction	No adjustments or weighting of scores
Eysenbach, G., 2004. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). Journal of medical Internet research, 6(3), p.e34.		

Appendix 4-3: Survey Advert



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THIS.Institute The Healthcare Improvement Studies Institute

PARTICIPANTS NEEDED

An e-survey for understanding the views and experiences of staff regarding the Sentinel Stroke National Audit Programme (SSNAP)

Do you:

- Work in a community stroke rehabilitation team?
- Commission community stroke rehabilitation?
- Manage services delivering community stroke rehabilitation?

Then **your input** would be appreciated

WHO?

Are you **working in, commissioning, or managing** a community stroke rehabilitation team that collects SSNAP data.

We are looking for representation from **all involved:** administrative, clinical, leadership, management or commissioning roles.

HOW?

We're asking for **5-10 minutes** of your time to complete an electronic survey. Responses are recorded anonymously.

WHY?

Our aim is to understand how individuals, teams and services use the audit, their experiences of doing so and the role audit may play in service improvement in the community.

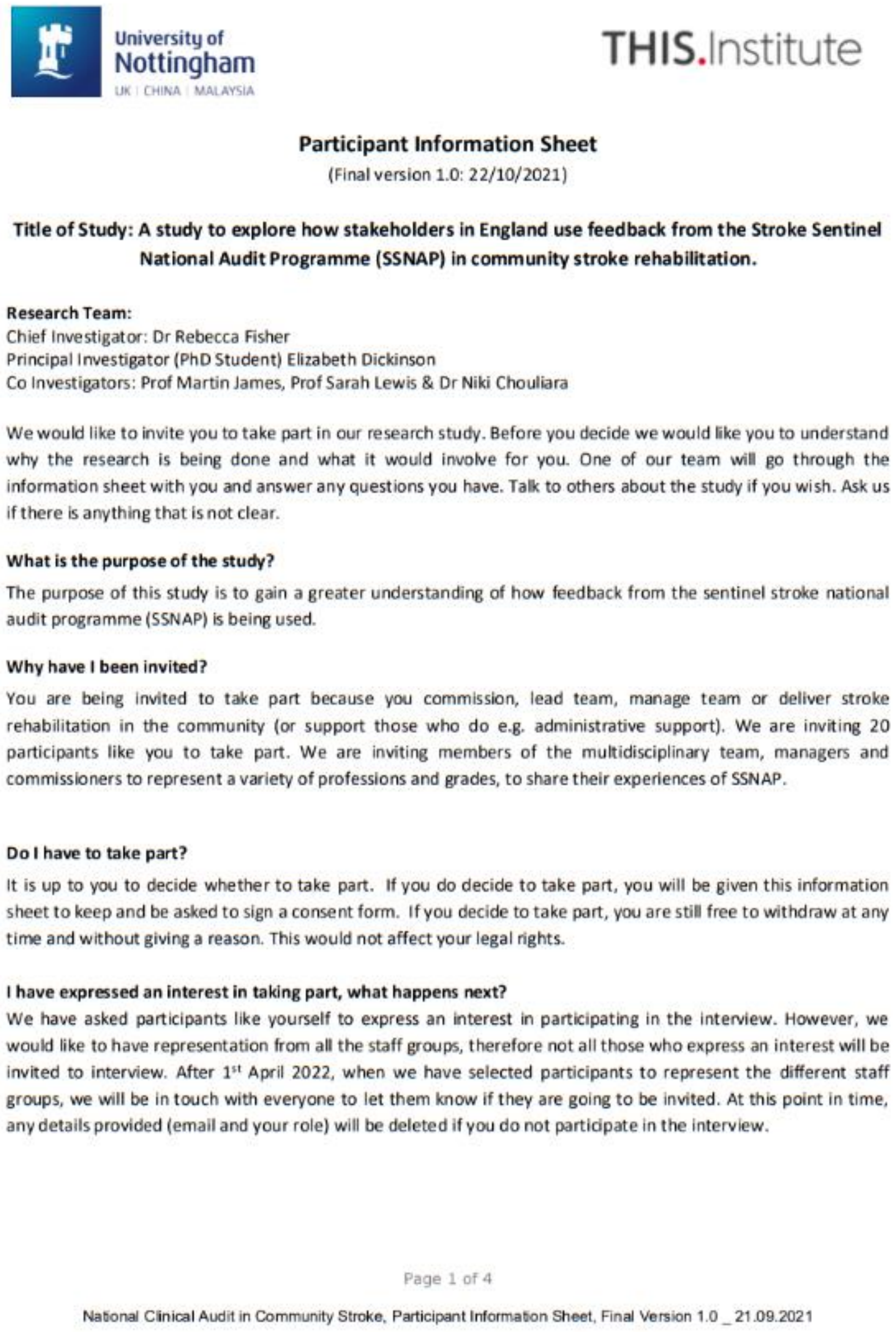
This study forms part of a PhD supervised by Prof Martin James, Dr Rebecca Fisher, Prof Sarah Lewis & Dr Niki Chouliara

If you have any questions, email Lal Russell: lal.russell@nottingham.ac.uk

Please **share this information** with colleagues in community stroke services, it is an opportunity to inform research into SSNAP.

School of Medicine
nottingham.ac.uk/medicine

Appendix 4-4: Participant Information Sheet



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Participant Information Sheet

(Final version 1.0: 22/10/2021)

Title of Study: A study to explore how stakeholders in England use feedback from the Stroke Sentinel National Audit Programme (SSNAP) in community stroke rehabilitation.

Research Team:
Chief Investigator: Dr Rebecca Fisher
Principal Investigator (PhD Student) Elizabeth Dickinson
Co Investigators: Prof Martin James, Prof Sarah Lewis & Dr Niki Chouliara

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of this study is to gain a greater understanding of how feedback from the sentinel stroke national audit programme (SSNAP) is being used.

Why have I been invited?

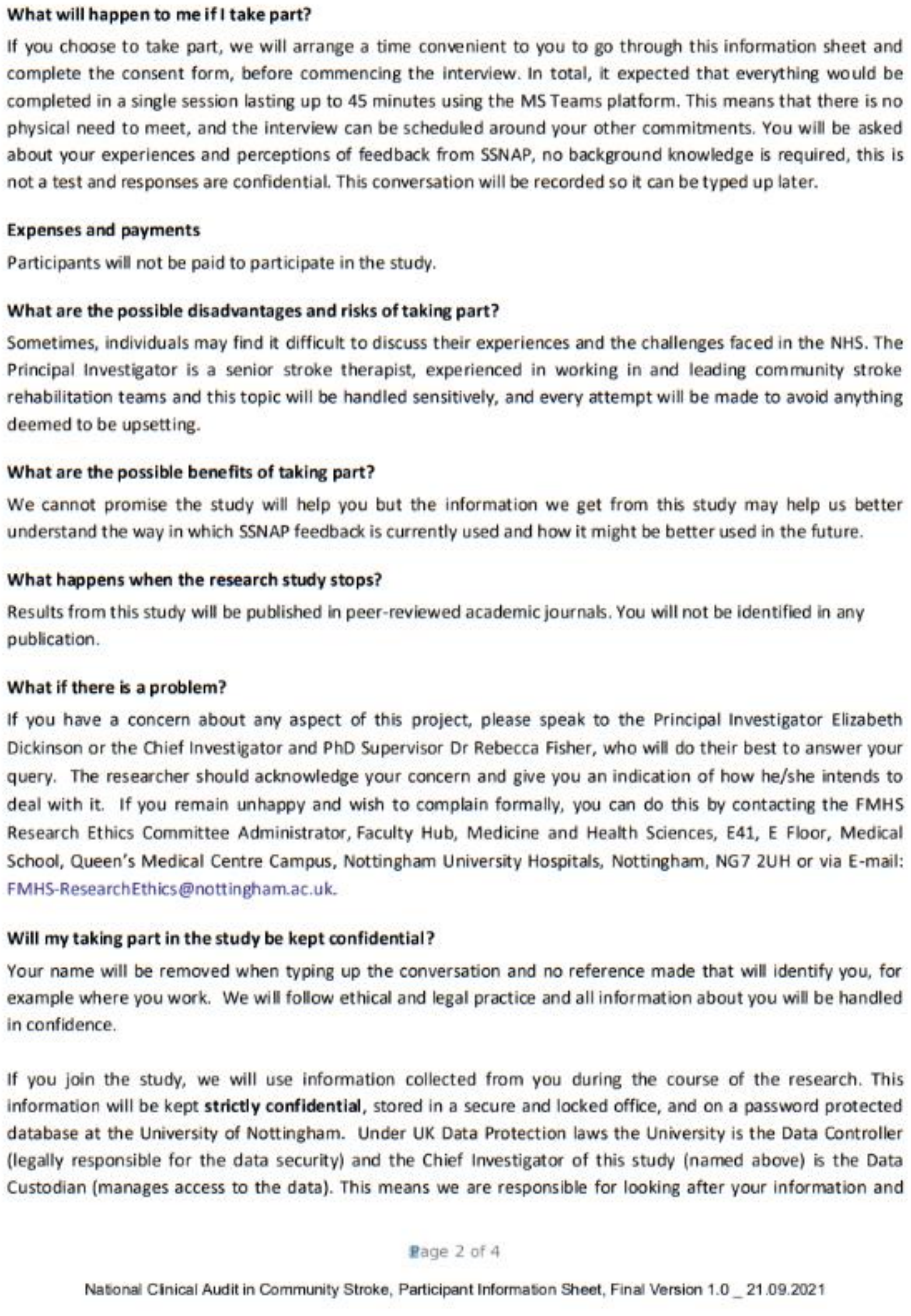
You are being invited to take part because you commission, lead team, manage team or deliver stroke rehabilitation in the community (or support those who do e.g. administrative support). We are inviting 20 participants like you to take part. We are inviting members of the multidisciplinary team, managers and commissioners to represent a variety of professions and grades, to share their experiences of SSNAP.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

I have expressed an interest in taking part, what happens next?

We have asked participants like yourself to express an interest in participating in the interview. However, we would like to have representation from all the staff groups, therefore not all those who express an interest will be invited to interview. After 1st April 2022, when we have selected participants to represent the different staff groups, we will be in touch with everyone to let them know if they are going to be invited. At this point in time, any details provided (email and your role) will be deleted if you do not participate in the interview.



What will happen to me if I take part?

If you choose to take part, we will arrange a time convenient to you to go through this information sheet and complete the consent form, before commencing the interview. In total, it expected that everything would be completed in a single session lasting up to 45 minutes using the MS Teams platform. This means that there is no physical need to meet, and the interview can be scheduled around your other commitments. You will be asked about your experiences and perceptions of feedback from SSNAP, no background knowledge is required, this is not a test and responses are confidential. This conversation will be recorded so it can be typed up later.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

Sometimes, individuals may find it difficult to discuss their experiences and the challenges faced in the NHS. The Principal Investigator is a senior stroke therapist, experienced in working in and leading community stroke rehabilitation teams and this topic will be handled sensitively, and every attempt will be made to avoid anything deemed to be upsetting.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help us better understand the way in which SSNAP feedback is currently used and how it might be better used in the future.

What happens when the research study stops?

Results from this study will be published in peer-reviewed academic journals. You will not be identified in any publication.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the Principal Investigator Elizabeth Dickinson or the Chief Investigator and PhD Supervisor Dr Rebecca Fisher, who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how he/she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.

Will my taking part in the study be kept confidential?

Your name will be removed when typing up the conversation and no reference made that will identify you, for example where you work. We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Recordings may be transcribed by a transcription company who will have a confidentiality agreement in place with the University. All personal identifiers will be removed from transcriptions and each participant will be allocated identifying code and a pseudonym to be used in the report. Audio files will be stored securely on The University of Nottingham One-Drive, until transcription is complete. Anonymised electronic copies of transcripts will be stored in the same way.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the research study?

Results from this study will be published in peer-reviewed academic journals. You will not be identified in any publication. This study forms part of a PhD and will be written up in the associated doctoral thesis.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by a PhD Fellowship from THIS Institute (https://www.thisinstitute.cam.ac.uk)

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Nottingham Research Ethics Committee.

Further information and contact details

Principal Investigator:
Elizabeth Dickinson
THIS Institute PhD Fellow
Mental Health & Clinical Neurosciences
School of Medicine
University of Nottingham
Email: Elizabeth.dickinson@nottingham.ac.uk

Chief investigator:
Dr Rebecca Fisher,
Stroke Association Senior Lecturer,
Mental Health & Clinical Neurosciences
School of Medicine
University of Nottingham
Email: Rebecca.fisher@nottingham.ac.uk

Appendix 4-5: Refinement of CPT1 using quantitative and qualitative data

1. Individual perception of audit influences motivation to engage			**Supporting data**
Context	**Mechanism**	**Outcome**	[1]60 % of participants reported they perceived the audit a worthwhile use of their time **(Item-9)**. [2]Participants alluded to a lack of organisational support with "*no senior management buy-in*" **[P3:Team Lead-C]**, which influenced their motivation to engage. [2] A perceived "*lack of leadership support*" and "*organisational priorities lying elsewhere* [acute services]" were described **[P153:MDT5+]**. [3]Qualitative findings suggest participants were frustrated with *"no funding available*" **[numerous]** or "*lack of trust support*" for service improvement **[P29:MDT5+]**. [3]"*It's no point collecting data and not taking it forward for service improvement*" **[P3:Team Lead-C]** [3]*"Difficult to get motivated or motivate the team if we know there is no funding to make changes"* **[P178:Team Lead-C]** [3]58% agreed it benefitted their service and 55% agreed it benefitted their patients **(Item-9)**. [4]Negative experiences of the use of audit data were reported as demotivating for participants: *"It can feel like the data and report is a stick to beat us by not an enabler for conversations and improvement"* **[P26:Team Lead-NC]** [5]86% of participants reported accessing resources to support their audit activities **(Item-10)**. [6]All participants reported engaging in at least one audit activity **(Item-6)**. Participants reported these factors influenced the likelihood of their engagement in varying degrees**.** Therefore the outcome of the refined theory uses likelihood as a scale rather than "will not" as an absolute.
If individuals perceive audit to be a worthwhile activity	Then they are motivated by the potential benefits	Individuals will engage with the audit and access resources	
Refined IPT1			
If individuals perceive the audit to be a worthwhile activity[1] because there is: - Organisational support (Leadership[2] or financial[3]) - Experience of constructive use of data[4]	They will access the available audit resources[5] provided by SSNAP because they are motivated by the potential benefits[3]	Individuals are more likely to engage with the audit[6]	

Appendix 4-6: Refinement of CPT2 using quantitative and qualitative data

<table>
<tr>
<th colspan="3">**2.** If information regarding the audit is available, individuals are empowered to participate</th>
<th>Supporting data</th>
</tr>
<tr>
<th>Context</th>
<th>Mechanism</th>
<th>Outcome</th>
<td rowspan="4">[1]86% of participants reported accessing resources to support their audit activities **(Item-10)**.
Participants reported insight into the audit purpose and their role therein:
[2]96% understood the purpose of the audit **(Item-4)**
[2]90% understood their role in the audit **(Item-5)**
[2]91% understood the activities needed for the audit **(Item-5)**
[3]88% understood how to complete these activities **(Item-5)**
[4]Qualitative findings highlighted contexts in which participants struggled to prioritise audit activity and therefore complete audit tasks **(Item-7a).** These included contexts where individual had split roles and multiple responsibilities.
[4]*“This is one of many areas I am responsible for I can't always ring fence time”* **[P196:Commissioner]**
[4]*“We do not have time to do our job let alone this”* **[P145:Team Lead-C]**
[4]“*SSNAP is not a recognised (time given) part of my role, therefore it is in addition.”* **[P32:Team Lead-NC]**
[5]47% of participants reported they were unable to prioritise audit when needed, which influenced their ability to participate **(Item7)**.
[6]Only 31% of participants described being able to fully complete audit activities **(Item-8)**.
Qualitative findings suggest that despite having access to information, if participants did not have audit recognised as part of their role, they were unable to prioritise audit activities against competing demands.
Participants reported these factors influenced their ability to complete audit tasks in varying degrees, rather than absolutely.
[6]“When I’m busy patient discharge takes priority, and I can’t get as much audit done as I’d like” **[P180:MDT<5]**
[6]Participants reported not having always having sufficient time to “*complete as fully as we would like, so our reports are incomplete*” **[P72:Manager-S]**.</td>
</tr>
<tr>
<td>If the purpose and process of audit is explained and roles articulated</td>
<td>Then individuals have insight into what is expected of them and are empowered to participate</td>
<td>Individuals will complete the audit tasks appropriate for their role</td>
</tr>
<tr>
<th colspan="3">Refined IPT2</th>
</tr>
<tr>
<td>If individuals access audit information provided by SSNAP[1]
and
If individuals have audit recognised as part of their role[4]</td>
<td>Then they will use information resources to gain insight into audit and what is expected of them[2] and are empowered to participate[3].
Then individuals have allocated time for audit activities and are enabled to prioritise audit against competing demands[5]</td>
<td>Individuals are more likely to complete the audit tasks associated with their role[6]</td>
</tr>
</table>

Appendix 4-7: Refinement of CPT3 using quantitative and qualitative data

3. If stakeholders have resources to support participation, data will be inputted completely			**Supporting data**
Context	**Mechanism**	**Outcome**	[1]91% reported they had equipment required to complete activities e.g. computers **(Item-7)**. [2]However only 54% reported data as complete for all stroke patients seen by their service **(Item-11)**. A context where audit was perceived as burdensome is alluded to in qualitative findings. "*There is an admin burden on teams*" **[P9:Manager-S]**. The burden described commonly related to the electronic platform, therefore the context was refocused to explore this specifically. Participants described: [3]"*being unable to navigate the database effectively*" **[P72:Manager-S]**. [4]"*Incompatible IT systems*" **[P59:Admin]** resulting in "*wasted effort in duplicating tasks*" **[P109:Manager-S]**. [5]A lack of agency regarding the data they submit "*It is time consuming. If you are allowed to submit you should be allowed to amend it*" **[P15:Admin]**. [6]Frustrations with being "*at the end of chain*" in terms of their "*dependence on the acute team to have completed their part*" **[P38:MDT<5]**. [7]Particpants described their frustrations with "*a huge amount of time chasing the acute teams to input their data*" **[P204:Admin]**. Participants described being overwhelmed by these tasks, resulting in a failure to submit records for all patients on the caseload. [8]"*Unlocking and transferring records is such an arduous task…some patients just never get done*" **[P54:Admin]**.
If resources such as laptops are available to complete audit activities[1]	Then individuals are enabled by the resources and motivated by the perceived value placed on the audit by their organisation	Data inputted will be complete[2]	
Refined IPT3			
If individuals encounter challenges related to the online SSNAP platform such as: Difficulty in navigating the platform[3] Duplicate tasks[4] A lack of agency over data[5] Dependency on earlier teams[6]	Then they may become frustrated and overwhelmed[7], unable to overcome obstacles	Data is less likely to be complete for all patients on the caseload[8]	

Appendix 4-8: Refinement of CPT4 using quantitative and qualitative data

4. If data is perceived as accurate then it will be used to inform quality improvement			**Supporting data**
Context	**Mechanism**	**Outcome**	[1]Only 26% of participants perceived data inputted accurately reflected services delivered **(Item-11)**. In addition to concerns regarding the incomplete nature of the data already highlighted, participants reported a number of factors that undermine their confidence in the accuracy of the data. When asked: [2]28% of participants perceived the report accurately reflected the changes made by patients **(Item-14d)** [2]Participants reported the measures used were *"not sensitive to this patient group, complexity or needs"* **[P85:Commissioner]** and that they failed to "*show the real changes that teams make*" **[P170:MDT5+]**. [3]35% perceived the report accurately reflected rehabilitation delivered by their service **(Item-14d)**. [3]Participants described the report as failing to reflect the service, not only the interventions *"It doesn't capture the full scope of a service provided*" **[P63:Team Lead-C]**, but also because it is "*artificially ended in SSNAP in order to complete the 6 month*" **[P48:Team Lead-NC]** data *"fails to capture the entirety of a service"* **[P13:Team Lead-C].** [4]In qualitative findings, participants alluded to mistrust regarding the reporting practices of other teams, which may explain only 18% of participants agreeing that national report reflect rehabilitation delivered by other services **(Item-14d)**. [4]Concerns were highlighted such as "*huge discrepancies between teams* [in] *how data is recorded, reported and interpreted*" **[P37:Team Lead-C]** which were perceived to make it "*difficult to benchmark with other trusts*" **[P53:Team Lead-C].**
If data contained in feedback report is perceived as accurate	Then the report will be perceived as trustworthy, and individuals will have the confidence to act upon it	Audit feedback is used to inform quality improvement	
Refined IPT4			
If data contained in feedback report is not perceived as accurate[1] because stakeholders: Perceive data fails to capture changes made by patients[2] Perceive data fails to reflect services delivered[3] Perceive there to be variations in reporting practices[4]	Then the report will not be perceived as trustworthy[5], and individuals will not have the confidence to use it to make comparisons[6] or plan service improvements[7]	Audit feedback reports are less likely to inform quality improvement[8]	

Continued on next page.

			[4]These were attributed to a lack of shared understanding regarding a variety of aspects e.g. "*What does a seven-day service mean – full service, or assessment only? I'm not sure the same thing is always being measured across services"* **[P75:MDT5+]**. [5]44% of participants perceived the national report as trustworthy **(Item-14d)**. [6]However, 57% of participants reported they were aware of the report being used for comparison **(Item-15)**. This suggests that despite the limitations identified, over half of participants perceive it to have utility. Participants alluded their doubts regarding accuracy resulting in a reduced [6]confidence to act on the report, therefore less likely to use it for comparison[7]. *"If this is replicated across the country, I'm not sure what conclusions you can draw from the report"* **[P35:Team Lead-NC]** [7]39% of participants were aware of the report being used to inform service improvement **(Item-16)**. [8]Participants described being unable to use their data for quality improvement because they lacked confidence in it: "*Our reports are incomplete so we can't use the data*" **[P72:Manager-S]** or delays in receiving feedback "*means we can't use it to develop our service because it's out of date by the time we get it*" **[P123:Team Lead-C].**

Appendix 5-1: Consolidated criteria for reporting qualitative studies (COREQ)

No. Item	Guide questions/description	Reported in section
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author conducted the interview?	2.5
2. Credentials	What were the researcher's credentials?	2.5
3. Occupation	What was their occupation at the time of the study?	2.5
4. Gender	Was the researcher male or female?	2.5
5. Experience and training	What experience or training did the researcher have?	2.5
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	5.2.5
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g., personal goals, reasons for doing the research	2.5 & 7.4
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	2.5
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study?	2.4 & 5.2.1
Participant selection		
10. Sampling	How were participants selected?	5.2.3
11. Method of approach	How were participants approached?	5.2.3
12. Sample size	How many participants were in the study?	5.2.3
13. Non-participation	How many people refused to participate or dropped out? Reasons?	5.2.3
Setting		
14. Setting of data collection	Where was the data collected?	5.2.4
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	5.2.4
16. Description of sample	What are the important characteristics of the sample?	5.3.1
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5.2.2 & Appendix 5-3
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Visual recording	Did the research use audio or visual recording to collect the data?	5.2.4
20. Field notes	Were field notes made during interview?	Yes
21. Duration	What was the duration of the interviews?	5.3
22. Data saturation	Was data saturation discussed?	NA

23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	5.2.5
25. Description of the coding tree	Did authors provide a description of the coding tree?	5.2.5
26. Derivation of themes	Were themes identified in advance or derived from the data?	5.2.5
27. Software	What software, if applicable, was used to manage the data?	5.2.4
28. Participant checking	Did participants provide feedback on the findings?	NA
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings?	5.3.3-5.3.6
30. Data and findings consistent	Was there consistency between the data presented and the findings?	5.3.3-5.3.6
31. Clarity of major themes	Were major themes clearly presented in the findings?	5.3.3-5.3.6
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	NA

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007.19(6):349 – 357.

Appendix 5-2: Participant Information Sheet

Participant Information Sheet

(Final version 1.0: 22/10/2021)

Title of Study: A study to explore how stakeholders in England use feedback from the Stroke Sentinel National Audit Programme (SSNAP) in community stroke rehabilitation.

Research Team:
Chief Investigator: Dr Rebecca Fisher
Principal Investigator (PhD Student) Elizabeth Dickinson
Co Investigators: Prof Martin James, Prof Sarah Lewis & Dr Niki Chouliara

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of this study is to gain a greater understanding of how feedback from the sentinel stroke national audit programme (SSNAP) is being used.

Why have I been invited?

You are being invited to take part because you commission, lead team, manage team or deliver stroke rehabilitation in the community (or support those who do e.g. administrative support). We are inviting 20 participants like you to take part. We are inviting members of the multidisciplinary team, managers and commissioners to represent a variety of professions and grades, to share their experiences of SSNAP.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

I have expressed an interest in taking part, what happens next?

We have asked participants like yourself to express an interest in participating in the interview. However, we would like to have representation from all the staff groups, therefore not all those who express an interest will be invited to interview. After 1st April 2022, when we have selected participants to represent the different staff groups, we will be in touch with everyone to let them know if they are going to be invited. At this point in time, any details provided (email and your role) will be deleted if you do not participate in the interview.

What will happen to me if I take part?

If you choose to take part, we will arrange a time convenient to you to go through this information sheet and complete the consent form, before commencing the interview. In total, it expected that everything would be completed in a single session lasting up to 45 minutes using the MS Teams platform. This means that there is no physical need to meet, and the interview can be scheduled around your other commitments. You will be asked about your experiences and perceptions of feedback from SSNAP, no background knowledge is required, this is not a test and responses are confidential. This conversation will be recorded so it can be typed up later.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

Sometimes, individuals may find it difficult to discuss their experiences and the challenges faced in the NHS. The Principal Investigator is a senior stroke therapist, experienced in working in and leading community stroke rehabilitation teams and this topic will be handled sensitively, and every attempt will be made to avoid anything deemed to be upsetting.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help us better understand the way in which SSNAP feedback is currently used and how it might be better used in the future.

What happens when the research study stops?

Results from this study will be published in peer-reviewed academic journals. You will not be identified in any publication.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the Principal Investigator Elizabeth Dickinson or the Chief Investigator and PhD Supervisor Dr Rebecca Fisher, who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how he/she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.

Will my taking part in the study be kept confidential?

Your name will be removed when typing up the conversation and no reference made that will identify you, for example where you work. We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Recordings may be transcribed by a transcription company who will have a confidentiality agreement in place with the University. All personal identifiers will be removed from transcriptions and each participant will be allocated identifying code and a pseudonym to be used in the report. Audio files will be stored securely on The University of Nottingham One-Drive, until transcription is complete. Anonymised electronic copies of transcripts will be stored in the same way.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the research study?

Results from this study will be published in peer-reviewed academic journals. You will not be identified in any publication. This study forms part of a PhD and will be written up in the associated doctoral thesis.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by a PhD Fellowship from THIS Institute (https://www.thisinstitute.cam.ac.uk)

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Nottingham Research Ethics Committee.

Further information and contact details

Principal Investigator:
Elizabeth Dickinson
THIS Institute PhD Fellow
Mental Health & Clinical Neurosciences
School of Medicine
University of Nottingham
Email: Elizabeth.dickinson@nottingham.ac.uk

Chief investigator:
Dr Rebecca Fisher,
Stroke Association Senior Lecturer,
Mental Health & Clinical Neurosciences
School of Medicine
University of Nottingham
Email: Rebecca.fisher@nottingham.ac.uk

Appendix 5-3: Semi-structured Interview Schedule

Opening:

Thank you for agreeing to take part in this conversation and completing the online consent form.

I am keen to hear from you about your experiences with the Stroke Sentinel National Audit Programme, or SSNAP.

Before we start, I need to confirm:

- You are happy to have the interview recorded
- This is confidential, and nothing shared will go any further no one else sees the recording. Once typed up all names or identifying information such as hospital name are removed.
- There are no right or wrong answers, I'm interested to hear about your experiences and thoughts. I am happy to be challenged on any statements made.
- Do you have any questions before we start? If anything comes to mind during our conversation, feel free to ask for clarification.

Introduction

This study focusses on how SSNAP is used in the community setting, and what its role may be in the quality improvement of stroke rehabilitation services in the community.

Following a review of the available evidence and using feedback from online surveys, there are a number of theories that I would like to explore with you and understand how they compare with your experiences.

<u>Question 1</u>

Opening: What activities do you undertake as part of SSNAP, how are you involved in the audit?

Question		**Follow - up**
• Do you feel that SSNAP is valued within your organisation? • Is SSNAP a worthwhile activity – is the effort put in worth the benefits experienced?		• What makes you say that? • What do you see or experience that makes you think that? • How does that make you (or colleagues) feel? • Does this change how you feel about participating in the audit? • Does this influence how you engage with audit activities? (e.g. how motivated or enthusiastic you are) • Do you have any examples? **Confirmation** • Does what I have said match your experiences? • Have I understood / summarised what you meant correctly?
• Do you feel there is a benefit to being involved in SSNAP? • Has anything changed as a result of SSNAP feedback? (For you, your patients or your service? positive or negative) • Do you feel there is support for audit within your organisation? (Prompt to separate leadership / financial) • Do you feel there in anyone in leadership who takes an interest in SSNAP? • Does anyone ask to see your SSNAP feedback?		
Introduce IPT (There is an idea that...)	If individuals perceive SSNAP as a worthwhile activity, they are more likely to engage with the audit	• Does this match your experiences? • Is there anything we haven’t talked about that you think influences this?

Question 2

Opening: There were suggestions from the survey that individuals sometimes struggle to complete SSNAP activities for a variety of reasons. Two common reasons that were suggested were a lack of ring-fenced time (not having it recognised as part of their job) and a lack of information to support their participation. I'd like to talk about your experiences.

Question		Follow - up
• Do you have audit recognised as part of your role? • What about other members of your team? • Do you feel you have access to sufficient resources to support you to complete the audit activities required for your role?		• Is this formally or informally? • If not, why not? • What is missing / would help you? • What makes you say that? • Is this something you recognise from your experiences? • Do you see or hear colleagues struggling with this? • How does that make you (or colleagues) feel? • Do you have any examples? **Confirmation** • Does what I have said match your experiences? • Have I understood / summarised what you meant correctly?
• Do you (or are you aware of others who) struggle to participate in the audit or complete audit activities fully? • Why this is a challenge? • When there are competing demands on your time, what is the process of prioritisation? What is the impact for audit activities? • What would influence your ability to prioritise or complete audit tasks?		
Introduce IPT (There is an idea that...)	If individuals have access to information to support participation and audit is recognised as part of their role, they are more likely to complete audit tasks	• Does this match your experiences or those of colleagues? • Is there anything we haven't talked about that you think influences this?

Question 3

Opening: There have also been suggestions that the SSNAP online platform may also present challenges to individuals

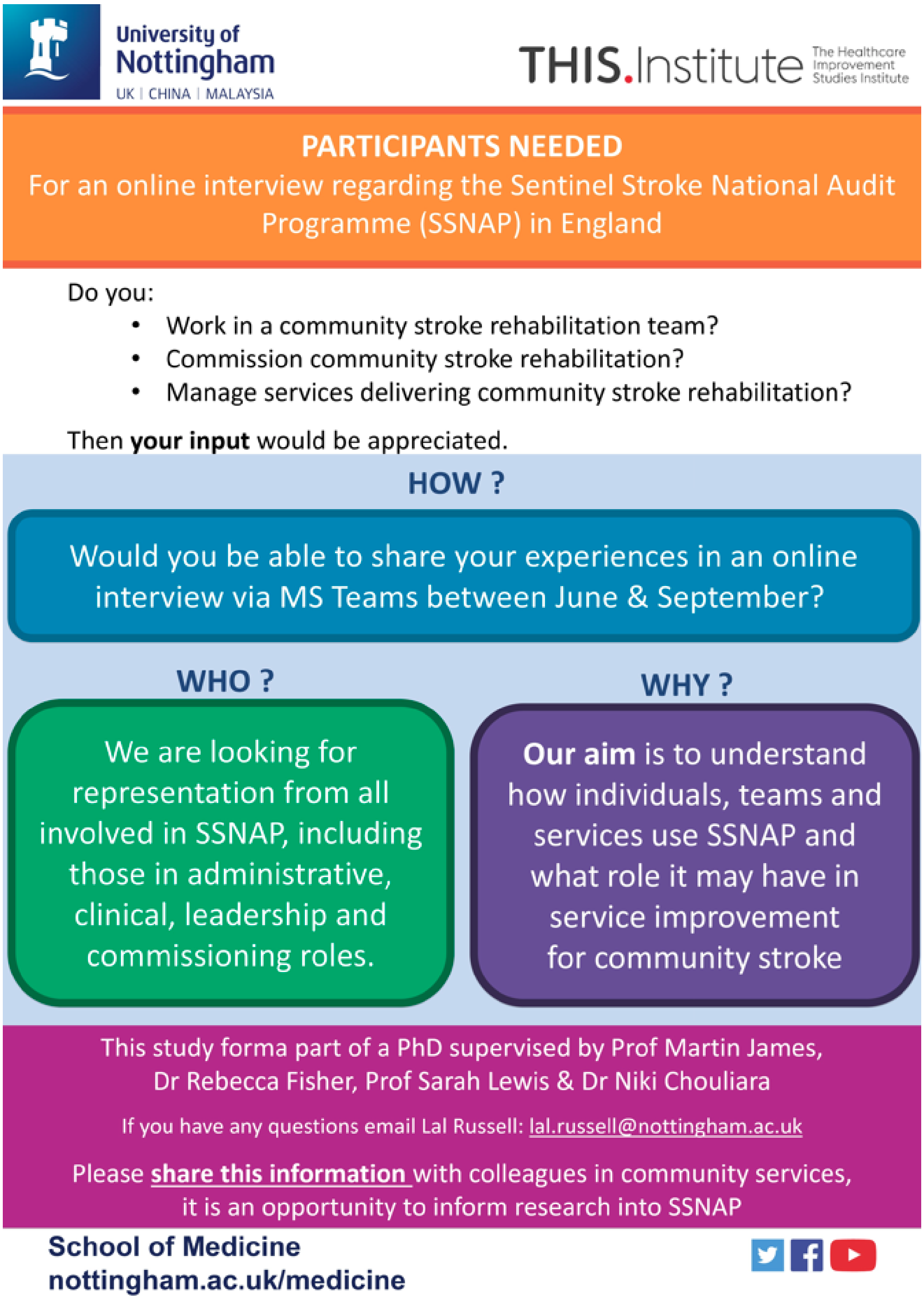
Question		Follow - up
• Have you experienced, observed others, or heard reports of people struggling with the online platform?		• Do you have any examples? • What are the consequences of these challenges? • Is this a common occurrence? • Is this something you recognise from your experiences? • Do you see or hear colleagues struggling with this? • How does that make you (or colleagues) feel? **Confirmation** • Does what I have said match your experiences? • Have I understood / summarised what you meant correctly?
• Do challenges with the online platform prevent data being uploaded or tasks being completed? • What tasks aren't completed / proportion of patients without data submitted? • What specifically is it about the platform ? (Navigation, tedium / duplicity of tasks, agency over data, issues with earlier teams not locking or transferring)		
Introduce IPT (There is an idea that...)	If individuals encounter additional challenges related to the IT platform, then data submitted may be incomplete and not reflect the whole caseload	• Does this match your experiences or those of colleagues? • Is there anything we haven't talked about that you think influences this?

<u>Question 4</u>

Opening: The final theory explores what influences the use of feedback reports.

<table>
<tr><th colspan="2">Question</th><th>Follow - up</th></tr>
<tr><td colspan="2">• Responses from the survey raised concerns that data collected may not reflect the rehabilitation delivered by teams.
• There were also suggestions that it may fail to capture the changes made by stroke patients in the community setting
• Do you think SSNAP currently provides an opportunity to capture what your service does and what you think is important?
• Do you feel the data contained in the feedback report is an accurate representation of the rehabilitation delivered by other teams? (if not, why not?)
• There have been suggestions that some teams may not be 100% accurate in what they report and there may be instances where they use the opportunity to enhance their performance <i>on paper</i></td><td rowspan="2">• Is that a fair criticism?
• Is there any truth in that?
• What makes you say that?
• What do you see or experience that makes you think that?
• What would you change in the audit?
• What do you think causes that?
• How does that make you (or colleagues) feel?
• Does this change how you feel about using the data?
• Do you have any examples?
Confirmation
• Does what I have said match your experiences?
• Have I understood / summarised what you meant correctly?</td></tr>
<tr><td colspan="2">• Do you use feedback report to make comparisons with other teams? (If not, why not?)
• Do you use data for other quality improvement purposes such as building business cases? (If not, why not?)
• Are you confident in using the data? (Do you trust it is accurate?)</td></tr>
<tr><td>Introduce IPT
(There is an idea that...)</td><td>Teams may be likely to use the feedback reports (e.g. to make comparisons between themselves and other services) if they don’t trust the data is accurate.</td><td>• Does this match your experiences?
• Is there anything you would add or change about this?</td></tr>
</table>

Appendix 5-4: Recruitment advert



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THIS.Institute The Healthcare Improvement Studies Institute

PARTICIPANTS NEEDED

For an online interview regarding the Sentinel Stroke National Audit Programme (SSNAP) in England

Do you:

- Work in a community stroke rehabilitation team?
- Commission community stroke rehabilitation?
- Manage services delivering community stroke rehabilitation?

Then **your input** would be appreciated.

HOW ?

Would you be able to share your experiences in an online interview via MS Teams between June & September?

WHO ?

We are looking for representation from all involved in SSNAP, including those in administrative, clinical, leadership and commissioning roles.

WHY ?

Our aim is to understand how individuals, teams and services use SSNAP and what role it may have in service improvement for community stroke

This study forma part of a PhD supervised by Prof Martin James, Dr Rebecca Fisher, Prof Sarah Lewis & Dr Niki Chouliara

If you have any questions email Lal Russell: lal.russell@nottingham.ac.uk

Please **share this information** with colleagues in community services, it is an opportunity to inform research into SSNAP

School of Medicine
nottingham.ac.uk/medicine

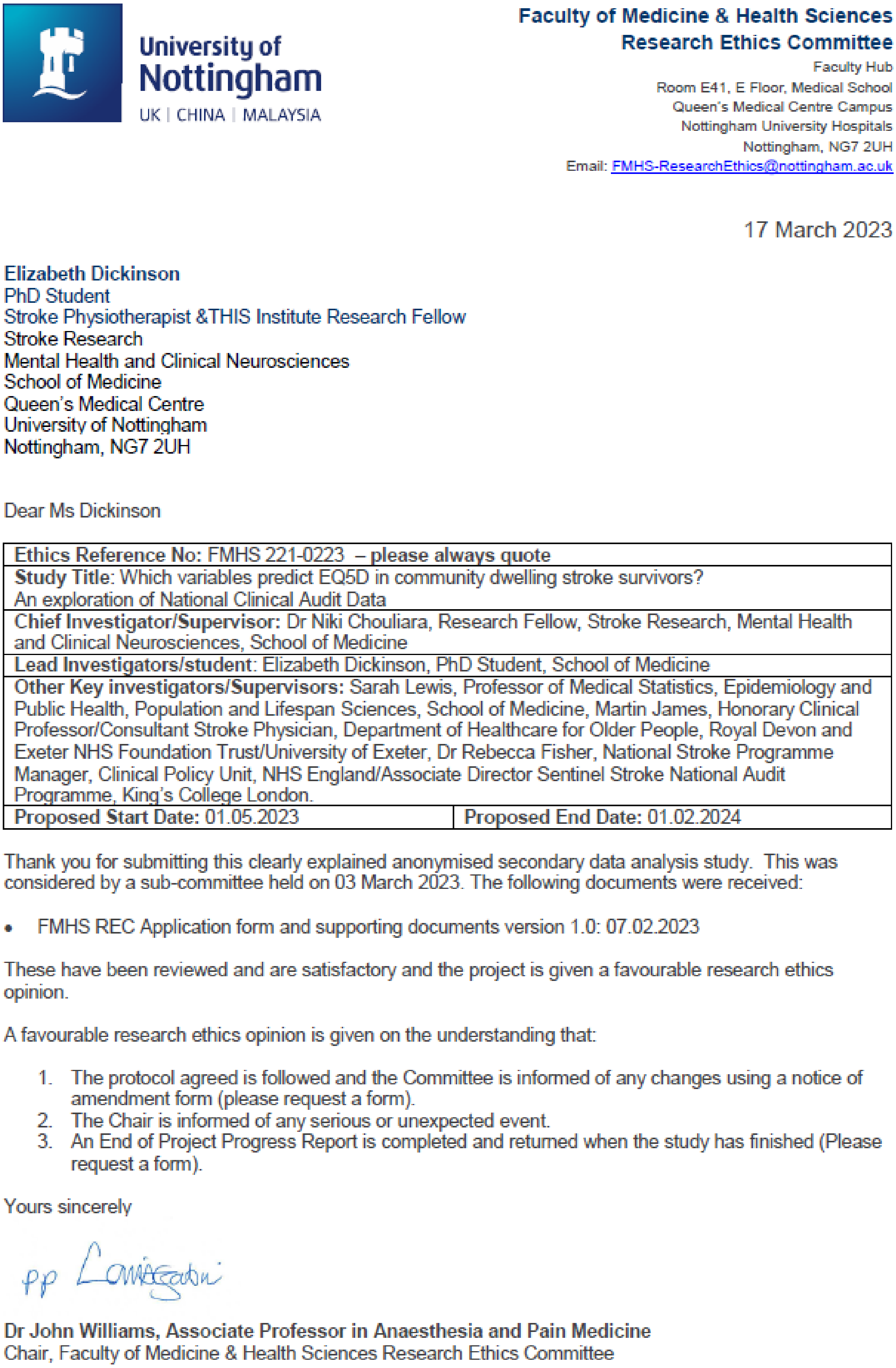
Appendix 6-1: STROBE Checklist

	Item	Recommendation	Section
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	NA
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	NA
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6.1
Objectives	3	State specific objectives, including any prespecified hypotheses	6.2
Methods			
Study design	4	Present key elements of study design early in the paper	6.3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6.3.1
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	6.3.1
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6.3.4
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6.3.3
Bias	9	Describe any efforts to address potential sources of bias	6.3.5
Study size	10	Explain how the study size was arrived at	6.3.1
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6.3.5
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	
		(*b*) Describe any methods used to examine subgroups and interactions	
		(*c*) Explain how missing data were addressed	
		(d) Describe any sensitivity analyses	

Results			
Participants	13	(a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6.4 & 6.5
		(b) Consider use of a flow diagram	
Descriptive data	14	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	6.4 & 6.5
		(b) Indicate number of participants with missing data for each variable of interest	
Outcome data	15	Report numbers of outcome events or summary measures	6.4 & 6.5
Main results	16	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g. 95% confidence interval). Make clear which confounders were adjusted for and why they were included	6.4 & 6.5
Other analyses	17	Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	6.4 & 6.5
Discussion			
Key results	18	Summarise key results with reference to study objectives	6.6
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	6.6.4
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	6.6.3
Generalisability	21	Discuss the generalisability (external validity) of the study results	6.6.3
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Preface

von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. 2007;147:573-577.

Appendix 6-2: University of Nottingham Ethics Approval



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Faculty of Medicine & Health Sciences
Research Ethics Committee
Faculty Hub
Room E41, E Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH
Email: FMHS-ResearchEthics@nottingham.ac.uk

17 March 2023

Elizabeth Dickinson
PhD Student
Stroke Physiotherapist &THIS Institute Research Fellow
Stroke Research
Mental Health and Clinical Neurosciences
School of Medicine
Queen's Medical Centre
University of Nottingham
Nottingham, NG7 2UH

Dear Ms Dickinson

Ethics Reference No: FMHS 221-0223 – **please always quote**	
Study Title: Which variables predict EQ5D in community dwelling stroke survivors? An exploration of National Clinical Audit Data	
Chief Investigator/Supervisor: Dr Niki Chouliara, Research Fellow, Stroke Research, Mental Health and Clinical Neurosciences, School of Medicine	
Lead Investigators/student: Elizabeth Dickinson, PhD Student, School of Medicine	
Other Key investigators/Supervisors: Sarah Lewis, Professor of Medical Statistics, Epidemiology and Public Health, Population and Lifespan Sciences, School of Medicine, Martin James, Honorary Clinical Professor/Consultant Stroke Physician, Department of Healthcare for Older People, Royal Devon and Exeter NHS Foundation Trust/University of Exeter, Dr Rebecca Fisher, National Stroke Programme Manager, Clinical Policy Unit, NHS England/Associate Director Sentinel Stroke National Audit Programme, King's College London.	
Proposed Start Date: 01.05.2023	**Proposed End Date:** 01.02.2024

Thank you for submitting this clearly explained anonymised secondary data analysis study. This was considered by a sub-committee held on 03 March 2023. The following documents were received:

- FMHS REC Application form and supporting documents version 1.0: 07.02.2023

These have been reviewed and are satisfactory and the project is given a favourable research ethics opinion.

A favourable research ethics opinion is given on the understanding that:

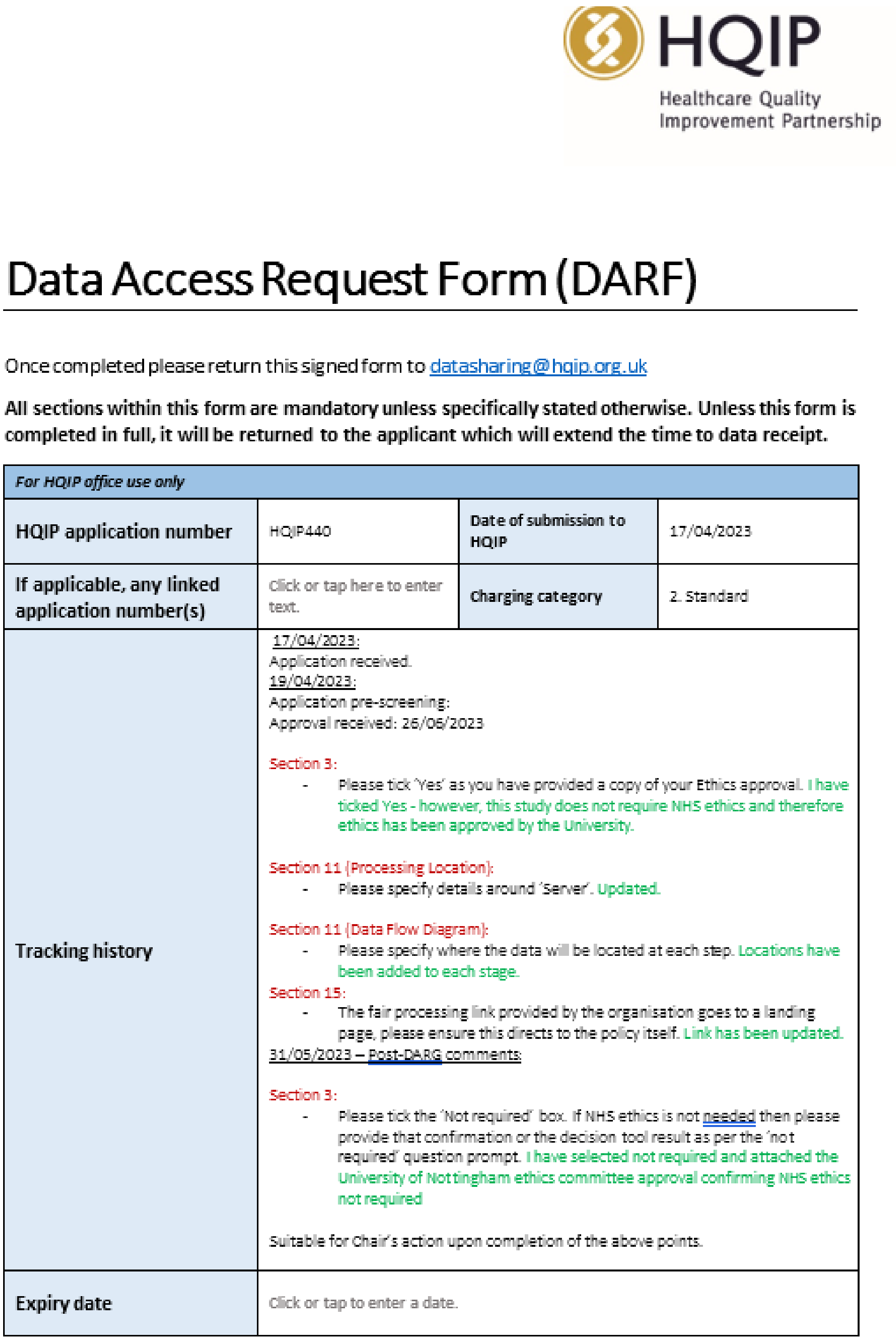
1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

pp

Dr John Williams, Associate Professor in Anaesthesia and Pain Medicine
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix 6-3: Excerpts of Data Access Request Form (Page 1/6)



HQIP
Healthcare Quality
Improvement Partnership

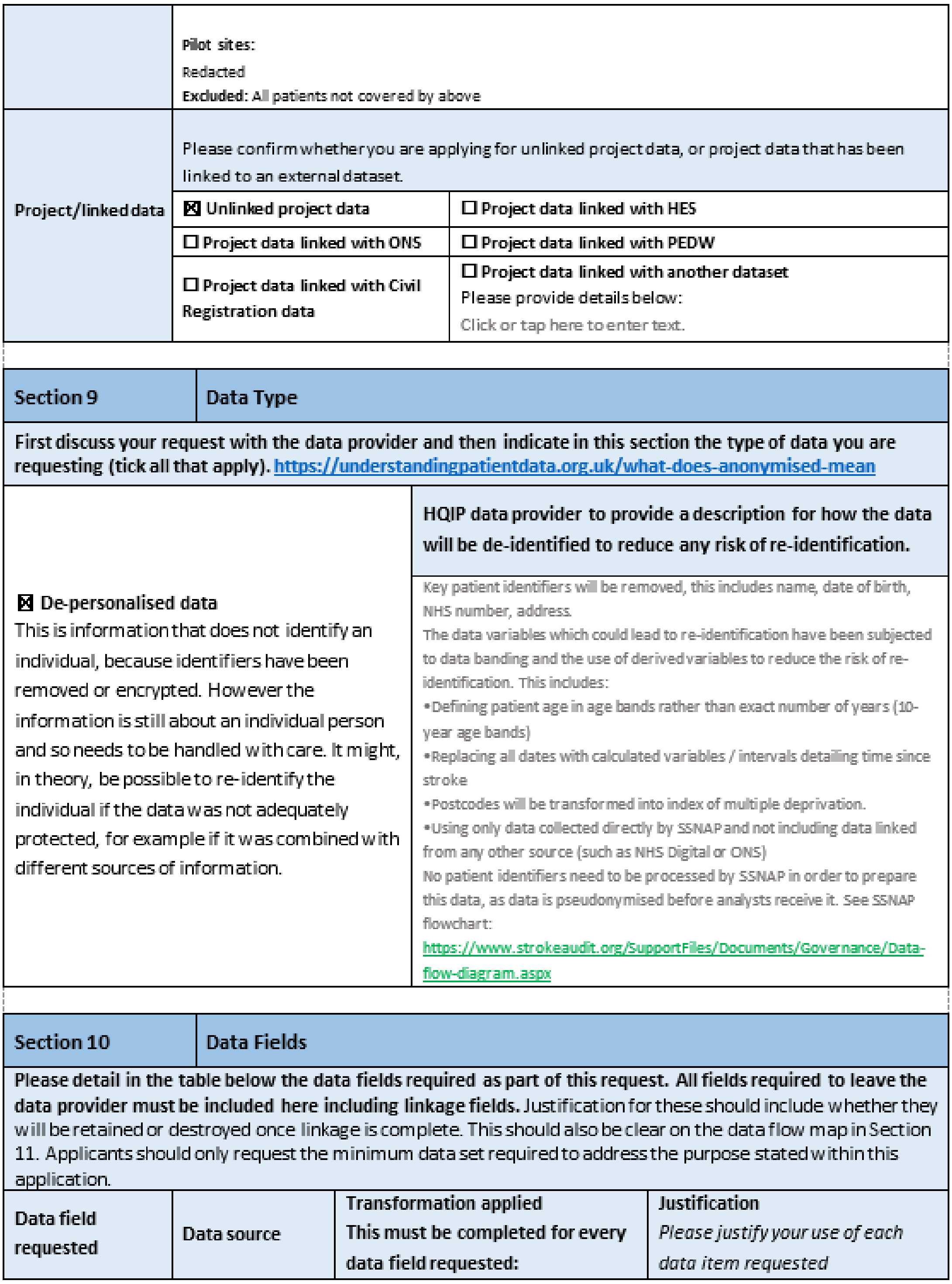
Data Access Request Form (DARF)

Once completed please return this signed form to datasharing@hqip.org.uk

All sections within this form are mandatory unless specifically stated otherwise. Unless this form is completed in full, it will be returned to the applicant which will extend the time to data receipt.

For HQIP office use only			
HQIP application number	HQIP440	**Date of submission to HQIP**	17/04/2023
If applicable, any linked application number(s)	Click or tap here to enter text.	**Charging category**	2. Standard
Tracking history	17/04/2023: Application received. 19/04/2023: Application pre-screening: Approval received: 26/06/2023 Section 3: - Please tick 'Yes' as you have provided a copy of your Ethics approval. I have ticked Yes - however, this study does not require NHS ethics and therefore ethics has been approved by the University. Section 11 (Processing Location): - Please specify details around 'Server'. Updated. Section 11 (Data Flow Diagram): - Please specify where the data will be located at each step. Locations have been added to each stage. Section 15: - The fair processing link provided by the organisation goes to a landing page, please ensure this directs to the policy itself. Link has been updated. 31/05/2023 – Post-DARG comments: Section 3: - Please tick the 'Not required' box. If NHS ethics is not needed then please provide that confirmation or the decision tool result as per the 'not required' question prompt. I have selected not required and attached the University of Nottingham ethics committee approval confirming NHS ethics not required Suitable for Chair's action upon completion of the above points.		
Expiry date	Click or tap to enter a date.		

Appendix 6-3: Data Access Request Form (DARF) (Page 2/6)

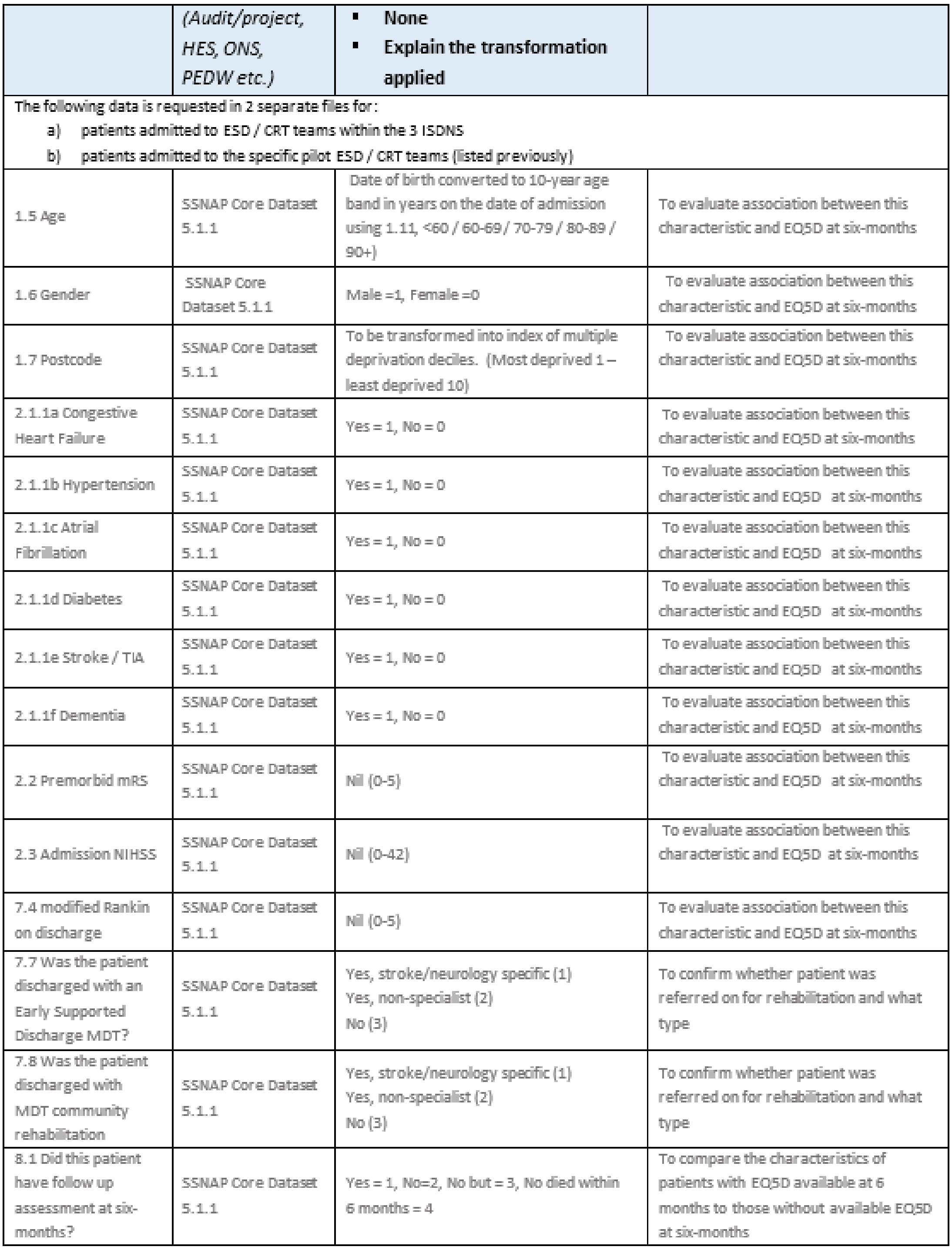


	Pilot sites: Redacted **Excluded:** All patients not covered by above	
Project/linked data	Please confirm whether you are applying for unlinked project data, or project data that has been linked to an external dataset.	
	☒ Unlinked project data	☐ Project data linked with HES
	☐ Project data linked with ONS	☐ Project data linked with PEDW
	☐ Project data linked with Civil Registration data	☐ Project data linked with another dataset Please provide details below: Click or tap here to enter text.

Section 9	**Data Type**
First discuss your request with the data provider and then indicate in this section the type of data you are requesting (tick all that apply). https://understandingpatientdata.org.uk/what-does-anonymised-mean	
☒ De-personalised data This is information that does not identify an individual, because identifiers have been removed or encrypted. However the information is still about an individual person and so needs to be handled with care. It might, in theory, be possible to re-identify the individual if the data was not adequately protected, for example if it was combined with different sources of information.	**HQIP data provider to provide a description for how the data will be de-identified to reduce any risk of re-identification.**
	Key patient identifiers will be removed, this includes name, date of birth, NHS number, address. The data variables which could lead to re-identification have been subjected to data banding and the use of derived variables to reduce the risk of re-identification. This includes: •Defining patient age in age bands rather than exact number of years (10-year age bands) •Replacing all dates with calculated variables / intervals detailing time since stroke •Postcodes will be transformed into index of multiple deprivation. •Using only data collected directly by SSNAP and not including data linked from any other source (such as NHS Digital or ONS) No patient identifiers need to be processed by SSNAP in order to prepare this data, as data is pseudonymised before analysts receive it. See SSNAP flowchart: https://www.strokeaudit.org/SupportFiles/Documents/Governance/Data-flow-diagram.aspx

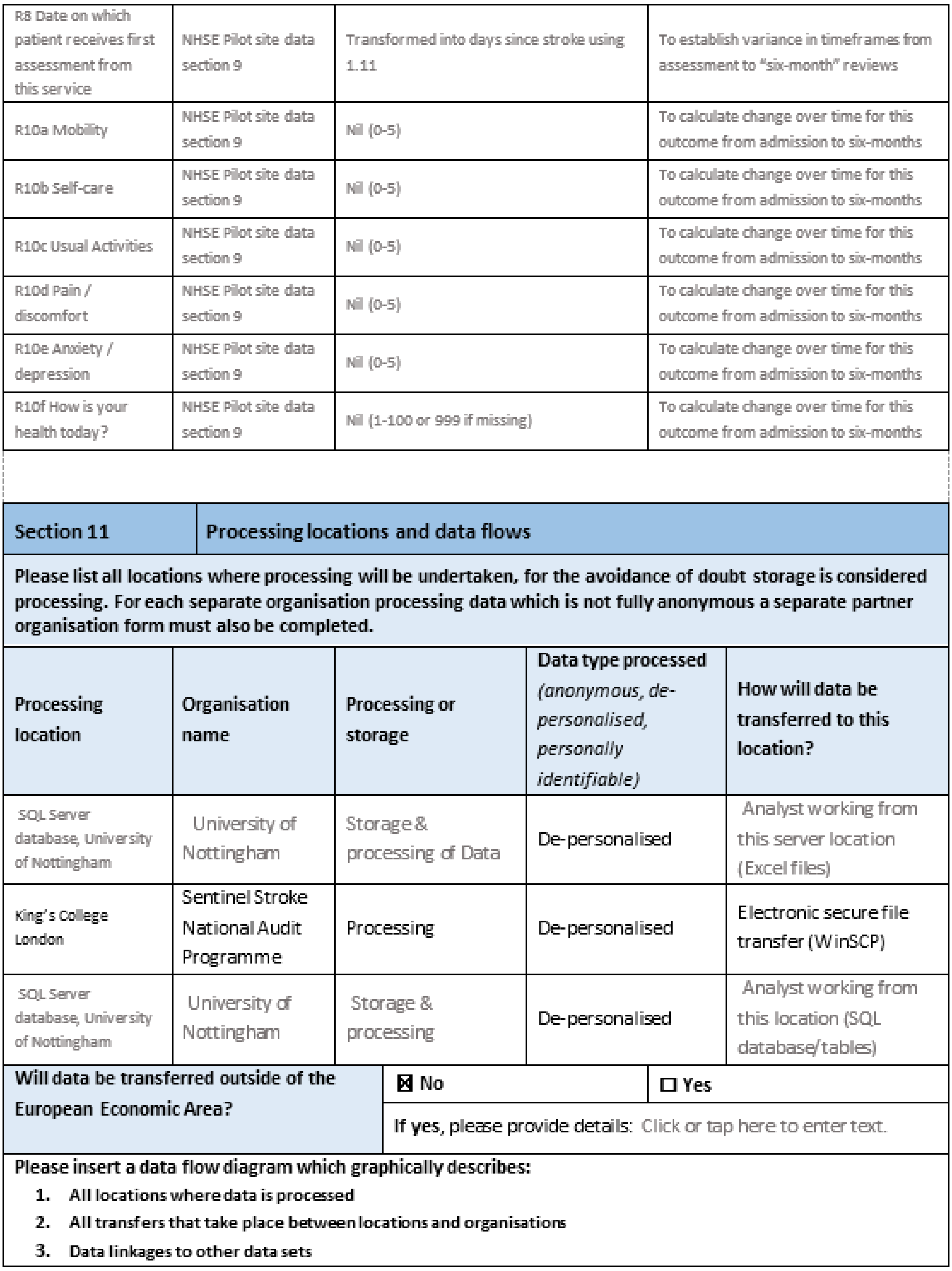
Section 10	**Data Fields**		
Please detail in the table below the data fields required as part of this request. All fields required to leave the data provider must be included here including linkage fields. Justification for these should include whether they will be retained or destroyed once linkage is complete. This should also be clear on the data flow map in Section 11. Applicants should only request the minimum data set required to address the purpose stated within this application.			
Data field requested	**Data source**	**Transformation applied** **This must be completed for every data field requested:**	**Justification** *Please justify your use of each data item requested*

Appendix 6-3: Data Access Request Form (DARF) (Page 3/6)



	(Audit/project, HES, ONS, PEDW etc.)	**▪ None** **▪ Explain the transformation applied**	
The following data is requested in 2 separate files for: a) patients admitted to ESD / CRT teams within the 3 ISDNS b) patients admitted to the specific pilot ESD / CRT teams (listed previously)			
1.5 Age	SSNAP Core Dataset 5.1.1	Date of birth converted to 10-year age band in years on the date of admission using 1.11, <60 / 60-69 / 70-79 / 80-89 / 90+)	To evaluate association between this characteristic and EQ5D at six-months
1.6 Gender	SSNAP Core Dataset 5.1.1	Male =1, Female =0	To evaluate association between this characteristic and EQ5D at six-months
1.7 Postcode	SSNAP Core Dataset 5.1.1	To be transformed into index of multiple deprivation deciles. (Most deprived 1 – least deprived 10)	To evaluate association between this characteristic and EQ5D at six-months
2.1.1a Congestive Heart Failure	SSNAP Core Dataset 5.1.1	Yes = 1, No = 0	To evaluate association between this characteristic and EQ5D at six-months
2.1.1b Hypertension	SSNAP Core Dataset 5.1.1	Yes = 1, No = 0	To evaluate association between this characteristic and EQ5D at six-months
2.1.1c Atrial Fibrillation	SSNAP Core Dataset 5.1.1	Yes = 1, No = 0	To evaluate association between this characteristic and EQ5D at six-months
2.1.1d Diabetes	SSNAP Core Dataset 5.1.1	Yes = 1, No = 0	To evaluate association between this characteristic and EQ5D at six-months
2.1.1e Stroke / TIA	SSNAP Core Dataset 5.1.1	Yes = 1, No = 0	To evaluate association between this characteristic and EQ5D at six-months
2.1.1f Dementia	SSNAP Core Dataset 5.1.1	Yes = 1, No = 0	To evaluate association between this characteristic and EQ5D at six-months
2.2 Premorbid mRS	SSNAP Core Dataset 5.1.1	Nil (0-5)	To evaluate association between this characteristic and EQ5D at six-months
2.3 Admission NIHSS	SSNAP Core Dataset 5.1.1	Nil (0-42)	To evaluate association between this characteristic and EQ5D at six-months
7.4 modified Rankin on discharge	SSNAP Core Dataset 5.1.1	Nil (0-5)	To evaluate association between this characteristic and EQ5D at six-months
7.7 Was the patient discharged with an Early Supported Discharge MDT?	SSNAP Core Dataset 5.1.1	Yes, stroke/neurology specific (1) Yes, non-specialist (2) No (3)	To confirm whether patient was referred on for rehabilitation and what type
7.8 Was the patient discharged with MDT community rehabilitation	SSNAP Core Dataset 5.1.1	Yes, stroke/neurology specific (1) Yes, non-specialist (2) No (3)	To confirm whether patient was referred on for rehabilitation and what type
8.1 Did this patient have follow up assessment at six-months?	SSNAP Core Dataset 5.1.1	Yes = 1, No=2, No but = 3, No died within 6 months = 4	To compare the characteristics of patients with EQ5D available at 6 months to those without available EQ5D at six-months

Appendix 6-3: Data Access Request Form (DARF) (Page 4/6)



R8 Date on which patient receives first assessment from this service	NHSE Pilot site data section 9	Transformed into days since stroke using 1.11	To establish variance in timeframes from assessment to "six-month" reviews
R10a Mobility	NHSE Pilot site data section 9	Nil (0-5)	To calculate change over time for this outcome from admission to six-months
R10b Self-care	NHSE Pilot site data section 9	Nil (0-5)	To calculate change over time for this outcome from admission to six-months
R10c Usual Activities	NHSE Pilot site data section 9	Nil (0-5)	To calculate change over time for this outcome from admission to six-months
R10d Pain / discomfort	NHSE Pilot site data section 9	Nil (0-5)	To calculate change over time for this outcome from admission to six-months
R10e Anxiety / depression	NHSE Pilot site data section 9	Nil (0-5)	To calculate change over time for this outcome from admission to six-months
R10f How is your health today?	NHSE Pilot site data section 9	Nil (1-100 or 999 if missing)	To calculate change over time for this outcome from admission to six-months

Section 11 **Processing locations and data flows**

Please list all locations where processing will be undertaken, for the avoidance of doubt storage is considered processing. For each separate organisation processing data which is not fully anonymous a separate partner organisation form must also be completed.

Processing location	**Organisation name**	**Processing or storage**	**Data type processed** *(anonymous, de-personalised, personally identifiable)*	**How will data be transferred to this location?**
SQL Server database, University of Nottingham	University of Nottingham	Storage & processing of Data	De-personalised	Analyst working from this server location (Excel files)
King's College London	Sentinel Stroke National Audit Programme	Processing	De-personalised	Electronic secure file transfer (WinSCP)
SQL Server database, University of Nottingham	University of Nottingham	Storage & processing	De-personalised	Analyst working from this location (SQL database/tables)

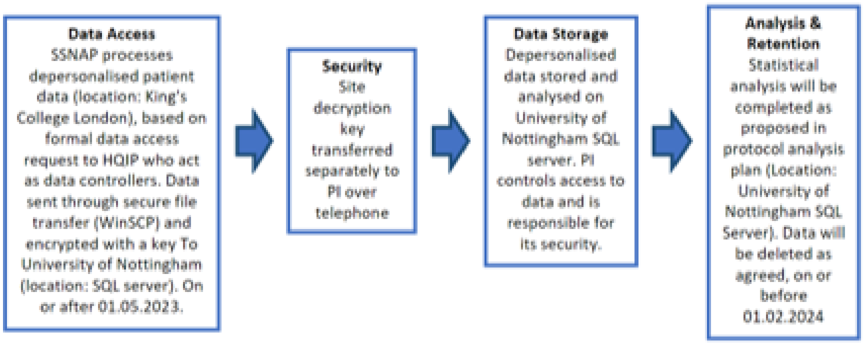
Will data be transferred outside of the European Economic Area?	☒ **No**	☐ **Yes**
	If yes, please provide details: Click or tap here to enter text.	

Please insert a data flow diagram which graphically describes:

1. **All locations where data is processed**
2. **All transfers that take place between locations and organisations**
3. **Data linkages to other data sets**

Appendix 6-3: Data Access Request Form (DARF) (Page 5/6)

Please insert data flow diagram here



Data Access
SSNAP processes depersonalised patient data (location: King's College London), based on formal data access request to HQIP who act as data controllers. Data sent through secure file transfer (WinSCP) and encrypted with a key To University of Nottingham (location: SQL server). On or after 01.05.2023.

Security
Site decryption key transferred separately to PI over telephone

Data Storage
Depersonalised data stored and analysed on University of Nottingham SQL server. PI controls access to data and is responsible for its security.

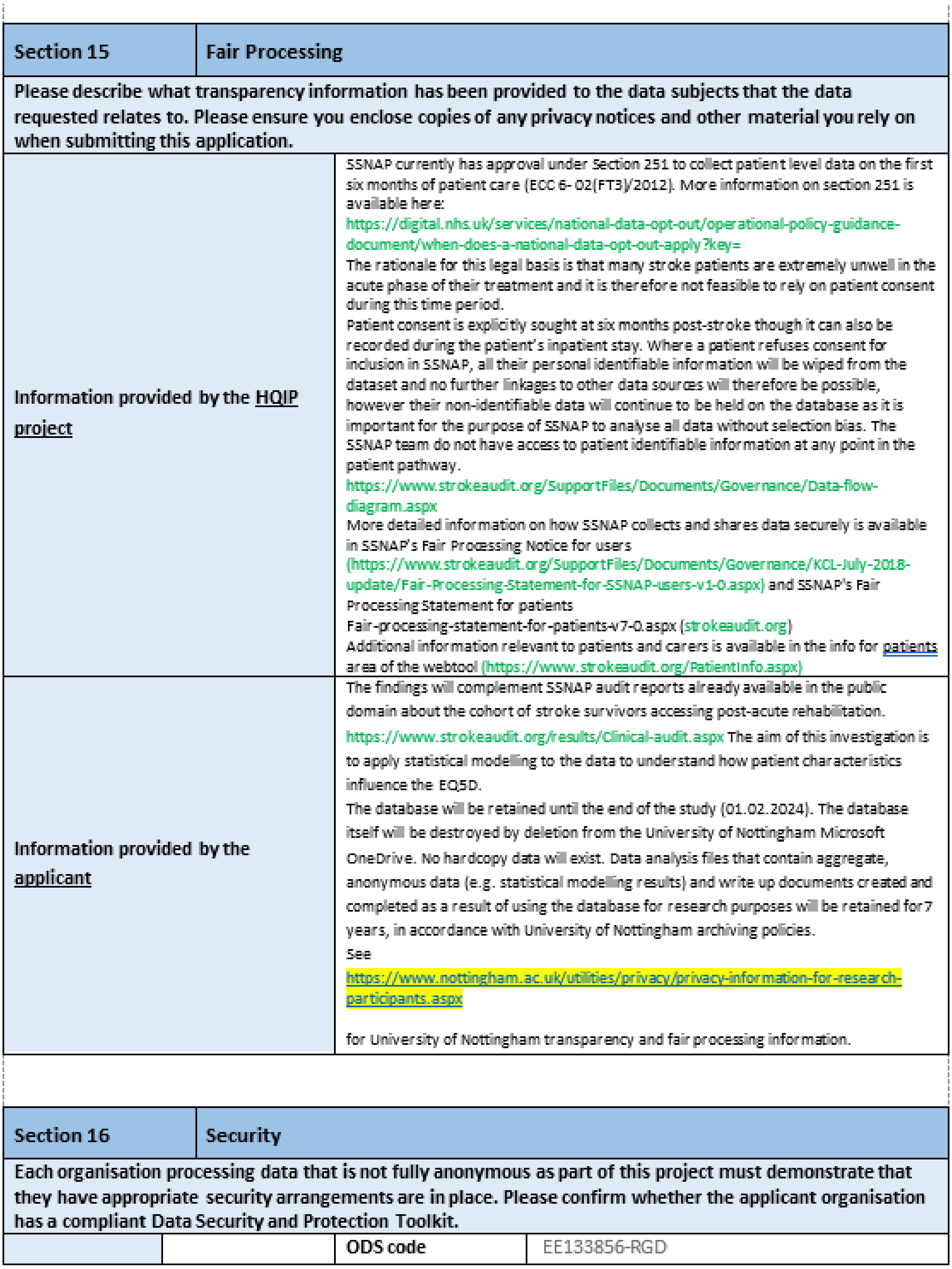
Analysis & Retention
Statistical analysis will be completed as proposed in protocol analysis plan (Location: University of Nottingham SQL Server). Data will be deleted as agreed, on or before 01.02.2024

Section 12	**Project team employed by the applicant organisation**		
Please list the name and job title of each member of the applicant organisation who will have access to the data for the purposes of this request. Please also confirm that they have a formal contract with the applicant organisation and will therefore be covered by the HQIP Data Sharing Agreement. Please add additional rows if necessary.			
Team member	**Name**	**Job title**	**Contract in place with applicant organisation**
Principal investigator	Niki Chouliara	Senior Researcher	☐ No ☒ Yes
Project member 1	Elizabeth Dickinson	Research Evaluator	☐ No ☒ Yes
Project member 2	Sarah Lewis	Medical Statistician	☐ No ☒ Yes

Section 13	**Data Protection**
Registered name	The University of Nottingham
Registration number	Z5654762
Expiry date	19/08/2023

Section 14	**Legal basis (of the processing you intend to undertake)**
GDPR Legal Basis	**Article 6 legal basis:** Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. Processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party **Justification:** The data will be used to understand the influence of specific patient characteristics on stroke patient outcomes as measures by the EQ5D at six months. The aim of which is to support stakeholders to scrutinise their data, providing a narrative for their local data in strategic conversations e.g. commissioning.
	Article 9 legal basis: processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on domestic law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject. **Justification:** The index of multiple deprivation will be requested to understand this patient characteristic, but also has been shown in previous research demonstrates that aetiology and risk factors vary across deciles, therefore this needs to be acknowledged within the analysis.

Appendix 6-3: Data Access Request Form (DARF) (Page 6/6)



Section 15	**Fair Processing**
Please describe what transparency information has been provided to the data subjects that the data requested relates to. Please ensure you enclose copies of any privacy notices and other material you rely on when submitting this application.	
Information provided by the HQIP project	SSNAP currently has approval under Section 251 to collect patient level data on the first six months of patient care (ECC 6- 02(FT3)/2012). More information on section 251 is available here: https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/when-does-a-national-data-opt-out-apply?key= The rationale for this legal basis is that many stroke patients are extremely unwell in the acute phase of their treatment and it is therefore not feasible to rely on patient consent during this time period. Patient consent is explicitly sought at six months post-stroke though it can also be recorded during the patient's inpatient stay. Where a patient refuses consent for inclusion in SSNAP, all their personal identifiable information will be wiped from the dataset and no further linkages to other data sources will therefore be possible, however their non-identifiable data will continue to be held on the database as it is important for the purpose of SSNAP to analyse all data without selection bias. The SSNAP team do not have access to patient identifiable information at any point in the patient pathway. https://www.strokeaudit.org/SupportFiles/Documents/Governance/Data-flow-diagram.aspx More detailed information on how SSNAP collects and shares data securely is available in SSNAP's Fair Processing Notice for users (https://www.strokeaudit.org/SupportFiles/Documents/Governance/KCL-July-2018-update/Fair-Processing-Statement-for-SSNAP-users-v1-0.aspx) and SSNAP's Fair Processing Statement for patients Fair-processing-statement-for-patients-v7-0.aspx (strokeaudit.org) Additional information relevant to patients and carers is available in the info for patients area of the webtool (https://www.strokeaudit.org/PatientInfo.aspx)
Information provided by the applicant	The findings will complement SSNAP audit reports already available in the public domain about the cohort of stroke survivors accessing post-acute rehabilitation. https://www.strokeaudit.org/results/Clinical-audit.aspx The aim of this investigation is to apply statistical modelling to the data to understand how patient characteristics influence the EQ5D. The database will be retained until the end of the study (01.02.2024). The database itself will be destroyed by deletion from the University of Nottingham Microsoft OneDrive. No hardcopy data will exist. Data analysis files that contain aggregate, anonymous data (e.g. statistical modelling results) and write up documents created and completed as a result of using the database for research purposes will be retained for 7 years, in accordance with University of Nottingham archiving policies. See https://www.nottingham.ac.uk/utilities/privacy/privacy-information-for-research-participants.aspx for University of Nottingham transparency and fair processing information.

Section 16	**Security**		
Each organisation processing data that is not fully anonymous as part of this project must demonstrate that they have appropriate security arrangements are in place. Please confirm whether the applicant organisation has a compliant Data Security and Protection Toolkit.			
		ODS code	EE133856-RGD

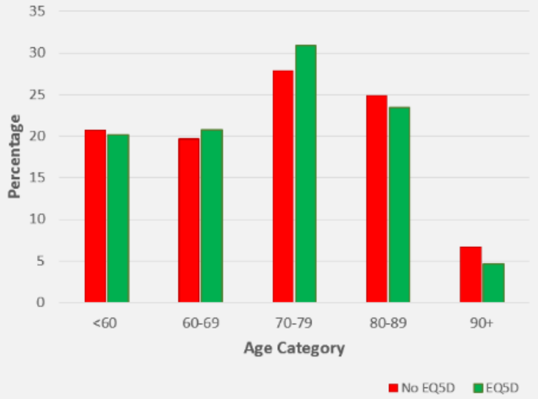
Appendix 6-4: Syntax for calculating EQIndex in SPSS$^{\text{TM}}$

```
*SPSS syntax code for the computation of index*

*values with ENG TTO value set*


IF (mobility=1) disut_mo=0.
IF (mobility=2) disut_mo=0.058.
IF (mobility=3) disut_mo=0.076.
IF (mobility=4) disut_mo=0.207.
IF (mobility=5) disut_mo=0.274.

IF (selfcare=1) disut_sc=0.
IF (selfcare=2) disut_sc=0.050.
IF (selfcare=3) disut_sc=0.080.
IF (selfcare=4) disut_sc=0.164.
IF (selfcare=5) disut_sc=0.203.

IF (activity=1) disut_ua=0.
IF (activity=2) disut_ua=0.050.
IF (activity=3) disut_ua=0.063.
IF (activity=4) disut_ua=0.162.
IF (activity=5) disut_ua=0.184.

IF (pain=1) disut_pd=0.
IF (pain=2) disut_pd=0.063.
IF (pain=3) disut_pd=0.084.
IF (pain=4) disut_pd=0.276.
IF (pain=5) disut_pd=0.335.

IF (anxiety=1) disut_ad=0.
IF (anxiety=2) disut_ad=0.078.
IF (anxiety=3) disut_ad=0.104.
IF (anxiety=4) disut_ad=0.285.
IF (anxiety=5) disut_ad=0.289.


Compute disut_total= disut_mo +disut_sc +disut_ua +disut_pd +disut_ad.


Compute EQindex = 1-disut_total.
Formats EQindex(F8.3).
execute.
```

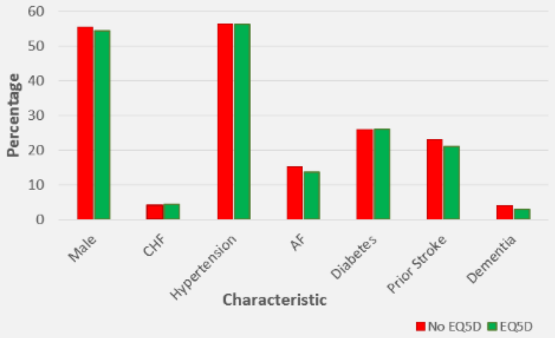
Appendix 6-5: Q1. Comparison of patients with and without EQ5D-5L

(Page 1/2) Age, binary characteristics, IMD and NIHSS

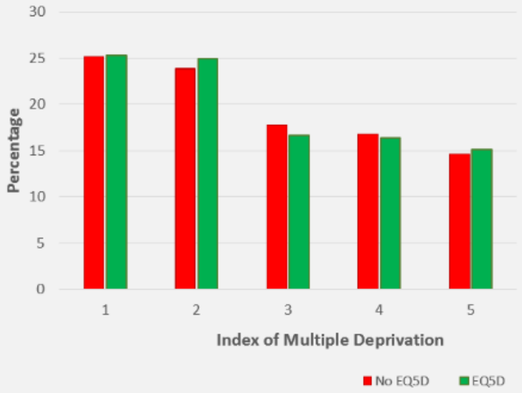
AGE	No EQ5D % (n=3693)	EQ5D % (n=3813)
<60	20.7	20.2
60-69	19.7	20.8
70-79	27.9	30.9
80-89	24.9	23.5
90+	6.8	4.6



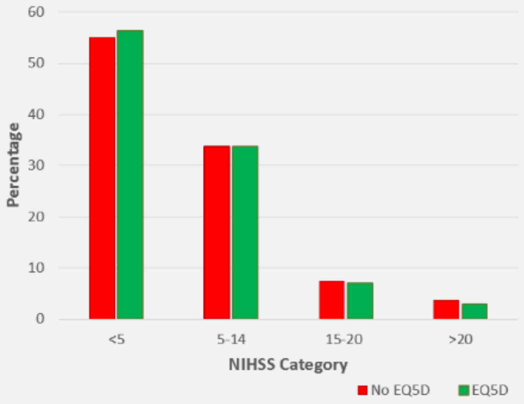
Characteristic	No EQ5D % (n=3693)	EQ5D % (n=3813)
Gender (Male)	55.6	54.4
CHF	4.1	4.3
Hypertension	56.4	56.4
AF	15.3	13.6
Diabetes	25.9	26.1
Prior Stroke	23	21.1
Dementia	4	2.9



Index of Multiple Deprivation (IMD)	No EQ5D % (63 missing*n=3630)	EQ5D % (62 missing*, n=3751)
1 (Most)	25.2	25.3
2	23.9	24.9
3	17.8	16.7
4	16.8	16.4
5 (Least)	14.6	15.1

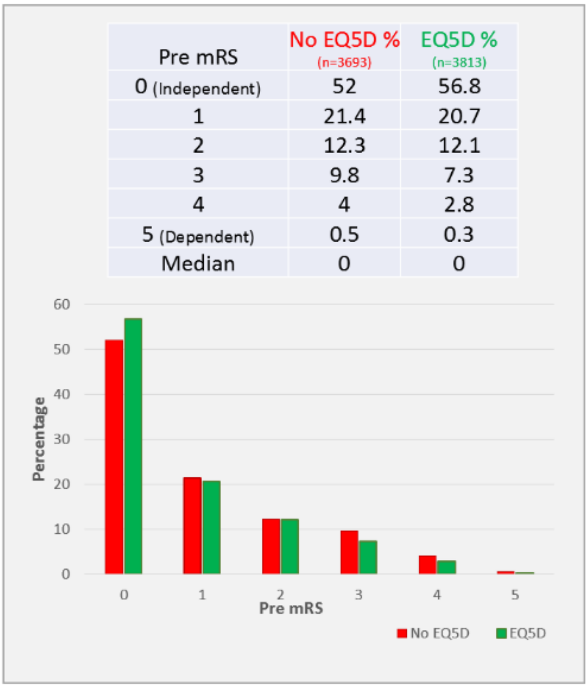


NIHSS on arrival	No EQ5D % (n=3693)	EQ5D % (n=3813)
<5	55	56.3
5-14	33.8	33.8
15-20	7.5	7.1
>20 (Most severe)	3.7	2.8

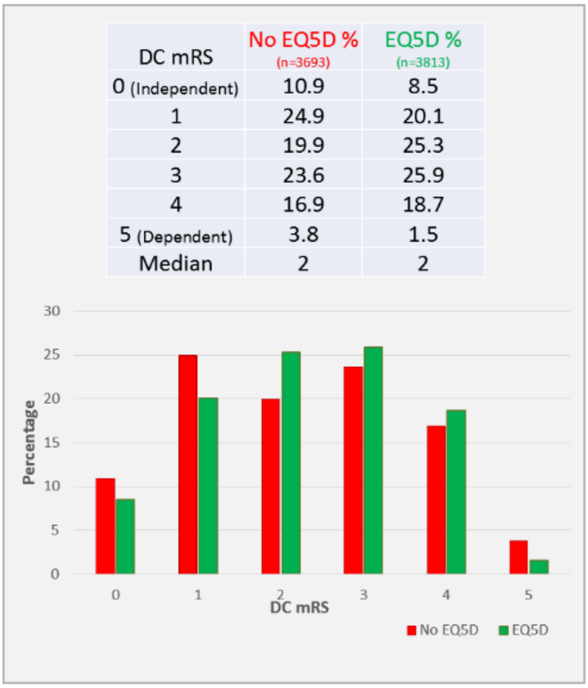


Appendix 6-5: Q1. Comparison of patients with and without EQ5D-5L

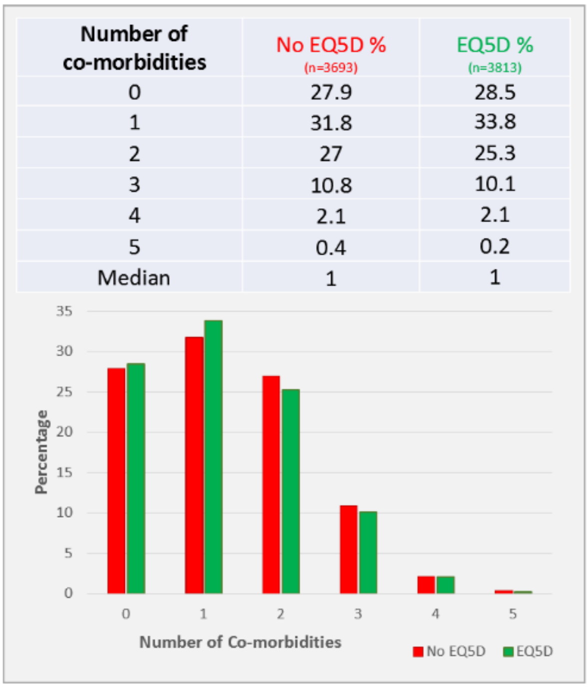
(Page 2/2) Pre mRS, DC mRS and Number of co-morbidities



Pre mRS	No EQ5D % (n=3693)	EQ5D % (n=3813)
0 (Independent)	52	56.8
1	21.4	20.7
2	12.3	12.1
3	9.8	7.3
4	4	2.8
5 (Dependent)	0.5	0.3
Median	0	0



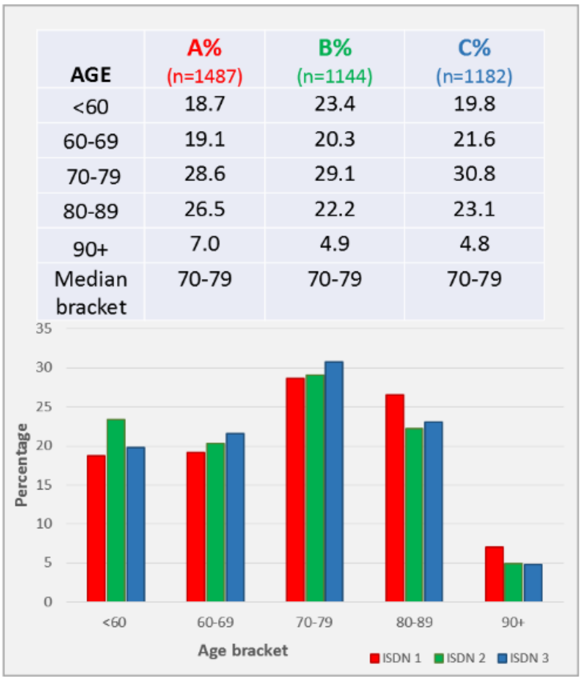
DC mRS	No EQ5D % (n=3693)	EQ5D % (n=3813)
0 (Independent)	10.9	8.5
1	24.9	20.1
2	19.9	25.3
3	23.6	25.9
4	16.9	18.7
5 (Dependent)	3.8	1.5
Median	2	2



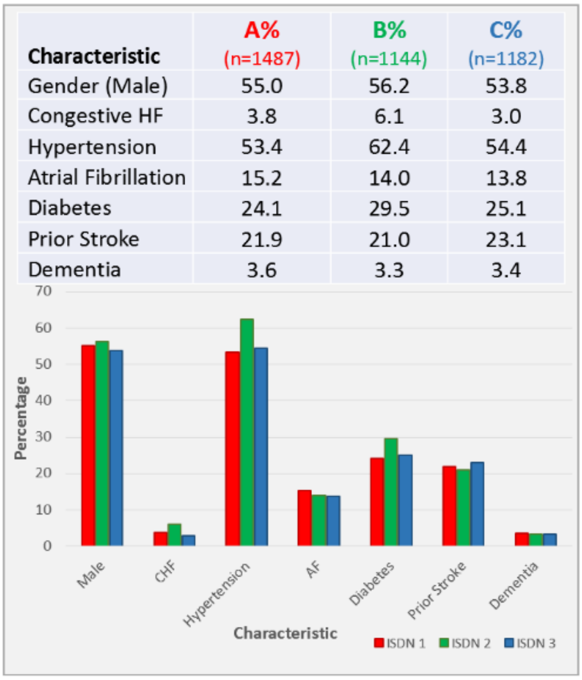
Number of co-morbidities	No EQ5D % (n=3693)	EQ5D % (n=3813)
0	27.9	28.5
1	31.8	33.8
2	27	25.3
3	10.8	10.1
4	2.1	2.1
5	0.4	0.2
Median	1	1

Appendix 6-6: Q1. Comparison of characteristics between ISDNs

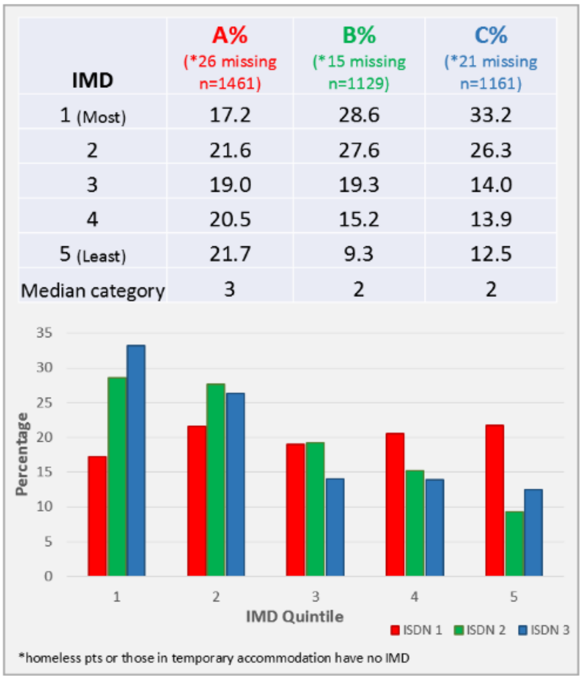
(Page 1/2) Age, binary characteristics, IMD and NIHSS



AGE	A% (n=1487)	B% (n=1144)	C% (n=1182)
<60	18.7	23.4	19.8
60-69	19.1	20.3	21.6
70-79	28.6	29.1	30.8
80-89	26.5	22.2	23.1
90+	7.0	4.9	4.8
Median bracket	70-79	70-79	70-79

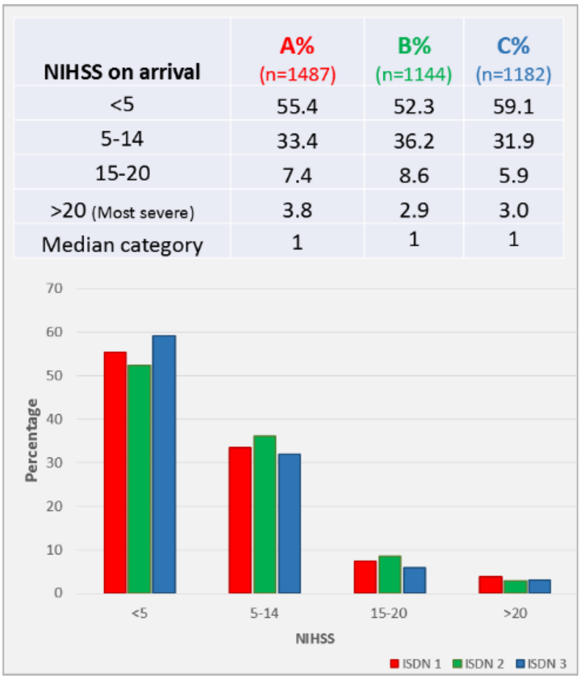


Characteristic	A% (n=1487)	B% (n=1144)	C% (n=1182)
Gender (Male)	55.0	56.2	53.8
Congestive HF	3.8	6.1	3.0
Hypertension	53.4	62.4	54.4
Atrial Fibrillation	15.2	14.0	13.8
Diabetes	24.1	29.5	25.1
Prior Stroke	21.9	21.0	23.1
Dementia	3.6	3.3	3.4



IMD	A% (*26 missing n=1461)	B% (*15 missing n=1129)	C% (*21 missing n=1161)
1 (Most)	17.2	28.6	33.2
2	21.6	27.6	26.3
3	19.0	19.3	14.0
4	20.5	15.2	13.9
5 (Least)	21.7	9.3	12.5
Median category	3	2	2

*homeless pts or those in temporary accommodation have no IMD

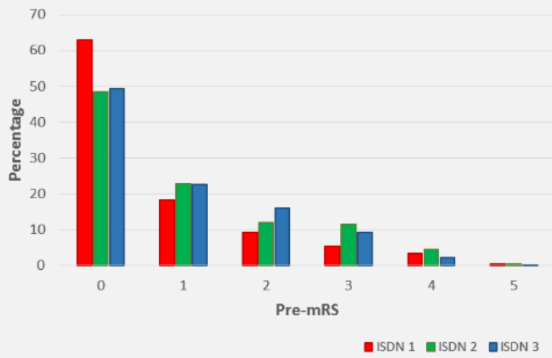


NIHSS on arrival	A% (n=1487)	B% (n=1144)	C% (n=1182)
<5	55.4	52.3	59.1
5-14	33.4	36.2	31.9
15-20	7.4	8.6	5.9
>20 (Most severe)	3.8	2.9	3.0
Median category	1	1	1

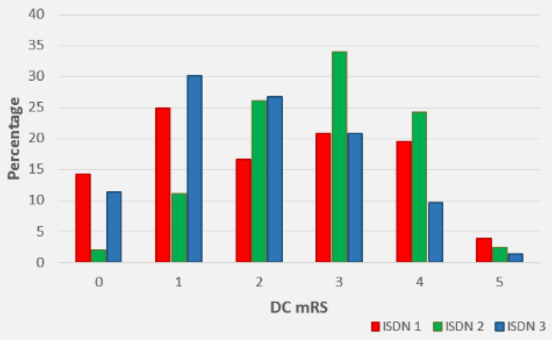
Appendix 6-6: Q1. Comparison of characteristics between ISDNs

(Page 2/2) Pre mRS, DC mRS and Number of co-morbidities

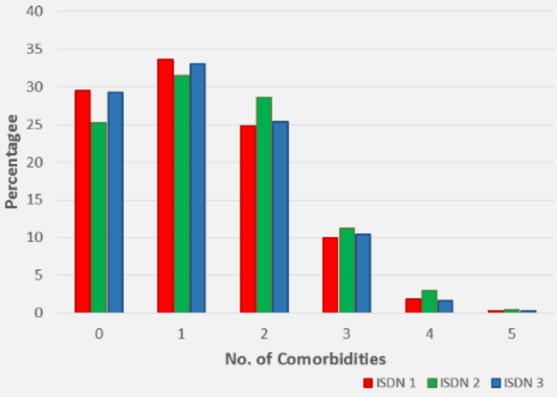
Pre mRS	A% (n=1487)	B% (n=1144)	C% (n=1182)
0 (Independent)	63.0	48.5	49.5
1	18.5	22.9	22.6
2	9.3	11.9	16.1
3	5.4	11.6	9.3
4	3.4	4.5	2.4
5 (Dependent)	0.5	0.5	0.2
Median	0	1	1



DC mRS	A% (n=1487)	B% (n=1144)	C% (n=1182)
0 (Independent)	14.3	2.0	11.3
1	24.8	11.1	30.2
2	16.7	26.1	26.7
3	20.9	34.0	20.9
4	19.5	24.3	9.7
5 (Dependent)	3.9	2.4	1.3
Median	2	3	2

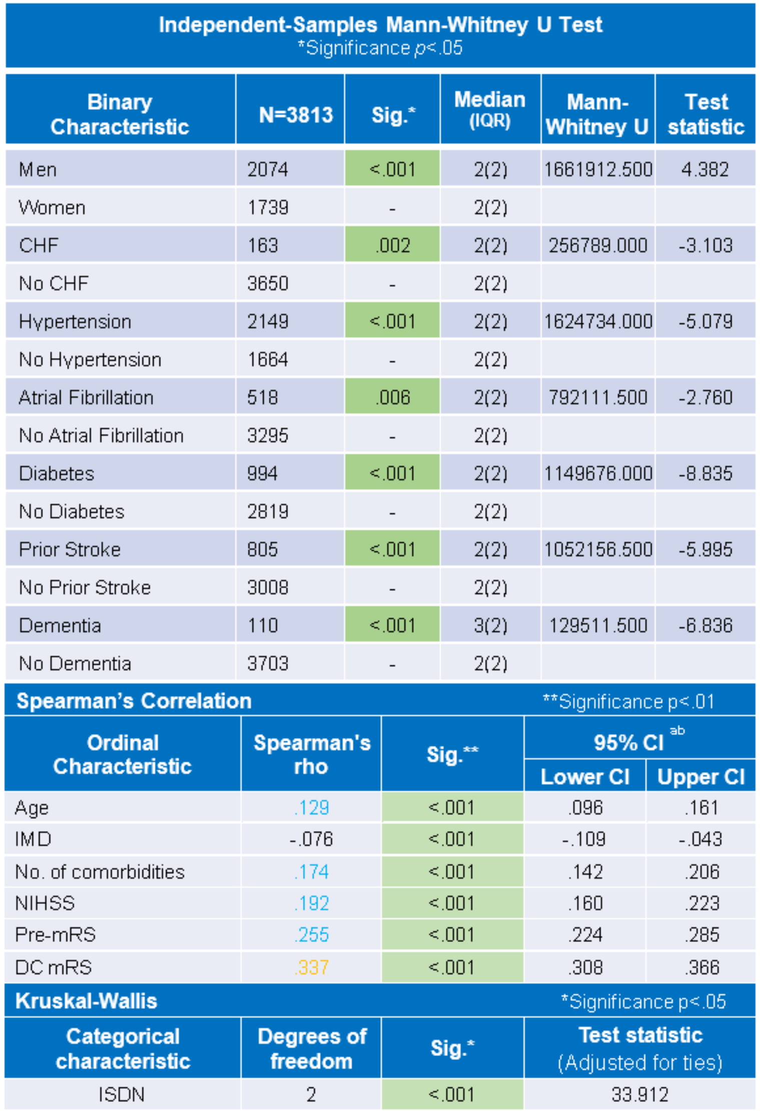


Number of co-morbidities	A % (n=1487)	B % (n=1144)	C % (n=1182)
0	29.5	25.3	29.3
1	33.6	31.5	33.1
2	24.8	28.6	25.4
3	9.9	11.2	10.4
4	1.9	2.9	1.6
5	0.3	0.5	0.3



Appendix 6-7: Q1. Univariate analysis of patient characteristics & domain outcomes Page 1/3

Associations between characteristics and Mobility domain



Independent-Samples Mann-Whitney U Test

*Significance p<.05

Binary Characteristic	N=3813	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	2074	<.001	2(2)	1661912.500	4.382
Women	1739	-	2(2)		
CHF	163	.002	2(2)	256789.000	-3.103
No CHF	3650	-	2(2)		
Hypertension	2149	<.001	2(2)	1624734.000	-5.079
No Hypertension	1664	-	2(2)		
Atrial Fibrillation	518	.006	2(2)	792111.500	-2.760
No Atrial Fibrillation	3295	-	2(2)		
Diabetes	994	<.001	2(2)	1149676.000	-8.835
No Diabetes	2819	-	2(2)		
Prior Stroke	805	<.001	2(2)	1052156.500	-5.995
No Prior Stroke	3008	-	2(2)		
Dementia	110	<.001	3(2)	129511.500	-6.836
No Dementia	3703	-	2(2)		

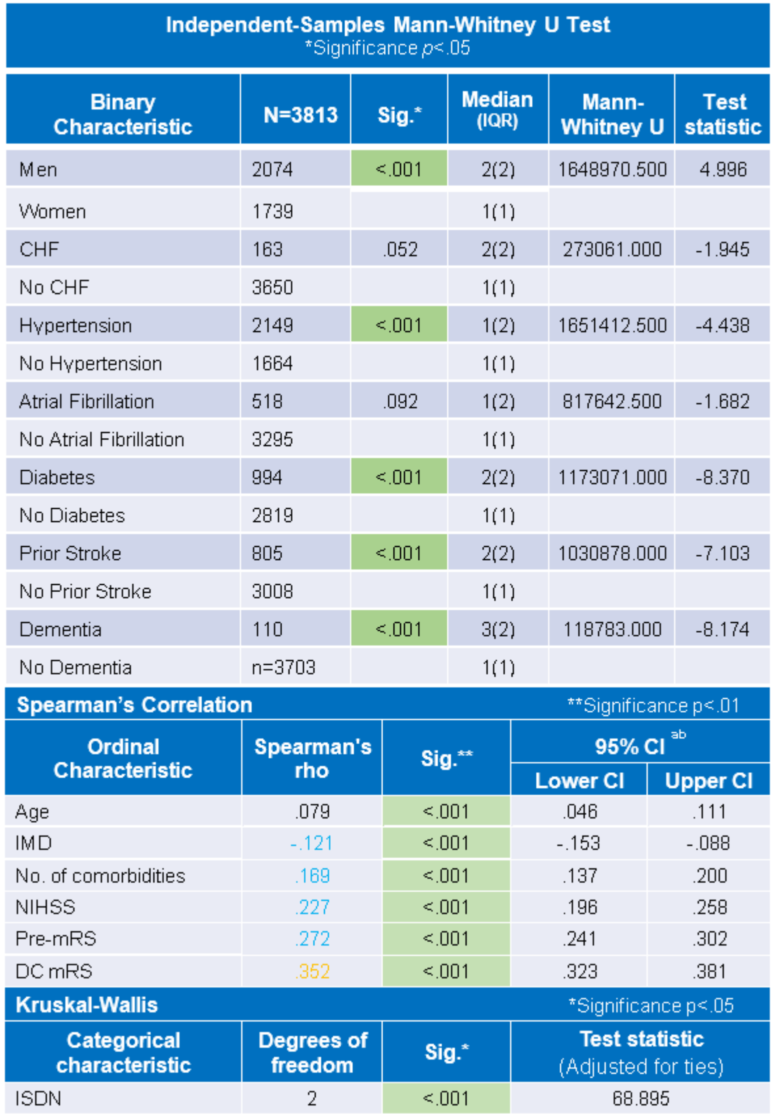
Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI ^{ab}	
			Lower CI	Upper CI
Age	.129	<.001	.096	.161
IMD	-.076	<.001	-.109	-.043
No. of comorbidities	.174	<.001	.142	.206
NIHSS	.192	<.001	.160	.223
Pre-mRS	.255	<.001	.224	.285
DC mRS	.337	<.001	.308	.366

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
ISDN	2	<.001	33.912

Associations between characteristics and Self-Care domain



Independent-Samples Mann-Whitney U Test

*Significance p<.05

Binary Characteristic	N=3813	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	2074	<.001	2(2)	1648970.500	4.996
Women	1739		1(1)		
CHF	163	.052	2(2)	273061.000	-1.945
No CHF	3650		1(1)		
Hypertension	2149	<.001	1(2)	1651412.500	-4.438
No Hypertension	1664		1(1)		
Atrial Fibrillation	518	.092	1(2)	817642.500	-1.682
No Atrial Fibrillation	3295		1(1)		
Diabetes	994	<.001	2(2)	1173071.000	-8.370
No Diabetes	2819		1(1)		
Prior Stroke	805	<.001	2(2)	1030878.000	-7.103
No Prior Stroke	3008		1(1)		
Dementia	110	<.001	3(2)	118783.000	-8.174
No Dementia	n=3703		1(1)		

Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI ^{ab}	
			Lower CI	Upper CI
Age	.079	<.001	.046	.111
IMD	-.121	<.001	-.153	-.088
No. of comorbidities	.169	<.001	.137	.200
NIHSS	.227	<.001	.196	.258
Pre-mRS	.272	<.001	.241	.302
DC mRS	.352	<.001	.323	.381

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
ISDN	2	<.001	68.895

Appendix 6-7: Q1. Univariate analysis of patient characteristics and domain outcomes (Page2/3)

Associations between characteristics and Activity domain

Independent-Samples Mann-Whitney U Test *Significance *p*<.05

Binary Characteristic	N=3813	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	2074	<.001	2(2)	1648816.000	4.748
Women	1739		2(2)		
CHF	163	.033	2(3)	269223.000	-2.137
No CHF	3650		2(2)		
Hypertension	2149	.002	2(2)	1689457.500	-3.040
No Hypertension	1664		2(2)		
Atrial Fibrillation	518	.018	2(2)	800367.000	-2.369
No Atrial Fibrillation	3295		2(2)		
Diabetes	994	<.001	2(2)	1198149.500	-7.073
No Diabetes	2819		2(2)		
Prior Stroke	805	<.001	2(2)	1084666.500	-4.727
No Prior Stroke	3008		2(2)		
Dementia	110	<.001	3(3)	130959.500	-6.647
No Dementia	3703		2(2)		

Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI [ab]	
			Lower CI	Upper CI
Age	.041	.011	.009	.074
IMD	-.121	<.001	-.153	-.088
No. of comorbidities	.132	<.001	.100	.164
NIHSS	.222	<.001	.190	.252
Pre-mRS	.224	<.001	.192	.254
DC mRS	.335	<.001	.305	.363

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
ISDN	2	<.001	64.911

Associations between characteristics and Pain domain

Independent-Samples Mann-Whitney U Test *Significance *p*<.05

Binary Characteristic	N=3813	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	2074	.001	1(1)	1703378.500	3.210
Women	1739		2(2)		
CHF	163	.032	2(2)	270331.500	-2.146
No CHF	3650		1(1)		
Hypertension	2149	.094	1(2)	1736031.500	-1.675
No Hypertension	1664		1(1)		
Atrial Fibrillation	518	.543	1(1)	840384.000	-.608
No Atrial Fibrillation	3295		1(1)		
Diabetes	994	<.001	2(2)	1263051.000	-5.028
No Diabetes	2819		1(1)		
Prior Stroke	805	.105	2(2)	1169386.000	-1.620
No Prior Stroke	3008		1(1)		
Dementia	110	.438	1(1)	195545.000	-.776
No Dementia	3703		1(1)		

Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI [ab]	
			Lower CI	Upper CI
Age	-.058	.001	-.090	-.027
IMD	-.097	<.001	-.128	-.065
No. of comorbidities	.065	<.001	.033	.096
NIHSS	.076	<.001	.044	.108
Pre-mRS	.102	<.001	.071	.133
DC mRS	.095	<.001	.063	.126

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
ISDN	2	<.001	14.798

Appendix 6-7: Q1. Univariate analysis of patient characteristics and domain outcomes (Page 3/3)

Associations between characteristics and Anxiety domain

Independent-Samples Mann-Whitney U Test *Significance *p*<.05

Binary Characteristic	N=3813	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	2074	<.001	1(1)	1658518.500	4.733
Women	1739		1(1)		
CHF	163	.534	1(1)	289750.500	-.622
No CHF	3650		1(1)		
Hypertension	2149	.034	1(1)	1723534.000	-2.115
No Hypertension	1664		1(1)		
Atrial Fibrillation	518	.497	1(1)	839108.500	-.679
No Atrial Fibrillation	3295		1(1)		
Diabetes	994	.012	1(1)	1333102.500	-2.519
No Diabetes	2819		1(1)		
Prior Stroke	805	.300	1(1)	1184745.000	-1.036
No Prior Stroke	3008		1(1)		
Dementia	110	.442	1(1)	195763.500	-.768
No Dementia	3703		1(1)		

Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI ^{ab}	
			Lower CI	Upper CI
Age	-.167	<.001	-.198	-.135
IMD	-.103	<.001	-.136	-.070
No. of comorbidities	-.003	.852	-.036	.030
NIHSS	.113	<.001	.080	.145
Pre-mRS	.076	<.001	.043	.108
DC mRS	.079	<.001	.047	.112

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
ISDN	2	<.001	25.447

[a] Estimation is based on Fisher's r-to-z transformation.

[b] Estimation of standard error is based on the formula proposed by Fieller, Hartley, and Pearson

Strength of relationship: 0.5-1 Strong, 0.3-0.49 Mod, 0.1-0.29 Weak

Appendix 6-8: Q1. Univariate analysis of patient characteristics & EQIndex

Associations between binary characteristics and EQIndex

Independent-Samples Mann-Whitney U Test   Significance *p*<.05

Binary Characteristic	N=3813	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	2074	<.001	.82900 (.288)	2002398.500	5.894
Women			.78100 (.297)		
CHF	163	.015	.77900 (.480)	264063.500	-2.436
No CHF			.81100 (.293)		
Hypertension	2149	.005	.80900 (.309)	1694192.500	-2.788
No Hypertension			.81400 (.278)		
AF	518	.097	.79950 (.327)	814884.500	-1.658
No AF			.81100 (.296)		
Diabetes	994	<.001	.75850 (.351)	1153198.500	-8.325
No Diabetes			.82900 (.280)		
Prior Stroke	805	<.001	.77500 (.333)	1058489.500	-5.501
No Prior Stroke			.81400 (.285)		
Dementia	110	<.001	.64850 (.490)	142922.000	-5.352
No Dementia			.81200 (.291)		

Associations between categorical characteristic and EQIndex

Significance *p*<.05

ISDN	n=3813	Median	IQR	Mean	Std. Dev
A	1008	0.84	0.242	0.7818	0.219793
B	1397	0.779	0.353	0.7086	0.259499
C	1408	0.811	0.288	0.7464	0.24756
Independent Samples Kruskal-Wallis Test *p* <.001 (Test statistic = 48.577)					

Associations between ordinal characteristics and EQIndex

Significance *p*<.05

Age	**n=3813**	**Median**	**IQR**	**Mean**	**Std. Dev**	**Significant Association** Independent Samples Kruskal-Wallis	**Linear Trend** (Jonckheere-Terpstra)
< 60	769	0.783	0.314	0.7273	0.256705	**.003** Test statistic = 16.261	**.540**
60-69	793	0.814	0.288	0.7532	0.239118		
70-79	1178	0.829	0.292	0.7531	0.249259		
80-89	895	0.808	0.282	0.7360	0.243142		
90+	178	0.779	0.342	0.7102	0.232523		
IMD	**n=3751**	**Median**	**IQR**	**Mean**	**Std. Dev**		
1	964	0.765	0.375	0.6968	0.269487	**<.001** Test statistic = 65.761	**<.001**
2	951	0.801	0.303	0.7333	0.244452		
3	636	0.809	0.293	0.7504	0.233511		
4	624	0.842	0.254	0.7792	0.225701		
5	576	0.84	0.232	0.7847	0.231347		
NIHSS	**n=3813**	**Median**	**IQR**	**Mean**	**Std. Dev**		
<5	2146	0.84	0.241	0.7850	0.218998	**<.001** Test statistic = 185.459	**<.001**
5-14	1287	0.779	0.327	0.7097	0.260126		
15-20	270	0.6885	0.443	0.6169	0.285392		
>20	110	0.6385	0.485	0.5850	0.271085		
PremRS	**n=3813**	**Median**	**IQR**	**Mean**	**Std. Dev**		
0	2165	0.842	0.262	0.7836	0.226156	**<.001** Test statistic = 259.388	**<.001**
1	791	0.812	0.272	0.7397	0.23823		
2	462	0.7495	0.323	0.6890	0.255827		
3	277	0.673	0.401	0.6083	0.268504		
4	106	0.516	0.488	0.5113	0.300075		
5	12	0.439	0.459	0.5135	0.260806		
DCmRS	**n=3813**	**Median**	**IQR**	**Mean**	**Std. Dev**		
0	325	0.879	0.262	0.8136	0.21072	**<.001** Test statistic = 425.765	**<.001**
1	767	0.879	0.26	0.8239	0.197432		
2	964	0.842	0.243	0.7873	0.215595		
3	986	0.781	0.274	0.7236	0.23796		
4	712	0.681	0.425	0.6138	0.276932		
5	59	0.339	0.361	0.3917	0.284253		
NoC	**n=3813**	**Median**	**IQR**	**Mean**	**Std. Dev**		
0	1086	0.842	0.262	0.7801	0.229967	**<.001** Test statistic = 79.959	**<.001**
1	1289	0.811	0.279	0.7553	0.230983		
2	963	0.783	0.335	0.7145	0.258529		
3	385	0.781	0.402	0.6901	0.274526		
4	81	0.646	0.474	0.6089	0.290871		
5	9	0.593	0.596	0.5513	0.278993		

Appendix 6-9: Q1. Univariate analysis of patient characteristics & EQ-VAS

Associations between binary characteristics and EQ-VAS

Independent-Samples Mann-Whitney U Test Significance *p*<.05

Binary Characteristic	N=3340	Missing	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	1840	234 (11.3%)	.020	70(34)	1315663.000	-2.334
Women	1500	239 (13.7%)		70(30)		
CHF	144	19 (11.7%)	.391	70(30)	239770.000	.858
No CHF	3196	454 (12.4%)		70(30)		
Hypertension	1466	198 (11.9%)	<.001	75(31)	1468806.500	3.460
No Hypertension	1874	275 (12.8%)		70(30)		
AF	425	66 (12.7%)	.005	70(30)	705882.500	2.806
No AF	2888	407 (12.4%)		70(30)		
Diabetes	2501	318 (11.3%)	<.001	70(35)	1154773.000	4.393
No Diabetes	839	155 (15.6%)		70(30)		
Prior Stroke	690	115 (14.3%)	<.001	70(30)	1007866.500	4.172
No Prior Stroke	2650	358 (11.9%)		70(34)		
Dementia	81	29 (26.4%)	.008	60(30)	154446.000	2.634
No Dementia	3259	444 (12.0%)		70(30)		

Associations between categorical characteristic and EQ-VAS

Significance *p*<.05

ISDN	n=3340	Median	IQR	Mean	Std. Dev
A	923	75	30	69.78	20.182
B	1184	70	30	67.58	20.451
C	1233	70	30	67.61	19.92

Independent Samples Kruskal-Wallis Test *p* =.011 (Test statistic = 9.024)

Associations between ordinal characteristics and EQ-VAS

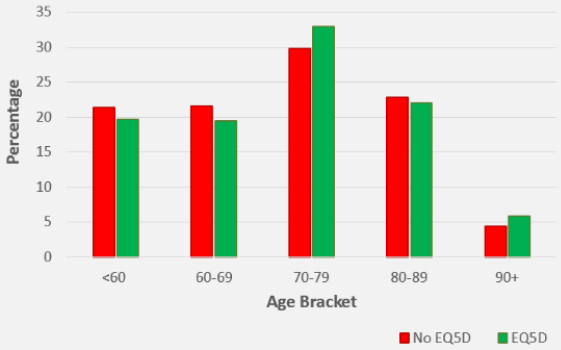
Significance *p*<.05

Age	n=3340	Median	IQR	Mean	Std. Dev	**Significant Association** Independent Samples Kruskal-Wallis	**Linear Trend** (Jonckheere-Terpstra)
< 60	691	70	30	66.04	21.186	**.017** Test statistic = 12.020	**.075**
60-69	695	70	30	68.74	19.962		
70-79	1042	70	20	68.66	20.194		
80-89	767	75	35	69.35	19.455		
90+	145	70	30	66.49	19.826		
IMD	**n=3294**	**Median**	**IQR**	**Mean**	**Std. Dev**	**<.001** Test statistic = 27.642	**<.001**
1	843	70	30	65.55	21.209		
2	831	70	30	68.03	19.968		
3	543	70	30	68.06	19.969		
4	563	75	25	70.15	19.575		
5	514	75	25	70.59	19.471		
NIHSS	**n=3340**	**Median**	**IQR**	**Mean**	**Std. Dev**	**<.001** Test statistic = 54.725	**<.001**
<5	1902	75	25	70.13	19.697		
5-14	1120	70	30	66.44	20.5		
15-20	223	60	30	63.96	19.8		
>20	95	60	25	60.28	22.376		
PremRS	**n=3340**	**Median**	**IQR**	**Mean**	**Std. Dev**	**<.001** Test statistic = 87.488	**<.001**
0	1961	75	25	70.42	19.486		
1	685	70	30	67.59	19.396		
2	390	65	30	65.02	20.381		
3	215	60	30	59.13	23.393		
4	77	60	28	59.01	23.313		
5	12	65	25	64.58	15.442		
DCmRS	**n=3340**	**Median**	**IQR**	**Mean**	**Std. Dev**	**<.001** Test statistic = 64.710	**<.001**
0	302	75	25	69.91	21.613		
1	713	75	25	70.8	18.274		
2	852	75	34	69.99	20.058		
3	836	70	30	67.29	19.987		
4	592	70	30	63.74	21.055		
5	45	60	33	57.24	21.207		
NoC	**n=3340**	**Median**	**IQR**	**Mean**	**Std. Dev**	**<.001** Test statistic = 47.222	**<.001**
0	976	75	25	70.89	20.009		
1	1140	70	30	68.37	19.924		
2	813	70	30	66.3	20.141		
3	336	70	30	66.06	20.598		
4	69	60	26	60.49	20.247		
5	6	70	58	65	30.822		

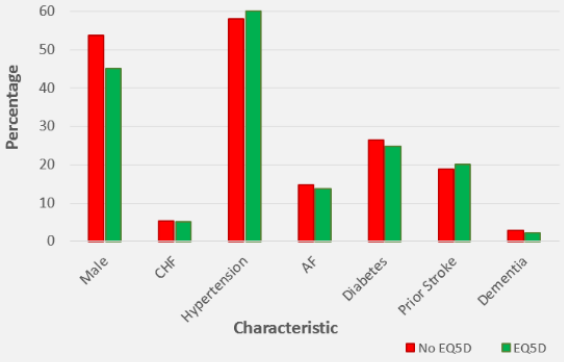
Appendix 6-10: Q2. Comparison of patients with and without EQ5D-5L

(Page 1/2) Age, binary characteristics, IMD and NIHSS

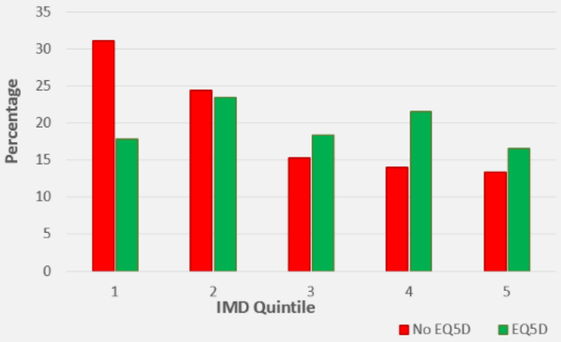
AGE	No EQ5D % (n=681)	EQ5D % (n=619)
<60	21.4	19.7
60-69	21.6	19.5
70-79	29.8	33.0
80-89	22.8	22.0
90+	4.4	5.8



Characteristic	No EQ5D % (n=681)	EQ5D % (n=619)
Gender (Male)	53.7	45.1
Congestive HF	5.4	5.2
Hypertension	58	60.1
Atrial Fibrillation	14.7	13.7
Diabetes	26.4	24.9
Prior Stroke	18.8	20
Dementia	2.8	2.3

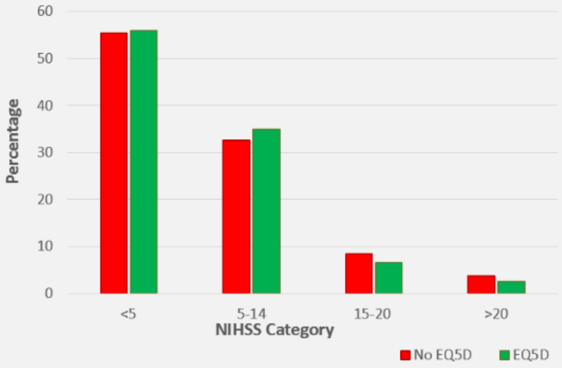


Index of Multiple Deprivation	No EQ5D % (13 missing*n=668)	EQ5D % (15 missing*, n=604)
1 (Most)	31.1	17.8
2	24.4	23.4
3	15.3	18.4
4	14	21.5
5 (Least)	13.4	16.5



*homeless pts or those in temporary accommodation have no IMD

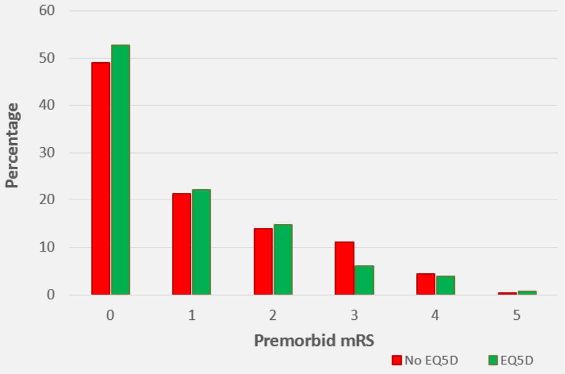
NIHSS on arrival	No EQ5D % (n=681)	EQ5D % (n=619)
<5	55.4	55.9
5-14	32.5	34.9
15-20	8.4	6.6
>20 (Most severe)	3.6	2.6



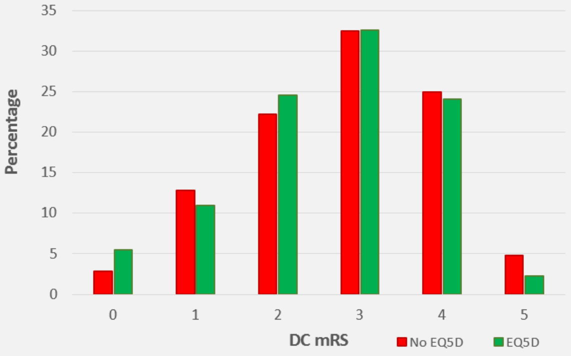
Appendix 6-10: Q2. Comparison of patients with and without EQ5D-5L

(Page 2/2) Pre mRS, DC mRS and Number of co-morbidities

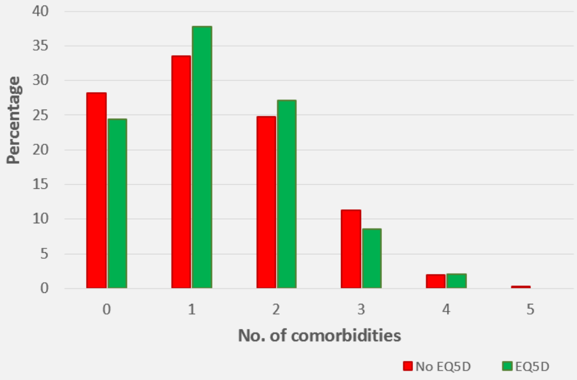
Pre-Morbid mRS	No EQ5D % (n=681)	EQ5D % (n=619)
0 (Independent)	49	52.7
1	21.4	22.1
2	14	14.7
3	11	6.0
4	4.3	3.9
5 (Dependent)	0.3	0.6
Median	0	1



DC mRS	No EQ5D % (n=681)	EQ5D % (n=619)
0 (Independent)	2.8	5.5
1	12.8	11.0
2	22.2	24.6
3	32.5	32.6
4	25	24.1
5 (Dependent)	4.7	2.2
Median	3	3

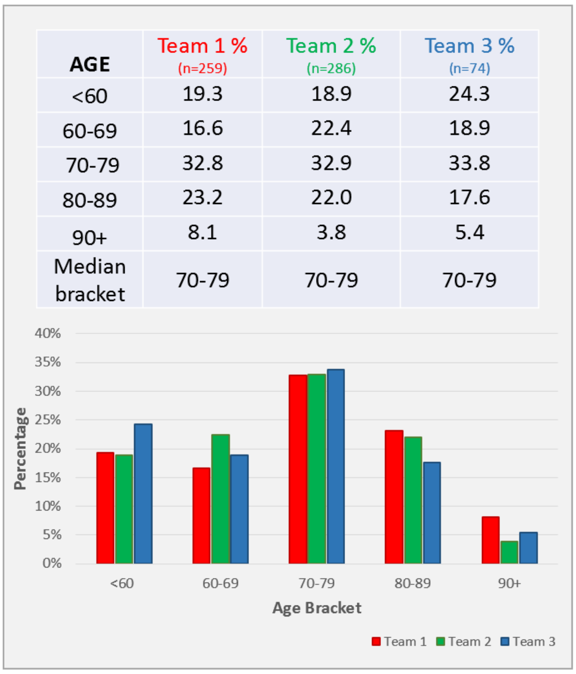


Number of co-morbidities	No EQ5D % (n=681)	EQ5D % (n=619)
0	28.2	24.4
1	33.5	37.8
2	24.8	27.1
3	11.3	8.6
4	1.9	2.1
5	0.3	0.0
Median	1	1

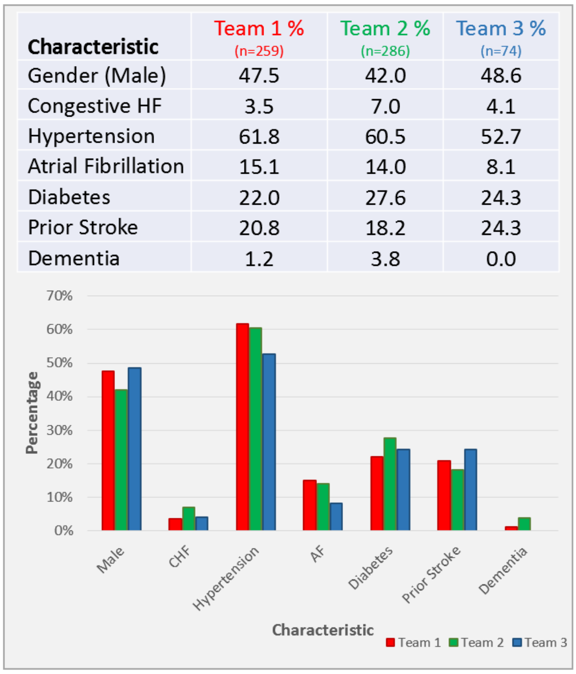


Appendix 6-11: Q2. Comparison of characteristics between teams

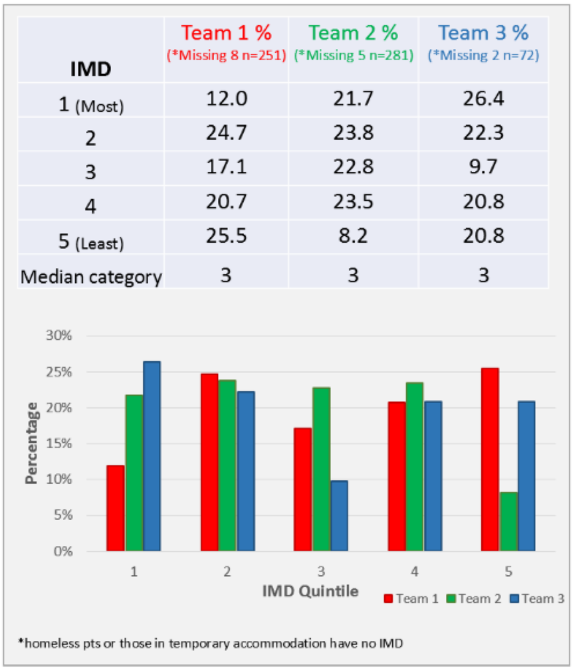
(Page 1/2) Age, binary characteristics, IMD and NIHSS



AGE	Team 1 % (n=259)	Team 2 % (n=286)	Team 3 % (n=74)
<60	19.3	18.9	24.3
60-69	16.6	22.4	18.9
70-79	32.8	32.9	33.8
80-89	23.2	22.0	17.6
90+	8.1	3.8	5.4
Median bracket	70-79	70-79	70-79

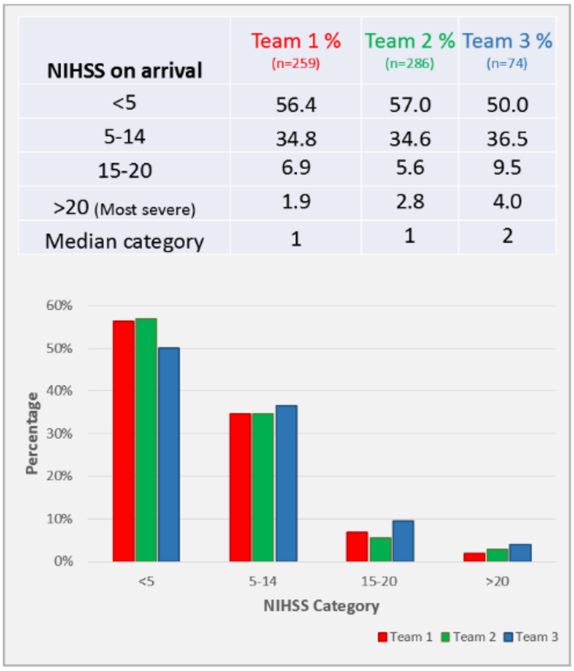


Characteristic	Team 1 % (n=259)	Team 2 % (n=286)	Team 3 % (n=74)
Gender (Male)	47.5	42.0	48.6
Congestive HF	3.5	7.0	4.1
Hypertension	61.8	60.5	52.7
Atrial Fibrillation	15.1	14.0	8.1
Diabetes	22.0	27.6	24.3
Prior Stroke	20.8	18.2	24.3
Dementia	1.2	3.8	0.0



IMD	Team 1 % (*Missing 8 n=251)	Team 2 % (*Missing 5 n=281)	Team 3 % (*Missing 2 n=72)
1 (Most)	12.0	21.7	26.4
2	24.7	23.8	22.3
3	17.1	22.8	9.7
4	20.7	23.5	20.8
5 (Least)	25.5	8.2	20.8
Median category	3	3	3

*homeless pts or those in temporary accommodation have no IMD

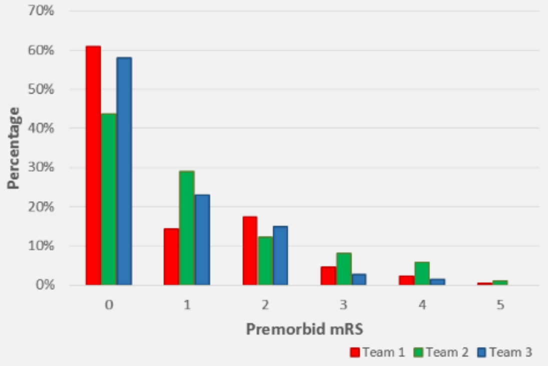


NIHSS on arrival	Team 1 % (n=259)	Team 2 % (n=286)	Team 3 % (n=74)
<5	56.4	57.0	50.0
5-14	34.8	34.6	36.5
15-20	6.9	5.6	9.5
>20 (Most severe)	1.9	2.8	4.0
Median category	1	1	2

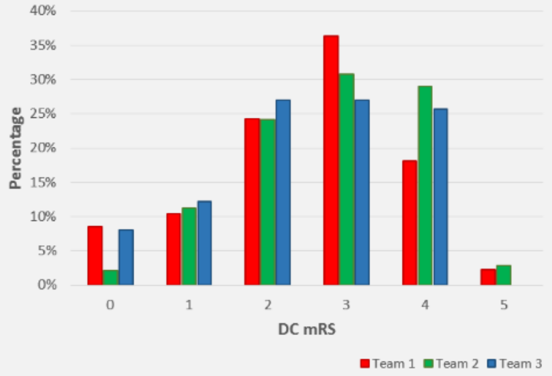
Appendix 6-11: Q2. Comparison of characteristics between teams

(Page 2/2) Pre mRS, DC mRS and Number of co-morbidities

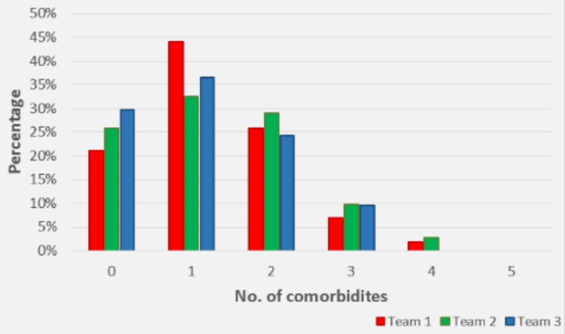
Pre mRS	Team 1 % (n=259)	Team 2 % (n=286)	Team 3 % (n=74)
0 (Independent)	61.0	43.7	58.1
1	14.3	29.0	23.0
2	17.4	12.4	14.9
3	4.6	8.0	2.6
4	2.3	5.9	1.4
5 (Dependent)	0.4	1.0	0.0
Median	0	1	0



DC mRS	Team 1 % (n=259)	Team 2 % (n=286)	Team 3 % (n=74)
0 (Independent)	8.5	2.1	8.1
1	10.4	11.2	12.2
2	24.3	24.1	27.0
3	36.3	30.8	27.0
4	18.2	29.0	25.7
5 (Dependent)	2.3	2.8	0.0
Median	3	3	3



Number of co-morbidities	Team 1 % (n=259)	Team 2 % (n=286)	Team 3 % (n=74)
0	21.3	25.9	29.7
1	44.0	32.5	36.5
2	25.9	29.0	24.3
3	6.9	9.8	9.5
4	1.9	2.8	0.0
5	0.0	0.0	0.0
Mean No.	1.2	1.3	1.1



Appendix 6-12: Q2. Univariate analysis of characteristics & change in domain

Associations between characteristics and change in mobility domain

Independent-Samples Mann-Whitney U Test *Significance *p*<.05

Binary Characteristic	N=619	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	279	.674	0(1)	46542.500	-.421
Women	340		0(1)		
CHF	587	.019	0(1)	7200.000	-2.338
No CHF	32		0(1)		
Hypertension	372	.394	0(1)	44175.500	-.852
No Hypertension	247		0(1)		
Atrial Fibrillation	85	.704	0(1)	22141.000	-.380
No Atrial Fibrillation	534		0(1)		
Diabetes	154	.769	0(1)	35268.500	-.293
No Diabetes	465		0(1)		
Prior Stroke	124	.435	0(1)	29367.000	-.781
No Prior Stroke	495		0(1)		
Dementia	14	.187	0(1)	3403.500	-1.321
No Dementia	605		0(1)		

Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI [ab]	
			Lower CI	Upper CI
Age	-.054	.178	-.135	.027
IMD	-.091	.025	-.172	-.009
No. of comorbidities	.012	.760	-.069	.093
NIHSS	.040	.319	-.041	.121
Pre-mRS	-.027	.497	-.108	.054
DC mRS	-.048	.234	-.128	.033

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
Team	2	.053	5.860

Associations between characteristics and change in self-care domain

Independent-Samples Mann-Whitney U Test *Significance *p*<.05

Binary Characteristic	N=619	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	279	.344	0(1)	45461.500	-.947
Women	340		0(1)		
CHF	587	<.001	0(1)	6214.000	-3.436
No CHF	32		0(1)		
Hypertension	372	.592	0(1)	44845.500	-.536
No Hypertension	247		0(1)		
Atrial Fibrillation	85	.537	0(1)	21807.000	-.618
No Atrial Fibrillation	534		0(1)		
Diabetes	154	.335	0(1)	34062.500	-.965
No Diabetes	465		0(1)		
Prior Stroke	124	.181	0(1)	28451.500	-1.339
No Prior Stroke	495		0(1)		
Dementia	14	.508	0(1)	3824.000	-.662
No Dementia	605		0(1)		

Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI [ab]	
			Lower CI	Upper CI
Age	-.086	.032*	-.166	-.005
IMD	-.104	.010*	-.185	-.022
No. of comorbidities	.012	.773	.773	.093
NIHSS	-.079	.050	-.159	.002
Pre-mRS	-.035	.382	-.116	.046
DC mRS	-.110	.006*	-.189	-.029

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
Team	2	.003*	11.777

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Appendix 6-12: Q2. Univariate analysis of patient characteristics & change in domain (Page2/3)

Associations between characteristics and change in activity domain

Independent-Samples Mann-Whitney U Test *Significance *p*<.05

Binary Characteristic	N=619	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	279	.928	-1(1)	47237.000	-.090
Women	340		-1(1)		
CHF	587	.004	0(2)	6677.500	-2.845
No CHF	32		-1(2)		
Hypertension	372	.479	-1(1)	44449.000	-.708
No Hypertension	247		-1(2)		
Atrial Fibrillation	85	.569	0(2)	21850.000	-.570
No Atrial Fibrillation	534		-1(2)		
Diabetes	154	.381	-1(2)	34174.000	-.876
No Diabetes	465		-1(1)		
Prior Stroke	124	.998	-1(1)	30685.500	-.003
No Prior Stroke	495		-1(2)		
Dementia	14	.013	0(1)	2647.000	-2.479
No Dementia	605		-1(2)		

Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI ab	
			Lower CI	Upper CI
Age	.013	.755	-.069	.094
IMD	-.023	.573	-.105	.059
No. of comorbidities	.032	.429	-.049	.113
NIHSS	-.024	.558	-.104	.058
Pre-mRS	.024	.551	-.057	.105
DC mRS	-.049	.220	-.130	.032

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
Team	2	.020*	7.823

Associations between characteristics and change in pain domain

Independent-Samples Mann-Whitney U Test *Significance *p*<.05

Binary Characteristic	N=619	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	279	.485	0(1)	45990.000	-.698
Women	340		0(0)		
CHF	587	.882	0(1)	9256.000	-.148
No CHF	32		0(1)		
Hypertension	372	.418	0(1)	44299.500	-.809
No Hypertension	247		0(1)		
Atrial Fibrillation	85	.945	0(1)	22597.000	-.069
No Atrial Fibrillation	534		0(1)		
Diabetes	154	.374	0(2)	34214.000	-.888
No Diabetes	465		0(0)		
Prior Stroke	124	.398	0(1)	29288.000	-.845
No Prior Stroke	495		0(1)		
Dementia	14	.148	0(2)	3344.500	-1.445
No Dementia	605		0(1)		

Spearman's Correlation **Significance p<.01

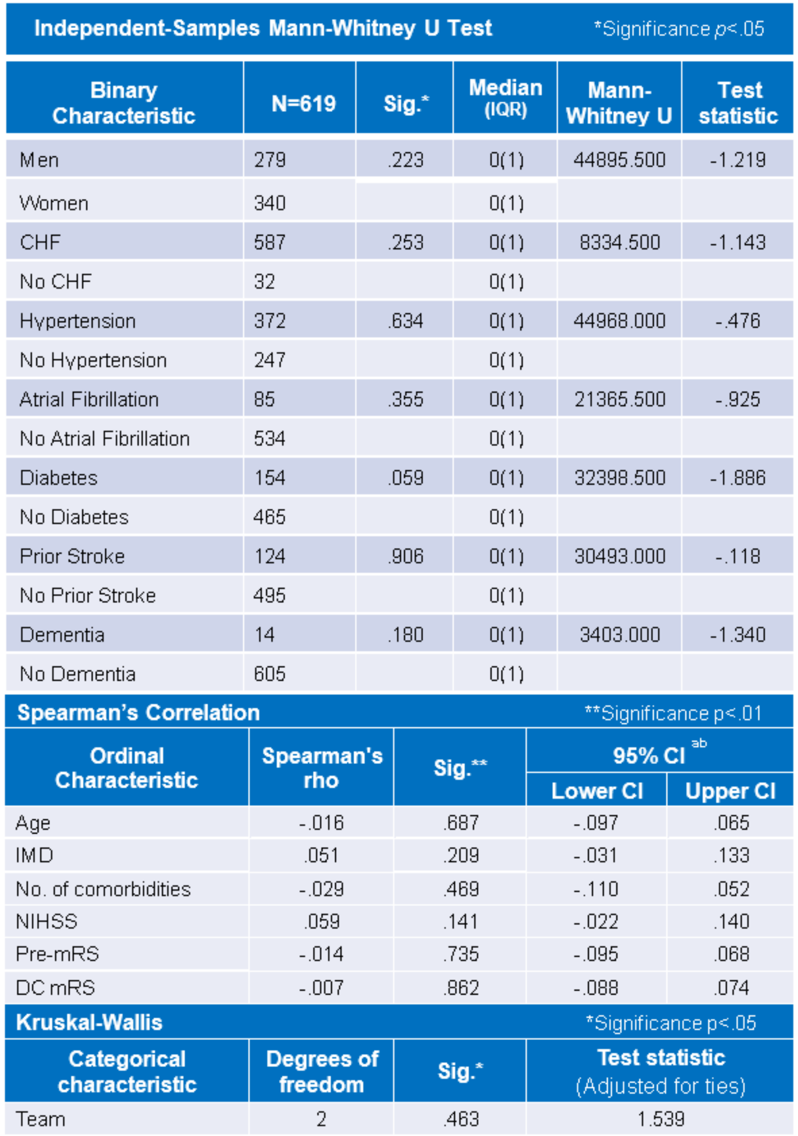
Ordinal Characteristic	Spearman's rho	Sig.**	95% CI ab	
			Lower CI	Upper CI
Age	-.023	.567	-.104	.058
IMD	.002	.960	-.080	.084
No. of comorbidities	-.017	.672	-.098	.064
NIHSS	.000	.990	-.081	.082
Pre-mRS	-.094	.019	-.174	-.013
DC mRS	-.050	.210	-.131	.031

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
Team	2	.205	3.168

Appendix 6-12: Q2. Univariate analysis of patient characteristics & change in domain (Page 3/3)

Associations between characteristics and change in anxiety domain



Independent-Samples Mann-Whitney U Test *Significance *p*<.05

Binary Characteristic	N=619	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	279	.223	0(1)	44895.500	-1.219
Women	340		0(1)		
CHF	587	.253	0(1)	8334.500	-1.143
No CHF	32		0(1)		
Hypertension	372	.634	0(1)	44968.000	-.476
No Hypertension	247		0(1)		
Atrial Fibrillation	85	.355	0(1)	21365.500	-.925
No Atrial Fibrillation	534		0(1)		
Diabetes	154	.059	0(1)	32398.500	-1.886
No Diabetes	465		0(1)		
Prior Stroke	124	.906	0(1)	30493.000	-.118
No Prior Stroke	495		0(1)		
Dementia	14	.180	0(1)	3403.000	-1.340
No Dementia	605		0(1)		

Spearman's Correlation **Significance p<.01

Ordinal Characteristic	Spearman's rho	Sig.**	95% CI [ab]	
			Lower CI	Upper CI
Age	-.016	.687	-.097	.065
IMD	.051	.209	-.031	.133
No. of comorbidities	-.029	.469	-.110	.052
NIHSS	.059	.141	-.022	.140
Pre-mRS	-.014	.735	-.095	.068
DC mRS	-.007	.862	-.088	.074

Kruskal-Wallis *Significance p<.05

Categorical characteristic	Degrees of freedom	Sig.*	Test statistic (Adjusted for ties)
Team	2	.463	1.539

[a] Estimation is based on Fisher's r-to-z transformation.

[b] Estimation of standard error is based on the formula proposed by Fieller, Hartley, and Pearson

Strength of relationship: 0.5-1 Strong, 0.3-0.49 Mod, 0.1-0.29 Weak

Appendix 6-13: Q2. Univariate analysis characteristics & change in EQIndex

Associations between binary characteristics and change in EQIndex

Independent-Samples Mann-Whitney U Test Significance *p*<.05

Binary Characteristic	N=619	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	279	.191	.0780 (.25)	44534.500	-1.308
Women	340		.0500 (.25)		
CHF	587	.010*	.0000 (.27)	6864.000	-2.567
No CHF	32		.0630 (.25)		
Hypertension	372	.563	.0565 (.26)	44683.000	-.578
No Hypertension	247		.0630 (.24)		
AF	85	.402	.0210 (.31)	21413.000	-.837
No AF	534		.0630 (.24)		
Diabetes	154	.403	.0795 (.31)	34196.000	-.837
No Diabetes	465		.0580 (.22)		
Prior Stroke	124	.784	.0585 (.30)	30201.500	-.274
No Prior Stroke	495		.0580 (.25)		
Dementia	14	.363	.0000 (.34)	3633.500	-.909
No Dementia	605		.0590 (.25)		

Associations between categorical characteristic and change in EQIndex

Significance *p*<.05

Team	n=619	Median	IQR	Mean	Std. Dev
1	259	.0810	.21	.0768	.21155
2	286	.0500	.27	.0611	.26231
3	74	.0850	.29	.1336	.25887

Independent Samples Kruskal-Wallis Test *p* =.100 (Test statistic = 4.608)

Associations between ordinal characteristics and change in EQIndex

Significance *p*<.05

Age	n=619	Median	IQR	Mean	Std. Dev	**Significant Association** Independent Samples Kruskal-Wallis	**Linear Trend** (Jonckheere-Terpstra)
< 60	122	.0605	.25	.0601	.24460	.843 Test statistic = 1.409	.450
60-69	121	.0810	.27	.0746	.25634		
70-79	204	.0500	.26	.0776	.24186		
80-89	136	.0595	.26	.0862	.24609		
90+	36	.1080	.18	.0927	.17931		
IMD	**n=604**	**Median**	**IQR**	**Mean**	**Std. Dev**	.829 Test statistic = 1.487	.452
1	110	.0585	.30	.0542	.30507		
2	145	.0650	.26	.0833	.23775		
3	114	.0435	.22	.0676	.20428		
4	133	.0610	.25	.0784	.24248		
5	102	.0650	.23	.0892	.21985		
NIHSS	**n=619**	**Median**	**IQR**	**Mean**	**Std. Dev**	.152 Test statistic = 5.293	.732
<5	346	.0600	.21	.0717	.21667		
5-14	216	.0640	.27	.0875	.26353		
15-20	41	.0560	.45	.0954	.31244		
>20	16	-.0240	.24	-.0236	.27258		
PremRS	**n=619**	**Median**	**IQR**	**Mean**	**Std. Dev**	.610 Test statistic = 3.589	.382
0	326	.0701	.22	.0697	.20991		
1	137	.0580	.23	.0716	.24700		
2	91	.1000	.28	.0896	.27239		
3	37	.0740	.41	.1230	.32781		
4	24	.0065	.29	.0659	.34080		
5	4	.2575	.56	.2560	.29860		
DCmRS	**n=619**	**Median**	**IQR**	**Mean**	**Std. Dev**	.220 Test statistic = 7.007	.205
0	34	.0540	.27	.0928	.19566		
1	68	.0655	.19	.0822	.21213		
2	152	.0500	.19	.0350	.23439		
3	202	.0580	.22	.0681	.22133		
4	149	.0950	.35	.1268	.29108		
5	14	-.0035	.43	.0401	.23415		
NoC	**n=619**	**Median**	**IQR**	**Mean**	**Std. Dev**	.049 Test statistic = 3.589	.732
0	151	.0560	.24	.0567	.23187		
1	234	.0840	.21	.0932	.23608		
2	168	.0565	.31	.0826	.23633		
3	53	.0590	.30	.0791	.30491		
4	13	-.0520	.31	-.1015	.22466		

Appendix 6-14: Q2. Univariate analysis patient characteristics & change in EQ-VAS

Associations between binary characteristics and change in EQVAS

Independent-Samples Mann-Whitney U Test   Significance *p*<.05

Binary Characteristic	N=619	Missing	Sig.*	Median (IQR)	Mann-Whitney U	Test statistic
Men	279	44 (12.9%)	.444	5 (30)	33582.500	-.766
Women	340	43 (15.4%)		10 (30)		
CHF	32	8 (25.0%)	.306	5 (54)	5345.000	-1.023
No CHF	587	79 (13.5%)		9 (25)		
Hypertension	372	56 (15.1%)	.862	10 (29)	34430.500	.174
No Hypertension	247	31 (12.6%)		5 (27)		
AF	85	18 (21.2%)	.137	0 (30)	13831.500	-1.488
No AF	534	69 (12.9%)		10 (29)		
Diabetes	154	25 (16.2%)	.346	10 (30)	27422.000	.942
No Diabetes	465	62 (13.3%)		5 (25)		
Prior Stroke	124	16 (12.9%)	.113	10 (25)	25151.000	1.585
No Prior Stroke	495	71 (14.3%)		5 (30)		
Dementia	14	5 (35.7%)	.055	35 (74)	3229.000	1.920
No Dementia	605	82 (13.6%)		8 (25)		

Associations between categorical characteristic and change in EQ-VAS

Significance *p*<.05

Team	n=532	Median	IQR	Mean	Std. Dev
1	232	10	25	10.65	23.963
2	239	0	35	2.71	25.556
3	61	10	25	10.66	20.557

Independent Samples Kruskal-Wallis Test *p* =.001 (Test statistic =13.762)

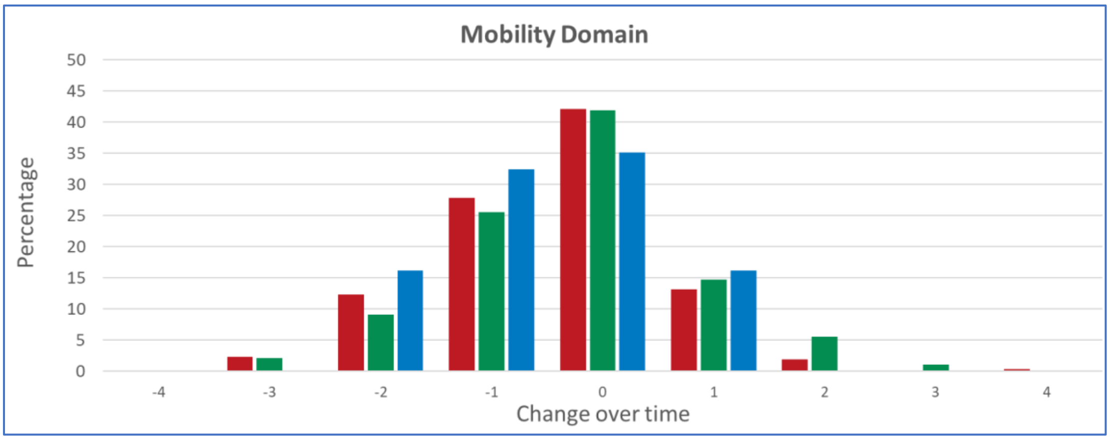
Associations between ordinal characteristics and Change in EQ-VAS

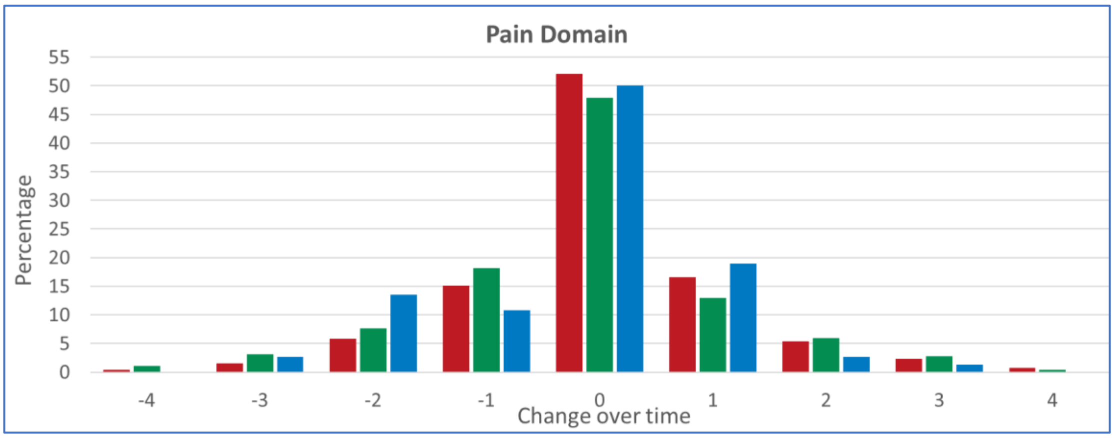
Significance *p*<.05

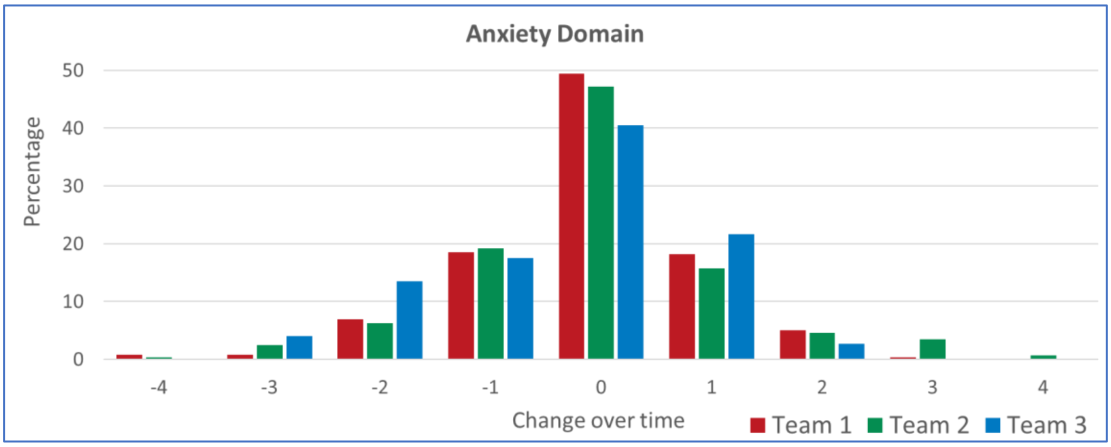
Age	n=532	Median	IQR	Mean	Std. Dev	**Significant Association** Independent Samples Kruskal-Wallis	**Linear Trend** (Jonckheere-Terpstra)
< 60	106	10	24	10.08	24.238	.028 Test statistic = 10.899	.263
60-69	105	0	25	5.58	22.349		
70-79	186	10	25	6.28	25.276		
80-89	104	8.5	25	9.64	26.932		
90+	31	0	28	-1.90	18.897		
IMD	n=519	**Median**	**IQR**	**Mean**	**Std. Dev**	.784 Test statistic = 1.736	.743
1	98	9	29	8.03	23.606		
2	129	8	30	4.45	23.773		
3	85	5	32	7.06	26.244		
4	113	5	30	6.46	25.446		
5	94	10	25	8.39	23.676		
NIHSS	**n=532**	**Median**	**IQR**	**Mean**	**Std. Dev**	.319 Test statistic = 3.511	.301
<5	306	5	29	5.95	24.463		
5-14	185	10	30	9.4	25.208		
15-20	28	5	29	6.86	20.419		
>20	13	5	33	1.08	27.660		
PremRS	**n=532**	**Median**	**IQR**	**Mean**	**Std. Dev**	.322 Test statistic = 5.842	.820
0	288	10	25	7.26	23.564		
1	117	0	25	5.95	24.354		
2	78	10	30	8.68	25.515		
3	27	0	20	1.89	29.289		
4	18	12.5	47	7.67	31.582		
5	4	35	36	28.75	20.156		
DCmRS	**n=532**	**Median**	**IQR**	**Mean**	**Std. Dev**	.560 Test statistic = 3.926	.120
0	31	0	35	3.55	27.348		
1	64	5	25	3.95	19.618		
2	136	8	29	5.68	25.621		
3	174	10	30	9.40	22.932		
4	116	10	30	8.52	26.472		
5	11	5	35	0.73	34.604		
NoC	**n=532**	**Median**	**IQR**	**Mean**	**Std. Dev**	.405 Test statistic = 4.009	.508
0	135	10	25	7.96	23.320		
1	202	5	30	4.96	24.551		
2	143	5	30	7.93	23.966		
3	43	15	30	12.26	29.196		
4	9	0	50	3.33	31.524		

Appendix 6-15: Q2. Distributions of change in individual domains

(By team)







Appendix 6-16: Comparison of study outcomes

Study	Sample	Time poststroke	Percentage of participants reporting problems in specific domain (scoring >1)					EQIndex Mean (SD) *Median (IQR)	EQ-VAS Mean (SD) *Median (IQR)
			Mobility	Self-Care	Activity	Pain	Anxiety		
Døhl[301] (2020) Norway	N=380	10-16 weeks	Not provided					0.83 (0.17)	Not provided
	Aim: To test whether generic HRQoL predicts health care utilisation for stroke survivors as well as more specific indexes								
Hernández[294] (2023) Columbia	N=91	6-12 months	55	48.3	59.5	52.8	55.1	*0.63 (1.0-0.26)	80 (Not provided)
	Aim: To assess HRQOL in Colombian patients with stroke and correlating its results with the modified Rankin Scale								
Mei[293] (2020) China	N=1709	Unlimited (38% > 5yrs)	61	26	38.8	69.8	23.3	0.88 (0.20)	68.4 (17.76)
	Aim: To identify influencing factors of HRQoL and its domain-specific contents in stroke patients in rural areas								
Oemrawsingh[302] (2019) Netherlands	N=1022	3 months	Not provided					*0.65 (1.0-0.83)	Not provided
	Aim: To develop and compare case-mix models for stroke mortality and a patient-reported outcome measure.								
Wong[295] (2021) Malaysia	N=366	Unlimited (49% > 1yr)	85	41	82	63	51	*0.67 (+/- 0.37)	60.3 (14.2)
	Aim: To assess the HRQoL profiles and explore dimension-specific factors of HRQoL among stroke survivors.								
Russell (2024) England	N=3,813	6 months	39	54	36	51	55	*.81 (.297)	*70 (30)
	Aim: To explore influences on EQ5D-5L variability for community dwelling stroke survivors in first six months post-stroke								

Abbreviations: SD – Standard deviation, IQR – Interquartile range