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Developing a new self-harm assessment tool with and for autistic adults

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Abstract

Research indicates that autistic individuals and those with high autistic traits are more likely to self-harm than non-autistic individuals. However, it remains unclear which, if any, self-harm assessment tools are available to assess self-harm in autistic adults. As a result, researchers and service providers struggle to accurately identify these difficulties and recommend appropriate support and treatment.

This thesis aims to develop a new self-harm assessment tool in collaboration with and for autistic adults across four empirical studies using mixed methodologies. First, a systematic review applying the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) identified frequently used self-harm assessment tools for autistic and general population adults and evaluated their measurement properties (Chapter 2). Second, perceptions of existing self-harm assessment tools were explored through focus groups of autistic adults with lived experience of self-harm and the professionals who support them (Chapter 3). Third, two rounds of cognitive interviews with autistic adults with lived experience of self-harm informed the development and refinement of a new self-harm assessment tool (Chapter 4). Finally, an online survey was used to pilot the newly developed tool in autistic adults with lived experience of self-harm and assess its preliminary measurement properties (Chapter 5).

Findings revealed that no existing self-harm assessment tools had been specifically developed or validated for autistic adults (Chapter 2). Moreover, autistic adults and the professionals who support them reported that existing self-harm assessment tools were neither appropriate nor acceptable for this population (Chapter 3). Over two rounds of cognitive interviews, the first self-harm assessment

tool for autistic adults was co-developed: the Self-harm Questionnaire – Autism (SHQ-A). Key issues related to item clarity, relevance, and representativeness were identified and addressed (Chapter 4). Additionally, preliminary evidence for measurement properties of the new tool was promising across content validity, structural validity (exploratory factor structure), internal consistency, test-retest reliability, and construct validity (convergent and divergent) in autistic adults with lived experience of self-harm (Chapter 5).

Therefore, this thesis highlights significant gaps in our understanding of self-harm in autism and underscores the importance of co-producing measurement instruments with autistic populations. Key strengths included the mixed methods approach and community involvement, while limitations of online research and sample representativeness are discussed. Overall, the findings have important implications for identifying and understanding self-harm in autism across research and clinical practice, along with recommendations for policy. However, further research is needed to validate the SHQ-A (i.e., confirmatory factor analysis) and adapt it for other populations, such as autistic youth and those with co-occurring ID.

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List of Abbreviations

Abbreviation	Definition
ADAT-A	Autistic Depression Assessment Tool – Adult
ADHD	Attention Deficit Hyperactivity Disorder
AQ	Autism Quotient
ASA-A	Anxiety Scale for Autism – Adults
ASC	Autism Spectrum Conditions
BSBEQ	Body-focused Self-damaging Behavior Expectancies Questionnaire
CaTS-A	Card Sort Task for Self-Harm – Autism
CANDI	Clinician-Administered Non-Suicidal Self-Injury Disorder Index
CFA	Confirmatory Factor Analysis
COSMIN	COnsensus-based Standards for the Selection of Health Measurement INstruments
CSII	Cardiff Self-Injury Inventory
DHSC	Department of Health and Social Care
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSHI	Deliberate Self-Harm Inventory
EFA	Exploratory Factor Analysis
FASM	Functional Assessment of Self-Mutilation
FFM	Four-Functions Model
GRADE	Grading of Recommendations Assessment, Development and Evaluation
ICD	International Classification of Diseases
ICC	Intraclass Correlation Coefficient

ID	Intellectual Disability
IfES	Inventory for the Functional Assessment of Self-Injurious Behavior
IPTS	Interpersonal Theory of Suicide
ISAS	Inventory of Statements About Self-Injury
KMO	Kaiser-Meyer-Olkin
MCAR	Missing Completely at Random
MCSDS	Marlowe-Crowne Social Desirability Scale
MINI	Mini-International Neuropsychiatric Interview
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NSSI	Non-Suicidal Self-Injury
NSSI-AT	Non-Suicidal Self-Injury – Assessment Tool
NSSI-D	Non-Suicidal Self-Injury Disorder
NSSIDS	Non-Suicidal Self-Injury Disorder Scale
OSI	Ottawa Self-Injury Inventory
PABAK	Prevalence and Bias-adjusted Kappa
PDA	Pathological Demand Avoidance
PHQ-9	Patient Health Questionnaire-9
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses Standards
QNSSI	Questionnaire for Non-Suicidal Self-Injury
R-NSSI-Q	Repetitive Non-Suicidal Self-Injury Questionnaire
SASII	Suicide Attempt Self-Injury Interview
SBQ-ASC	Suicidal Behaviours Questionnaire – Autism Spectrum Conditions
SBQ-R	Suicidal Behaviours Questionnaire-Revised

SHBQ	Self-Harm Behavior Questionnaire
SHI	Self-Harm Inventory
SHQ-A	Self-Harm Questionnaire – Autism
SIQ-TR	Self-Injury Questionnaire – Treatment Related
SIB	Self-Injurious Behaviour
SITBI	Self-Injurious Thoughts and Behaviour Interview

Chapter 1. General Introduction.

i. Preface

This chapter will establish the rationale for this thesis by providing context on self-harm and autism. First, the conceptualisation and epidemiology of self-harm in the general population will be established, followed by a discussion of theoretical models of self-harm and links to suicidal behaviour, as well as an evaluation of current measurement instruments and language use. The background for autism will then be provided, considering disability paradigms and language use. Once this foundation has been set, the literature on both self-harm and autism will be examined, highlighting differences in conceptualisations, epidemiology, risk factors and markers, and key research gaps – particularly the lack of validated self-harm assessment tools for autistic individuals. The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) method is then introduced as a framework for evaluating, adapting and developing self-harm assessment tools with and for autistic individuals. Finally, participatory approaches and ethical considerations are discussed in relation to the current methodology, leading to the presentation of the thesis aims.

1.1. Self-harm

1.1.1. Conceptualisations in the General Population

The National Institute for Health and Care Excellence (NICE, 2022) defines self-harm in guidance NG225 as any act of intentional self-poisoning or self-injury, regardless of underlying motivation. Self-harm behaviours include, but are not limited to, self-cutting, self-hitting, self-burning, self-biting, and skin-picking (Klonsky, 2011; Pompili et al., 2015). This definition encompasses both actions intended to end life (e.g., suicide attempts; Hawton et al., 2012) and those without suicidal intent (e.g., non-suicidal self-injury [NSSI]; Nock & Favazza, 2009). Some researchers argue that self-harm behaviours with suicidal intent versus those without are conceptually and functionally distinct, with the function of NSSI primarily serving to manage or alter internal states, rather than to end life (Butler & Malone, 2013). However, others suggest that these behaviours exist along a continuum, with motivations and risk fluctuating over time (Kapur et al., 2013). Regardless of intent, self-harm represents one of the strongest risk factors for future suicide, supporting the idea of a progression rather than a rigid distinction between categories (Favril et al., 2022; Hawton et al., 2020; Runeson et al., 2016). Furthermore, individuals who report engaging in NSSI often have a history of attempted suicide and vice versa (O'Connor et al., 2018). This overlap further challenges the categorisation of self-harm behaviours based solely on intent and underscores the need for a more nuanced understanding.

Various issues further compound this complexity surrounding self-harm. Research has often grouped self-harm behaviours without clarifying intent or has used inconsistent terminology such as “self-injury”, “parasuicide”, “self-mutilation”, or

“deliberate self-harm” (Nock, 2010). Historically, NSSI has also only existed in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a symptom of borderline personality disorder (Hooley et al., 2020). However, growing evidence suggests that self-harm is a transdiagnostic behaviour associated with a wide range of internalising, externalising, and personality diagnoses, which can also occur independently of psychiatric conditions (Glenn & Klonsky, 2013; Nock et al., 2006; Selby et al., 2012). Non-suicidal self-injury disorder (NSSI-D) has been proposed in the DSM-5 (American Psychiatric Association, 2013) as a condition warranting further study, with the aim to differentiate NSSI from suicide attempts and improve conceptual clarity in research and clinical practice (Zetterqvist et al., 2020).

1.1.2. Epidemiology in the General Population

Self-harm is a major public health concern within the general population, but the total number of specific self-harm episodes worldwide remains unknown (Knipe et al., 2022). Each year, more than 720,000 people die by suicide (World Health Organization, 2024), and it is estimated that there are approximately 20 self-harm episodes for every suicide death, with each episode referring to a non-fatal act of self-injury or self-poisoning (Vos et al., 2020). Moreover, prevalence estimates vary across age groups. A meta-analysis reported global lifetime prevalence rates of 22.1% for NSSI and 13.7% for deliberate self-harm among children and adolescents (Lim et al., 2019). In contrast, lifetime NSSI prevalence was 17.7% in college students across nine countries, while estimates ranged from 2.7% to 5.9% in nationally representative samples of adults (Christoffersen et al., 2015; Klonsky, 2011; Liu, 2023). These discrepancies are partly attributable to inconsistent terminology, but also the result of under-reporting. For example, evidence from the UK suggests that 59.4% of adults and 90% of adolescents (aged 12-17 years) who

engage in self-harm do not contact medical or psychological services afterwards (Geulayov et al., 2018; McManus et al., 2019).

Moreover, adolescence is considered a critical period for the onset of NSSI, with prevalence peaking between the ages of 14 and 16 and the highest risk observed at 14 and 15 years old (Gandhi et al., 2018; Plener et al., 2015). A meta-analysis of NSSI-specific risk factors revealed that a prior history of NSSI, Cluster B personality disorder and hopelessness were the strongest indicators for self-harm (Fox et al., 2020). Additionally, higher rates of self-harm are also observed among females, sexual and gender minorities, autistic individuals, younger age groups, individuals from disadvantaged socioeconomic backgrounds, and those with co-occurring psychiatric conditions (Blanchard et al., 2021; Bresin & Schoenleber, 2015; Kiekens et al., 2023; Liu, 2023). Beyond its association with suicide risk, self-harm is also linked to other adverse outcomes, including substance misuse, persistent mental health difficulties, and unemployment (Beckman et al., 2019; Moran et al., 2015; Ohlis et al., 2020). Given its far-reaching implications, addressing self-harm in research and clinical contexts is critical to reducing both immediate harm and long-term consequences.

1.1.3. *Theoretical Models of Self-harm*

Several theories seek to explain the development and maintenance of self-harm behaviour, sharing commonalities across behavioural reinforcement and the role of affect regulation (Hird et al., 2024). One of the earliest theories is the Experiential Avoidance Model (Chapman et al., 2006), which suggests NSSI is primarily maintained by negative reinforcement to escape or avoid aversive emotional experiences. This idea is extended further in the Emotional Cascade

Model (Selby et al., 2008), where NSSI serves as a distraction from cycles of heightened rumination and negative affect (i.e., emotional cascades). However, the Four-Function Model (FFM; Nock & Prinstein, 2004) is one of the few to consider interpersonal determinants and consequences of self-harm, as well as including a positive reinforcement component.

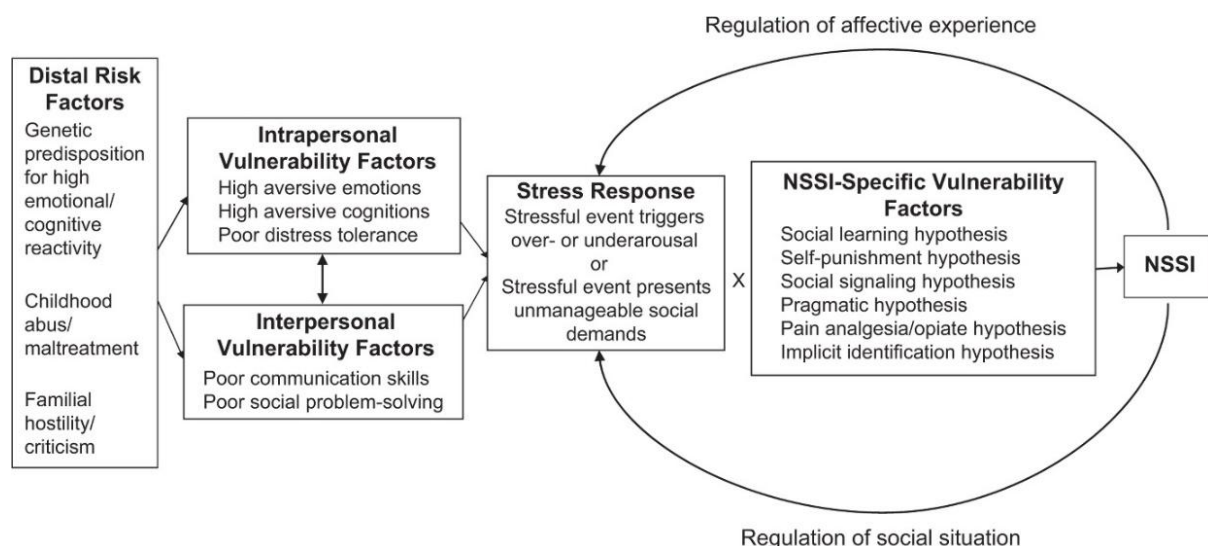
Specifically, the FFM proposes that NSSI serves four functions that differ along two dimensions: automatic vs social motives and positive vs negative reinforcement (Nock & Prinstein, 2004). Automatic-negative reinforcement occurs when an individual uses self-harm to escape, reduce or distract from unwanted affective states (e.g., to stop bad feelings); automatic-positive reinforcement to induce a desired affective state (e.g., to feel something, even if it is pain); social-negative reinforcement as a means of avoiding interpersonal demands from unpleasant tasks or situations (e.g., to avoid punishment from others); and social-positive reinforcement to gain something from others, such as care or attention (e.g., to let others know how unhappy they are; Hird et al., 2024; Nock & Prinstein, 2004). In line with this, empirical support is consistently provided for automatic functions of self-harm, particularly negative reinforcement, whereas evidence for interpersonal reinforcement is less conclusive (Bentley et al., 2014; Hepp et al., 2020; Taylor et al., 2018).

However, a limitation of the FFM is that it does not account for broader risk factors or cognitive processes that contribute to self-harm behaviour. To address this gap, Nock (2009) developed the Integrated Model (see Figure 1). This model proposes that genetic and environmental risk factors contribute to the development of intra- and interpersonal vulnerabilities, which increase the likelihood of engaging in NSSI as a stress response. These vulnerability factors correspond with the functions

outlined in the FFM and have parallels with the Experiential Avoidance and Emotional Cascade Models, where individuals with high aversive cognitions or emotions may be more likely to use NSSI to regulate their distress. Further NSSI-specific vulnerability factors also increase the risk that an individual will engage in self-harm behaviours rather than other maladaptive coping strategies (e.g., alcohol or drug use; Nock & Favazza, 2009). For example, exposure to self-harm behaviours through family, friends or media may increase the likelihood of engagement (i.e., social learning hypothesis; Syed et al., 2020). Alternatively, self-harm may satisfy a commonly endorsed function of self-punishment (i.e., self-punishment hypothesis; Taylor et al., 2018), or the physical pain from self-harm may trigger the release of endorphins which dull emotional distress and produce a sense of relief (e.g., pain analgesia/ opiate hypothesis; Selby et al., 2019).

Figure 1.

An integrated theoretical model of the development and maintenance of self-injury (Nock, 2009).



1.1.4. *Linking Self-harm and Suicidal Behaviour*

Alternatively, the Interpersonal Theory of Suicide (IPTS; Joiner, 2005; Van Orden et al., 2010) offers a framework for understanding the link between NSSI and suicidal behaviours. According to the IPTS, an individual must overcome the innate fear and pain associated with death in order to end their life – referred to as the acquired capability for suicide. Repeated NSSI may precede the development of suicidal behaviours by habituating an individual to painful and provocative events (Hamza et al., 2012). However, the IPTS suggests that suicide attempts only occur when acquired capability (i.e., from NSSI) is coupled with perceived burdensomeness (i.e., feeling like a burden on others) and thwarted belongingness (i.e., lack of social connectedness and support; Hamza et al., 2012; Joiner, 2005; Van Orden et al., 2010). Strong empirical support for the IPTS has been demonstrated in a meta-analysis of 114 studies, which showed significant interactions between thwarted belongingness and perceived burdensomeness with suicidal ideation, as well as between thwarted belongingness, perceived burdensomeness, and acquired capability with a greater number of prior suicide attempts (Chu et al., 2017).

Nevertheless, the IPTS is not without its limitations. For example, not all individuals who engage in NSSI develop a greater capacity for suicide, the theory does not account for the influence of other important factors (e.g., minority stress), and research examining the longitudinal relationship between NSSI and acquired capability remains limited (Hamza et al., 2012; Robison et al., 2024). Despite this, the IPTS provides valuable insight into the psychological mechanisms through which self-harm may increase suicide risk under specific conditions.

1.1.5. *Assessment of Self-harm*

To fully understand self-harm, it is essential to accurately identify it, which has led to the development of various assessment tools. However, inconsistencies in self-harm definitions mean these tools also rely on differing assumptions and terminology (Faura-Garcia et al., 2021; Hooley et al., 2020).

Some tools, such as the Deliberate Self-Harm Inventory (DSHI; Gratz, 2001) and the Self-Harm Inventory (SHI; Sansone et al., 1998), focus primarily on self-harm behaviours. Others, like the Inventory of Statements about Self-Injury (ISAS; Klonsky & Glenn, 2009) and the Non-suicidal Self-injury – Assessment tool (NSSI-AT; Whitlock et al., 2014), assess numerous self-harm characteristics, including frequency, recency, functions, contexts, body areas injured, severity, and the desire to stop. Additionally, tools such as the Cardiff Self-Injury Inventory (CSII; Snowden et al., 2022) and the Self-Injurious Thoughts and Behaviour Interview (SITBI; Nock et al., 2007) also consider thoughts of self-harm in addition to engagement, across both NSSI and suicidal behaviour. Furthermore, several clinical interviews have been developed to specifically assess the proposed diagnostic criteria for NSSI-D: the Clinician-Administered Non-Suicidal Self Injury Disorder Index (CANDI; Gratz et al., 2015), the Alexian Brothers Assessment of Self-Injury Scale (ABASI; Washburn et al., 2015), and the Non-Suicidal Self-Injury Disorder Scale (NSSIDS; Victor et al., 2017). Despite the available tools, a lack of uniformity in measurement can lead to varying prevalence estimates (Morales et al., 2018). Moreover, no gold standard is agreed upon; where a systematic review of 26 self-harm assessment tools (including those described above) found that although evidence of validity and reliability was generally positive, psychometric properties were limited and varied across tools (Faura-Garcia et al., 2021).

It is also important to consider self-harm risk screening and assessments, which are widely used in clinical settings to assess risk after self-harm despite limited evidence supporting their effectiveness (Quinlivan et al., 2014). Examples include the Manchester Self-Harm Rule (Cooper et al., 2006), the SAD PERSONS Scale (Patterson et al., 1983), and the ReACT Self-Harm Rule (Steeg et al., 2012), among others. Similarly, another systematic review evaluating 11 risk scales demonstrated a wide range of diagnostic accuracy statistics, concluding that none had sufficient evidence for clinical use (Quinlivan et al., 2016). Therefore, such scales should only be used as part of a comprehensive evaluation of an individual's self-harm risk rather than as standalone diagnostic tools.

Given the varied conceptualisations of self-harm, its prevalence, and links with suicidality (Favril et al., 2022; Hawton et al., 2020; Runeson et al., 2016), the lack of robust assessment and risk tools presents significant challenges for both scientific progress and clinical assessment (Faura-Garcia et al., 2021; Hooley et al., 2020; Quinlivan et al., 2016). Generally, self-harm assessment needs to be improved to prevent the use of non-validated instruments, misapplication of validated instruments, and reliance on those with insufficient evidence of clinical utility (Faura-Garcia et al., 2021; Quinlivan et al., 2016). Advancing measurement in this area will enable researchers and clinicians to better understand self-harm, improve risk assessment, and develop more effective prevention and intervention strategies.

1.1.6. *Language Use for Self-harm*

It is also important to consider the language used when discussing self-harm, as stigmatising terminology can perpetuate harmful myths and misconceptions. Inappropriate language can imply self-harm is manipulative or attention-seeking

behaviour, restricted to specific demographics (e.g., adolescent girls), or it is just a "phase" that individuals will outgrow (Klonsky et al., 2014). Additionally, much of the discourse around self-harm is rooted in a medical paradigm. For example, while the proposal for NSSI-D in the DSM-5 (American Psychiatric Association, 2013) may aid with conceptualisation, it still predominantly frames self-harm through a lens of dysfunction and pathology. This is reflected in theoretical models that emphasise "deficits" in emotion regulation, an "inability" to tolerate distress, or a "lack" of coping strategies as inherent to an individual (e.g., Chapman et al., 2006; Selby & Joiner, 2009). Moreover, terms such as "cutters" or "self-injurers" dehumanise individuals by reducing them to the behaviour, while referring to self-harm as a "contagion" implies it is akin to a disease that can spread to others (Hasking & Boyes, 2018; Lewis, 2017). More appropriate phrases identified by individuals with lived experience include "someone with lived experience/ a history of self-harm", "recovery from self-harm", "urges to self-harm", "coping strategies", "ongoing self-harm", and "recurrence of self-harm" (Hasking et al., 2021). Reflecting this, respectful and person-centred language will be used throughout this thesis to describe both the behaviour and individuals who self-harm.

1.2. Autism

1.2.1. *Background*

The internationally recognised diagnostic criteria for Autism Spectrum Condition (henceforth, Autism) is provided in the DSM-5 (American Psychiatric Association, 2013) and the International Classification of Diseases, Eleventh Revision (ICD-11; World Health Organization, 2019). Autism is described as a heterogeneous lifelong neurodevelopmental condition characterised by differences in

social communication and interaction, sensory sensitivities, focused interests, and preference for routine and familiarity (American Psychiatric Association, 2013). First described by Kanner (1968) and Asperger (1944), autism was historically considered a rare condition but is now recognised as more common, with current estimates suggesting that 1.5% of the population in developed countries are autistic (Lyll et al., 2017). Support needs can vary widely alongside 'spiky' cognitive profiles, where autistic individuals may demonstrate strengths in some domains but difficulties in others (American Psychiatric Association, 2013; Doyle, 2020; Milton & Moon, 2012). The male-to-female diagnostic ratio is approximately 3:1, though diagnostic biases place autistic females at a higher risk of remaining undiagnosed despite meeting clinical criteria (Loomes et al., 2017). Autism also frequently co-occurs with other developmental conditions, where intellectual disability (ID) and ADHD are the most common, with pooled prevalence rates of 33% and 37%, respectively (Micai et al., 2023). Research also suggests that a strong genetic component contributes to the development of autistic traits alongside environmental factors (Lyll et al., 2017; Sandin et al., 2017).

1.2.2. *Autism in Adulthood*

Autism was initially thought to be exclusively a childhood diagnosis, leading most research to focus on early recognition and intervention (Happé & Frith, 2020; Howlin, 2021). However, changes in diagnostic criteria, along with growing awareness of diverse autistic presentations, have improved our understanding that autism occurs across the lifespan (Bent et al., 2017; Howlin, 2021). Despite this progress, many autistic individuals reach adulthood without a diagnosis, particularly those with fewer support needs or who are assigned female at birth (Lai & Baron-Cohen, 2015). Diagnosis in adulthood is further complicated by the absence of

someone to provide a developmental history, learned strategies to conceal autistic traits and “fit in” (i.e., camouflaging or masking), and high rates of co-occurring conditions (Lai & Baron-Cohen, 2015). Even when seeking a diagnosis, autistic adults face significant barriers, such as fear of not being believed by professionals and long waiting times for diagnostic assessments, leading to a growing number of individuals who self-identify as autistic (Lewis, 2017; Rutherford et al., 2016).

Therefore, it is unsurprising that autistic adults experience significantly higher levels of unmet support needs compared to non-autistic adults (Nicolaidis et al., 2013) and autistic children (Turcotte et al., 2016). Consequently, it is essential to acknowledge the additional challenges that autistic adults face, as well as to recognise the validity of self-identification.

1.2.3. *Disability Paradigms*

How autism is conceptualised influences both scientific discourse and societal attitudes, shaping the way autistic individuals are perceived and treated. The classification of autism as a “disorder” within diagnostic manuals reflects an impairment and deficit-focused perspective rooted in a medical paradigm (Rutherford & Johnston, 2022). Specifically, the medical model of disability (Llewellyn & Hogan, 2000; Marks, 1997) identifies disability as a direct consequence of a person’s biological make-up and functioning (Pellicano & den Houting, 2022). Within this paradigm, research is mainly led by non-autistic people, where the focus is on a “treatment” or “cure” rather than incorporating autistic perspectives (Rutherford & Johnston, 2022). This framing essentially blames a person’s autism for the challenges they face while overlooking the influence of interpersonal and societal factors (Kapp, 2020). In doing so, it poses multiple harms to autistic people by reinforcing dehumanisation, denying fundamental respect and dignity, pathologising

traits that may be neutral or positive, and reducing autism to a social deficit despite its complexity and fluid nature (Kapp, 2020).

An alternative approach is the neurodiversity paradigm, introduced by Singer (1998), which frames differences in neurological development and functioning as natural and valuable aspects of human diversity (Kapp, 2020; Leadbitter et al., 2021). Closely aligned with the social model of disability, this perspective emphasises that disability arises not from the individual but from a society that fails to accommodate their needs (Llewellyn & Hogan, 2000; Pellicano & den Houting, 2022). This paradigm advocates for the meaningful inclusion of autistic voices in decision-making processes and promotes autism acceptance rather than intervention aimed at normalisation (Pellicano & den Houting, 2022; Rutherford & Johnston, 2022). By shifting focus from deficits to strengths, the neurodiversity paradigm challenges harmful stereotypes and supports efforts to create more inclusive environments for autistic individuals.

1.2.4. *Language Use for Autism*

In addition to disability paradigms, the language used to discuss autism, much like that of self-harm, plays a pivotal role in shaping perceptions (Bottema-Beutel et al., 2021; Dwyer et al., 2022). A key debate in this area concerns the use of person-first (e.g., “person with autism”) and identity-first language (e.g., “autistic person”). Person-first language emphasises the individual rather than their disability by clearly distinguishing between the person and autism (Maio, 2001). However, it is argued that this framing reinforces stigma, with negative connotations that autism is a “defect” to be removed (Botha et al., 2022; Gernsbacher, 2017). Conversely, identity-first language recognises autism as an integral aspect of identity, akin to features

such as race or hair colour (Botha et al., 2022). Many autistic self-advocates prefer identity-first language, viewing it as more affirming and representative of their lived experiences (Bottema-Beutel et al., 2021). While there are no universally accepted preferences, and this will likely continue to develop and change over time, a large-scale study of English-speaking autistic adults found that the most popular terms were "Autism", "Autistic person", and "is autistic" (Keating et al., 2023). Therefore, this thesis will use identity-first language, aligning with neuro-affirming perspectives and endorsed preferences.

1.3. Self-harm and Autism

1.3.1. *Conceptualisations*

Historically, self-harm in autism has been understood differently from the general population, framed as “challenging” and/ or “restrictive and repetitive” self-injurious behaviours (SIB) characteristic of autism (Duerden et al., 2012; South et al., 2005). These behaviours are more typically observed in children or those with co-occurring ID (Minshawi et al., 2014). As a result, broader experiences of NSSI and suicidality are frequently overlooked or misclassified as SIB, particularly in cognitively able autistic adults (Cassidy, 2020; Maddox et al., 2017). This conceptualisation has contributed to the systemic exclusion of autistic participants from self-harm research (Dickstein et al., 2015; Kim et al., 2015), and an under-representation of autism-specific experiences (Goldfarb et al., 2021; Matson & Turygin, 2012) related to meltdowns (i.e., intense physical and mental response, loss of control) and stimming (i.e., repetitive self-stimulatory actions that serve a regulatory mechanism). Nevertheless, studies indicate that the age of onset, methods used, and functional purpose of NSSI are similar in autistic and non-autistic

populations (Goldfarb et al., 2021; Maddox et al., 2017; Moseley et al., 2019). One of the most commonly identified functions across both groups is to regulate affective states, aligning with previously discussed theoretical models of self-harm (Hird et al., 2024). Despite these parallels, autistic individuals seeking support are often dismissed or disbelieved, with their self-harm and mental health difficulties attributed to autism rather than recognised as indicators of distress in their own right (Camm-Crosbie et al., 2019; Marsden et al., 2024).

1.3.2. *Epidemiology*

Although the literature is limited, emerging evidence suggests that autistic individuals are three to five times more likely to self-harm than non-autistic individuals across the lifespan (Blanchard et al., 2021; Stark et al., 2022). Moreover, prevalence rates range from 42% in autistic individuals with and without co-occurring ID (Steenfeldt-Kristensen et al., 2020) to 10.1 – 70.5% in autistic children and adolescents without co-occurring ID (Figueiredo et al., 2023). These estimates are considerably higher than the 2.7% – 22.1% reported in the general population (Christoffersen et al., 2015; Klonsky, 2011; Lim et al., 2019; Liu, 2023). Additionally, adults with high autistic traits report increased rates of self-harm (regardless of intent) and NSSI compared to those with lower autistic traits (Stewart et al., 2023; Wang & Wang, 2023). Given the known link with adverse outcomes in the general population (Beckman et al., 2019; Moran et al., 2015; Ohlis et al., 2020), recognising and understanding self-harm in autistic individuals is essential. However, further investigation is needed to clarify the role of self-harm in suicidality and identify potential risk factors or markers for self-harm in autism.

1.3.3. *Suicidality*

There is growing recognition that autistic individuals face an increased risk of suicidality. Several meta-analyses have reported significant pooled prevalence estimates of suicidal thoughts and behaviours in autistic youth (O'Halloran et al., 2022) across both diagnosed and potentially autistic samples (Newell et al., 2023) and at markedly higher rates than in the general population (Huntjens, Landlust, et al., 2024). Large-scale population studies further highlight that the risk of death by suicide among autistic individuals is two- to eight times higher than for non-autistic people, with the highest risk observed in autistic females and those without co-occurring ID (Hirvikoski et al., 2020; Jokiranta-Olkonien et al., 2021; Kølves et al., 2021).

Research in this area has also explored a range of risk factors for suicidality, consistently identifying co-occurring mental health and neurodevelopmental conditions – particularly depression, anxiety, and ADHD – as significant contributors (Bal et al., 2022; Cook et al., 2024; Hedley et al., 2021). In addition, autism-specific predictors of suicidality include camouflaging (i.e., the conscious or unconscious effort to hide autistic traits and “fit in” a predominantly non-autistic world) and unmet support needs (Cassidy et al., 2018). As in the general population, NSSI is also associated with heightened suicide risk in autistic individuals (Cassidy et al., 2018; Moseley et al., 2020). Notably, autistic individuals with a history of severe self-harm appear to be at an even greater risk of death from suicide than non-autistic individuals, particularly autistic males and those who engage in self-harm by cutting (Hull et al., 2024). Likewise, cutting is a significant predictor of suicidality in other studies with autistic adults (Moseley et al., 2020). Conversely, very few protective factors for suicidality have been identified, where greater satisfaction with social

support and higher overall personal wellbeing are among the few exceptions (Hedley, Uljarević, Foley, et al., 2018; Hedley, Uljarević, Wilmot, et al., 2018).

The relationship between autism and suicidality has also been examined using the IPTS (Joiner, 2005; Van Orden et al., 2010). Relationships between autistic traits and suicidality are found to be mediated by thwarted belongingness and perceived burdensomeness (Cassidy et al., 2020; Pelton et al., 2020; Stanley et al., 2021), or with perceived burdensomeness and a facet of acquired capability (mental rehearsal of suicide plans; Moseley et al., 2022). Likewise, risk factors such as anxiety, depression and NSSI have been linked to IPTS constructs in autistic samples (Dow et al., 2021; Moseley et al., 2022a; Pelton et al., 2023). Moreover, evidence from IPTS suggests that NSSI may serve as a precursor to suicidal behaviours in autistic individuals. Research shows acquired capability (reduced fear of death and mental rehearsal of suicide plans) mediates the relationship between NSSI and lifetime suicide attempts, with cutting and a greater number of NSSI behaviours linked to suicide attempts both directly and indirectly through acquired capability (Moseley et al., 2022a). These findings suggest self-harm may play a role in the heightened suicidality observed in autistic people, although the exact underlying mechanisms are currently unknown.

1.3.4. *Risk Markers and Factors*

Self-harm is not only associated with adverse outcomes but is also influenced by various factors that may increase risk in autistic people. Risk factors are measurable variables that must precede and be associated with a higher likelihood of developing a given outcome (e.g., self-harm), whereas risk markers are correlated with the outcome and measured concurrently (Kraemer et al., 1997). This distinction

can be more nuanced, where some risk factors may also serve as accompanying conditions or consequences of an outcome (Kraemer et al., 1997). For example, mental health difficulties might act as a risk factor if they precede and contribute to self-harm yet could equally function as a risk marker if both are measured simultaneously without a clear temporal relationship (Fliege et al., 2009). In autistic populations, the limited evidence in this area makes it challenging to definitively classify variables as one or the other. Therefore, the terminology used in this section will reflect that of the literature.

1.3.4.1. *Mental Health and Co-occurring Conditions*

Compared to the emerging research on self-harm and suicidality, it is already well-established that autistic people experience high levels of co-occurring mental health conditions, with an estimated 55% having at least one psychiatric diagnosis (Lugo-Marín et al., 2019). Anxiety and mood disorders are among the most common and persistent of these, with meta-analyses indicating a pooled prevalence of 20% for anxiety disorders and 11% for depression in the autistic population at any one time (Curnow et al., 2023; Hossain et al., 2020; Lai et al., 2019). Beyond this, autistic individuals face an increased risk of other psychiatric conditions, including eating disorders (anorexia nervosa in particular; Boltri & Sapuppo, 2021), psychosis (Varcin et al., 2022), bipolar disorder (Varcin et al., 2022), schizophrenia (Zheng et al., 2018), and substance use disorders (Haasbroek & Morojele, 2022). Moreover, autistic people encounter significant barriers to accessing and engaging with appropriate mental health support due to insufficient understanding or knowledge of autism and a lack of tailored services (Brede et al., 2022; Camm-Crosbie et al., 2019). Since both co-occurring conditions and unmet support needs are risk markers for suicidality in autistic people (Bal et al., 2022; Cassidy et al., 2018; Cook et al.,

2024; Hedley et al., 2021), this combination may also contribute to an increased likelihood of self-harm, as individuals attempt to manage distress without adequate resources.

Consistent with the above, a meta-analysis found that autistic individuals with psychiatric or mood conditions, as well as ADHD, have increased odds of self-harm compared to those without these conditions (Kim et al., 2024). Similarly, a longitudinal retrospective cohort study of autistic youth identified an increased risk of deliberate self-harm associated with internalising and externalising problems, substance use, psychosis or other thought problems, and chronic complex medical conditions (Lopez-Arvizu et al., 2025). Furthermore, evidence suggests that the increased risk of intentional self-harm among autistic individuals is largely driven by co-occurring psychiatric conditions, where risk decreases to non-significant after adjusting for these factors (Jokiranta-Olkonemi et al., 2021). Facets of these conditions, such as low mood and overactivity/ impulsivity, have also been identified as significant predictors of self-harm (Licence et al., 2020). Additionally, rumination and experiential avoidance moderate the indirect relationship between autistic traits and NSSI via anxiety, such that higher levels of these variables reinforce the pathways between autistic traits, anxiety and NSSI (Wang & Wang, 2023). Thus, co-occurring conditions and their associated traits may contribute to self-harm risk and represent potential targets for intervention.

1.3.4.2. *Acceptance and Stigma*

It is also important to acknowledge the complex interplay between autism acceptance, stigma and mental health. Experiences of discrimination, internalised stigma, and concealment of behaviours associated with autism are linked to poorer

mental health outcomes (Botha & Frost, 2020). Additionally, lower levels of acceptance, both from oneself and others, have been linked to higher rates of depression, while reduced acceptance from others has also been associated with increased stress (Cage et al., 2018). Higher self-reported camouflaging is further associated with worse mental health (Cook et al., 2021) and an increased risk of suicidality (Cassidy et al., 2018; Cassidy et al., 2020). Considering the links between mental health, suicidality, and self-harm, it is also possible that a lack of autism acceptance and increased stigma may further elevate self-harm risk.

1.3.4.3. *Sex and Gender*

On the other hand, sex differences in self-harm among autistic individuals and those with high autistic traits remain inconsistent, with some studies finding no significant difference (Schwartzman et al., 2024), and others reporting higher rates of self-harm in those identifying as male (Wang & Wang, 2023) or female (Lai et al., 2023; Lopez-Arvizu et al., 2025; Nyrenius et al., 2023). Additionally, emerging evidence suggests that the intersection of autism and gender diversity may heighten the risk of suicidality (Newell et al., 2023; Polidori et al., 2024), but this relationship has yet to be extended in the context of self-harm. Given the established overlap between autism and gender diversity (Kallitsounaki & Williams, 2023), along with findings linking gender diversity to increased self-harm risk in the general population (Mitchell et al., 2022), further investigation is warranted to determine whether there is a relationship between sex or gender diversity and self-harm risk in autism.

1.3.4.4. *Interpersonal Emotion Regulation*

Other psychological mechanisms may also contribute to self-harm in autism, such as the role of interpersonal emotion regulation. A recent study found that

autistic participants exhibited greater emotional empathy (i.e., sharing others' emotional states) relative to cognitive empathy (i.e., identifying others' emotions), which was linked to higher NSSI incidence through emotional reactivity (i.e., emotions that are intense, easily evoked or take longer to dissipate; Moseley et al., 2024). Notably, this pathway differed from that of non-autistic individuals, suggesting that heightened responsiveness to others' emotions may be an autism-specific risk factor for self-harm. While self-harm serves a key function in emotion regulation across autistic and non-autistic populations (Maddox et al., 2017; Moseley et al., 2019), both intra- and interpersonal emotion processes may play an important role in understanding NSSI in autistic people.

1.3.5. *Temporal Pathways*

In addition, the temporal proximity of risk factors and markers to a self-harm episode is often complex and dynamic (Townsend et al., 2016), with limited research focusing on autistic individuals. A novel Card sort Task for Self-harm (CaTS; Townsend et al., 2016) adapted for autistic adults explored the proximal and distal contributing factors (Pelton et al., 2025). Agitation and unbearable mental pain were the most common experiences, which reflects previous research and theoretical models that self-harm functions to regulate aversive affective states (Hird et al., 2024; Moseley et al., 2019). Access to means, impulsivity and being unable to tell anyone preceded a self-harm episode, reinforcing support for impulsivity as a risk marker (Licence et al., 2020), while also consistent with interpersonal vulnerabilities in the integrated model of self-harm (Nock, 2009) and unmet support needs experienced by autistic people (Camm-Crosbie et al., 2019). Feeling better and worse, exhausted and hopeless, followed self-harm, aligning with research suggesting that pain offset simultaneously stimulates positive and diminishes

negative affect, and that this temporary relief serves to reinforce behaviour (Franklin et al., 2013). Similar patterns of self-harm have also been observed in adults and young people, where impulsivity often precedes self-harm and positive emotions follow (Lockwood et al., 2023). Gaining a clearer insight into the temporal pathways to self-harm among autistic individuals will be essential for shaping effective treatment and intervention strategies.

1.4. Measure Development and Evaluation

1.4.1. *Issues with Current Measurement Tools*

Given the significant risks associated with self-harm in autism, it is crucial to be able to accurately identify and understand these behaviours. However, there is limited evidence on the availability and appropriateness of tools to assess self-harm in autistic people. Measures designed for non-autistic people already suffer from the previously described inconsistencies in self-harm definitions, which is further complicated by conceptualisations of self-harm in autism (e.g., SIB). Moreover, complex language, vague response options, the absence of autism-relevant items, and insensitive language can render such measures inaccessible to autistic people (Nicolaidis et al., 2020). Consistent with this, research adapting measures of suicidality and depression for autistic adults has shown that they interpret and respond to questionnaires designed for the general population differently than intended by the tool designers (Cassidy et al., 2020, 2021).

As such, autistic people have a tendency to interpret information literally (Vicente & Falkum, 2023) and may struggle with complex or abstract language and figures of speech (e.g., “to get a vacation from having to try so hard” QNSSI; Turner et al., 2012). This can include difficulties recalling what has happened in the past

(episodic memory) or imagining what might happen in the future (episodic future thinking; Lind et al., 2014; Lind & Bowler, 2010), which can impact the ability to answer questions about lifetime and future self-harm (e.g., “how many times in your life have you engaged in NSSI?” or “on a scale of 0 to 4, what do you think the likelihood is that you will engage in NSSI in the future?” SITBI; Nock et al., 2007). Previous research on the measurement properties of the Suicidal Behaviours Questionnaire-Revised (SBQ-R; Cassidy et al., 2020) demonstrated that autistic participants found a similar question regarding future suicide intent “impossible to answer” for this reason. Therefore, the mode of assessment and language used in traditional self-harm assessment tools may be less accessible and appropriate for autistic people.

Challenges in identifying, understanding, and describing one’s emotions (i.e., alexithymia) are also common for autistic people (Kinnaird et al., 2019). However, many self-harm assessment tools rely on self-report and the ability to identify often complex internal emotional experiences (e.g., “I hurt myself... to deal with anger/ to cope with uncomfortable feelings” NSSI-AT; Whitlock et al., 2014). Alexithymia is suggested to be associated with NSSI in autistic people, with NSSI functioning to regulate high-energy states (e.g., aggression, anxiety, anger; Moseley et al., 2020). Therefore, while autistic individuals may be more inclined to self-harm, they could find it challenging to communicate and report that this is due to emotional distress via a measurement tool.

There may also be aspects of self-harm in autism which are not captured by assessment tools initially designed for other populations, such as sensory processing differences (Moseley et al., 2019). For autistic people, sensory inputs across multiple modalities can either be experienced more intensely (hyper-

reactivity), not noticed at all or responded to in a delayed manner (hypo-reactivity), or engaged with repeatedly and for sustained periods (American Psychiatric Association, 2013; Lane, 2002). Consequently, certain sensory disturbances can induce high levels of distress for an autistic person (MacLennan et al., 2022; Robertson & Simmons, 2015; Robledo et al., 2012). Consistent with this, autistic people report using NSSI as a way to cope with overwhelming sensory input, and sensory differences have been found to predict body areas targeted, lifetime engagement and frequency of NSSI (Moseley et al., 2019). Worryingly, autistic individuals with hypo-reactivity might engage in self-harm at a higher frequency or severity, leading to injuries more serious than intended (Moseley et al., 2019). Similarly, a qualitative study found autistic participants describe self-harm as a physical release of sensory or emotional overload (e.g., meltdown) or as a consequence of harmful stimming (e.g., skin picking, hitting self; Marsden et al., 2024). Consequently, self-harm measures that are used with autistic populations need to be able to adequately capture functions of self-harm that are representative of their experiences.

1.4.2. *COSMIN*

The lack of assessment tools is a key barrier to understanding and preventing self-harm in autistic people, limiting research progress and the development of tailored interventions. The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN; Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018) is a validated research tool for evaluating the measurement properties of patient-reported outcome measures. First and foremost, COSMIN argues that content validity is the most important measurement property, serving as the foundation for all others (Terwee et al., 2018). Content validity ensures that the

items within an assessment tool accurately reflect the underlying construct being measured in that they are relevant, clear, and representative for the target population (Mokkink et al., 2010). Without content validity, evidence for all other measurement properties (structural validity, internal consistency, reliability, measurement error, construct validity, cross-cultural validity/ measurement invariance, criterion validity, and responsiveness) is less likely to be supported. For example, irrelevant or missing items can reduce internal consistency (i.e., degree of interrelatedness between items), structural validity (i.e., how well items reflect the constructs' dimensionality), and interpretability (i.e., whether items are understood by the target population as intended). Conversely, seemingly good measurement properties may actually arise from over- or underestimations of an incomplete or incorrect construct (Terwee et al., 2018). Furthermore, unclear or ambiguous items could introduce bias or reduce response rates, particularly within autistic populations who may process language differently (Vicente & Falkum, 2023).

Therefore, COSMIN offers a systematic approach to identifying and evaluating existing tools' suitability for specific populations. First, a systematic review is conducted to identify tools that measure a specified health outcome (e.g., self-harm) in a defined population (e.g., autistic adults). Tools frequently used (i.e., at least twice) with some evidence of validity (i.e., reference to a previously published study assessing its measurement properties) are then selected for further evaluation (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). Following this, another search is performed to find studies evaluating the measurement properties of the identified tools, using a comprehensive filter validated for this purpose (Terwee et al., 2009). The tools and corresponding studies are then assessed against the COSMIN checklist for risk of bias, criteria for good measurement properties, and

quality of evidence (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). This process enables the formulation of evidence-based recommendations for the appropriateness of tools in specific contexts. Consistent with this, previous research utilising COSMIN has highlighted a distinct lack of evidence for the measurement properties of tools assessing depression, suicidality, and stress in autistic populations (Cassidy et al., 2018b, 2018a; Thoen et al., 2023). Applying COSMIN to self-harm assessment tools could similarly identify which, if any, existing tools have been used with autistic individuals, if they are validated to do so, and if not, to determine the most robust candidate for adaptation or the need to develop a new one.

By prioritising content validity, COSMIN also underscores the importance of developing tools that are clear, relevant, and representative of the construct of interest for the target population. This emphasis is particularly critical when addressing the distinct needs of autistic individuals in self-harm assessment. Ensuring content validity not only strengthens a tool's overall reliability and validity but also enhances its utility in both research and clinical contexts. Consequently, COSMIN offers a comprehensive and evidence-based approach to advancing the identification and understanding of self-harm in autistic populations.

1.5. Methodological Considerations

1.5.1. *Community Involvement*

Concerns have been raised about the disconnect between research priorities set by academics and funding bodies, with those identified by the autistic community (Gowen et al., 2019; Keating et al., 2023). Participatory research methods help bridge this gap by enabling meaningful input from autistic individuals, ensuring their

perspectives shape what research is conducted, along with how it is carried out and implemented (Fletcher-Watson et al., 2019). This approach offers several benefits, including improving research quality and applicability of findings to real-world contexts (Keating, 2021), producing relevant and valuable outcomes for the autistic community (Long et al., 2017), and fostering greater involvement, collaboration, and trust between researchers, autistic individuals, and their allies (Fletcher-Watson et al., 2019). Active involvement of the autistic community has already led to pioneering research to identify and measure camouflaging as a unique risk factor for suicidality in autism (Cassidy et al., 2018) and to adapt safety plans for autistic people experiencing suicidal thoughts and behaviours (Goodwin et al., 2024; Rodgers et al., 2024).

Moreover, COSMIN is particularly well-suited to participatory research methods due to its emphasis on content validity and the need for tools to accurately reflect the construct of interest as described and defined by the target population (Terwee et al., 2018). Engaging autistic individuals in the tool development process aligns with this principle, ensuring that the items included are relevant, clear, and representative of their experiences. This participatory approach helps to ensure that the resulting tools are reliable, valid, and suitable for use with this population (Nicolaidis et al., 2020).

However, academic environments do not always facilitate the use of participatory methods, particularly for early-career researchers, due to constraints related to time and funding (Pickard et al., 2022). While autistic individuals were not involved in the initial conceptualisation of the PhD proposal, the research aligns with community and stakeholder priorities regarding suicide prevention (e.g., identifying risk factors) and mental health (Cassidy, Cogger-Ward, Robertson, et al., 2021;

Roche et al., 2021), whereby autistic people are now recognised as a priority group in the UK government's Suicide Prevention Strategy for England (2023–2028) (Department of Health and Social Care, 2023). Subsequently, autistic individuals informed each stage of the research process, in line with established guidelines that promote effective communication, partnership, and the inclusion of lived experience in research (Gowen et al., 2019; National Institute for Health and Care Research, 2022; Nicolaidis et al., 2019).

1.5.2. *Ethical Issues*

Generally, participation in self-harm and suicide research is not found to be detrimental to those involved (e.g. Cukrowicz et al., 2010; Lockwood et al., 2018). Moreover, co-production with autistic individuals can enhance the development of safe and accessible research methods for exploring sensitive mental health topics (Goodwin et al., 2024; Nimbley et al., 2024; Pelton et al., 2025). However, self-harm remains a complex and emotionally challenging subject that may be distressing for some individuals. Thus, it is essential to embed safeguarding measures throughout any research in this area.

There are various ways to ensure participant wellbeing and safety. Previous self-harm and suicide research with autistic adults has incorporated wellbeing plans (Goodwin et al., 2024; Pelton et al., 2025), detailing emergency contact information, communication needs, and how to support an individual if they become distressed (see Appendix B; <https://www.autistica.org.uk/downloads/files/Research-wellbeing-plan-by-Sarah-Cassidy-Emma-Nielsen-et-al.pdf>). Visual analogue scales can also be used to assess mood before and after participation, with procedures in place for individuals who demonstrate a substantial decrease in mood or other safety

concerns. This could include being supported to complete an autism-adapted safety plan (Rodgers et al., 2024). In contrast, while anonymous surveys do not allow for direct follow-up, participants can be forewarned about the sensitive nature of the research, provided with relevant signposting, and the option to skip questions or sections if needed. Additionally, research has shown that providing positive mood inducers at the end of a study can help reduce potential distress (e.g., videos of cute animals; Nittono et al., 2012; Townsend et al., 2016).

Moreover, conducting emotionally demanding research and engaging with sensitive data can impact researchers themselves (Mckenzie et al., 2017). Therefore, it is recommended that researchers have access to regular debriefing sessions with the supervisory team, independent psychological support, and appropriate training. Establishing healthy working practices and encouraging researchers to recognise their limits are also essential for maintaining wellbeing (Burrell et al., 2023).

1.6. Thesis Outline

As highlighted by this chapter of relevant literature, autistic individuals and those with high autistic traits exhibit greater rates of self-harm and increased risk compared to non-autistic individuals. However, despite the clear need, there is a lack of evidence on the availability and appropriateness of tools to assess self-harm in this population. Therefore, the overall aim of this thesis is to develop a new self-harm assessment tool in collaboration with and for autistic adults. To achieve this, four empirical chapters will employ a mix of methodologies. Chapter 2 will present a systematic COSMIN review to identify frequently used self-harm assessment tools for both autistic and general population adults and evaluate the measurement

properties of these. Chapter 3 will use focus groups with autistic adults who have lived experience of self-harm, as well as professionals who support them, to explore perceptions and content validity of existing self-harm assessment tools. Chapter 4 will involve cognitive interviews with autistic adults with lived experience of self-harm to refine and co-develop a new self-harm assessment tool. Lastly, Chapter 5 will pilot the newly developed tool through an online survey with autistic adults who have lived experience of self-harm to assess its preliminary measurement properties. Following this, the research findings and novel contributions from each chapter will be synthesised and evaluated in Chapter 6 in relation to the overall research aims.

Chapter 2. Measurement Properties of Tools Used to Assess Self-harm in Autistic and General Population Adults.

ii. Preface

Chapter 1 outlined the background and context of the thesis, highlighting why self-harm in autism is a significant concern and the urgent need for accurate identification of self-harm in this population. Chapter 2 directly addresses this need by applying COSMIN methodology to identify which self-harm assessment tools are frequently used with autistic and general population adults, evaluating these tools on their measurement properties, and providing recommendations for their use in research and clinical practice.

The research presented in Chapter 2 is published in:

Newell, V., Townsend, E., Richards, C., & Cassidy, S. (2024). Measurement properties of tools used to assess self-harm in autistic and general population adults. *Clinical Psychology Review*, 102412.

2.1. Introduction

As established in Chapter 1, autistic people experience high levels of self-harm across the lifespan (Figueiredo et al., 2023; Steinfeldt-Kristensen et al., 2020) and are more likely to self-harm than non-autistic people (Blanchard et al., 2021; Stark et al., 2022). Furthermore, adults with high autistic traits are at greater risk of self-harm compared to those with lower autistic traits (Stewart et al., 2023; Wang & Wang, 2023). In the general population, self-harm is a key predictor of future suicide risk and is associated with other adverse outcomes such as substance misuse, persistent mental health difficulties, and unemployment (Beckman et al., 2019; Moran et al., 2015; Ohlis et al., 2020). Self-harm may also serve as a precursor to suicidal behaviours in autistic people (Moseley et al., 2022a), with various factors contributing to the risk of developing these behaviours (e.g., co-occurring conditions; Kim et al., 2024). Given that autistic individuals already experience heightened rates of suicidality and mental health difficulties (e.g., Lai et al., 2019; Newell et al., 2023), accurately identifying self-harm in this population is crucial.

However, research suggests that autistic individuals may interpret and respond differently than intended to assessment tools designed for non-autistic people (Cassidy et al., 2020, 2021). This may stem from challenges identifying and describing emotions (i.e., alexithymia; Kinnaird et al., 2019), differences in episodic memory and future thinking (Lind et al., 2014; Lind & Bowler, 2010), or a tendency to interpret information literally (Vicente & Falkum, 2023). Autistic people may also experience unique presentations of self-harm that are not adequately captured by existing tools, such as sensory processing differences, meltdowns or stimming (Marsden et al., 2024; Moseley et al., 2019). In line with this, previous research has demonstrated insufficient evidence for the measurement properties of various mental

health instruments in autistic populations (Cassidy et al., 2018b, 2018a; Thoen et al., 2023). As a result, a major barrier to understanding and preventing self-harm in autism is the lack of validated and appropriate assessment tools.

Therefore, this chapter applies the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN; Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018) as a rigorous method to identify and evaluate the self-harm assessment tools currently used in research and clinical practice. To achieve this, the current review is split into two stages. The first stage aims to identify the self-harm assessment tools most frequently used, with some evidence of validity in a) autistic adults and b) general population adults, across research and clinical practice. The second stage is to evaluate evidence regarding the appropriateness and measurement properties of the identified tools in autistic and general population adults using the COSMIN checklist. This approach enables a comparison of the most commonly used tools and their measurement properties within each group. If no validated tools exist for autistic adults, either the most methodologically robust tool from the general population could be adapted, or a new tool may need to be developed. Finally, by synthesising the evidence on self-harm assessment tools and their measurement properties, recommendations can be made for the effective assessment of self-harm in these groups.

2.2. Methods: Stage 1

The protocol for this review was registered with the International Prospective Register of Systematic Reviews (Registration number: CRD42022352501) and can be accessed online

(https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=352501). This

systematic review followed the guidelines for Preferred Reporting Items for Systematic Reviews and Meta-Analyses standards (PRISMA; Page et al., 2021).

2.2.1. Search Strategy

Four electronic databases (Embase, PsycINFO, MEDLINE and Web of Science) were systematically examined using two search engines (PubMed and OVID) from inception to August 9, 2023. The Cochrane Database of Systematic Reviews was also searched to confirm that no other systematic reviews of the current study topic already existed. Two separate searches were carried out in stage 1 for measures of self-harm used in a) autistic adults with or without co-occurring intellectual disability (ID) and b) general population adults without any co-occurring conditions or ID. Autistic adults with co-occurring ID were included in the search due to the overlap of self-harm and self-injurious behaviours (SIB) in this group (Minshawi et al., 2014; Steinfeldt-Kristensen et al., 2020), which may highlight additional relevant measures. Search terms can be found in Table 1. These were derived from similar recent COSMIN reviews (Cassidy et al., 2018b, 2018a) and adapted to fit the specific search criteria of each database. Searches were restricted to human research, with articles published in English.

Table 1.

Stage 1 review search terms.

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1. ("General population" or "general public" or "population sampl*" or "community sampl*" or "national sampl*" or "national survey" or "household survey" or "non referred" or nonreferred or "non clinical" or nonclinical or "population screen*")
 2. ("Autis* spectrum*" or ASC or ASD or asperg* or autis* or "pervasive developmental disorder*" or PDD or "unspecified PDD" or PDD-NOS)
 3. (adult* or "young adult*" or "middle-aged" or "old* adult*" or elder*)
 4. (Assess* or measur* or test* or tool* or "treatment outcome*" or scale* or survey or screen* or questionnaire* or quotient* or inventor* or instrument* or interview* or checklist* or index* or indices)
 5. ("Self harm*" or selfharm* or "self injur*" or selfinjur* or "non suicid* self injur*" or "nonsuicid* self injur*" or NSSI or "self mutilat*" or "deliberate harm*" or "deliberate selfharm*" or "deliberate self harm*" or DSH or "self inflict*" or selfinflict* or "self cut*" or selfcut* or "self poison*" or selfpoison* or "self destruct*" or selfdestruct* or parasuicid* or "para suicid*")
 6. General Population Search (1 AND 3 AND 4 AND 5)
 7. Autism Spectrum Condition Search (2 AND 4 AND 5)
 8. Limit 6 and 7 to English Language
-

* Denotes wildcard search terms (i.e., multiple word endings)

2.2.2. Selection Criteria

A standardised approach using a well-defined group and outcome was employed for study selection, similar to previous COSMIN reviews (Cassidy et al., 2018b, 2018a). Studies had to focus on a tool specifically used to assess self-harm, as defined by the National Institute for Health and Care Excellence guideline [NG225] for self-harm: assessment, management and preventing recurrence (NICE, 2022). As a result, tools could use either a specific (i.e., NSSI, SIB) or broader conceptualisation of self-harm (i.e., including suicide attempts). However, those using a broader conceptualisation were required to cover self-harm both with and without suicidal intent, as a suicidality assessment tool has already been adapted for

autistic adults (Cassidy et al., 2021). Studies utilising a single self-harm related item or subscales contained within a more general measure (e.g., Mini-International Neuropsychiatric Interview (MINI; Sheehan et al., 1998) were not eligible for inclusion. This was because single items or subscales were less likely to capture the construct of self-harm compared to a specific measure, given its complex nature (Townsend et al., 2016). Additionally, it was required that tools be used in at least two studies for consideration in the next stage, so those created ad hoc (i.e., for the purpose of a single study) or without evidence of validity were excluded. Studies were also required to be in the format of peer-reviewed empirical publications, whereby conference proceedings, dissertations, theses, review articles, and books were excluded. This was necessary to maximise the probability that identified tools would have evidence of the measurement properties necessary for stage 2.

Eligible studies were required to utilise tools assessing either the prevalence of self-harm (e.g., epidemiological/ population studies) or assessing self-harm as an outcome (e.g., treatment/ intervention and longitudinal/ cohort studies). Studies also needed to focus on adults (aged 18 years and over). This age group was chosen as autistic adults have higher levels of unmet support needs than autistic children (Brede et al., 2022; Turcotte et al., 2016), and assessment tools developed for adults may not be valid for use with youth or vice versa. Consequently, if the age range was partly outside this, studies were only included if 50% or more of the total sample was over 18 years old or the mean age was 18 years and above. In line with previous similar COSMIN reviews, this was to ensure that the tools identified were likely to be appropriate for adults (Cassidy et al., 2018b, 2018a). Where a study had used a tool adapted for a specific population (e.g., older adults, a particular gender, or a specific culture), it was excluded. This was so the tool would be more widely applicable to

assess self-harm in autistic or general populations rather than just a narrow subgroup.

2.2.3. General Population Adult Search Criteria

Studies were included if they focused on general population adults (i.e., non-clinical, without any co-occurring conditions or ID). Data for the general population were required to be presented separately from any other population(s) and comprise at least 50% or more of the sample. Studies with an autistic comparison group were excluded and instead considered for inclusion in the autistic adults search.

2.2.4. Autistic Adults Search Criteria

Studies were included if focusing on autistic adults with or without co-occurring ID (i.e., IQ below 70), where data for the autistic group was presented separately, and 50% or more of the sample comprised of individuals with an autism diagnosis.

2.2.5. Screening And Data Extraction

As independent searches were conducted for studies of general population and autistic adults, the respective results were screened separately. Duplicates were removed before screening. VN screened the titles and abstracts of articles for inclusion. Where there was insufficient information at screening on whether an article should be read in full, it was included. VN then conducted a full-text screen of the remaining articles. To reduce the risk of researcher bias, 25% of papers at both stages were screened by an independent reviewer (NH) and inter-rater reliability was calculated. Inter-rater agreement was almost perfect for the title and abstract screen of articles with autistic adults (Prevalence and Bias-adjusted Kappa [PABAK] = .83,

91.4%), and substantial for articles with general population adults (PABAK = .72, 86.1%). Inter-rater agreement was substantial for the full-text screen of both articles with autistic adults (PABAK = .78, 88.9%) and general population adults (PABAK = .61, 80.4%). All discrepancies were discussed to reach a consensus, but where this could not be resolved, the opinion of a third reviewer was sought (SC, CR). Data extraction of assessment tool characteristics was performed by VN (i.e., original authors, year published, what it aimed to assess, mode of administration, number of items, subscales, and response options).

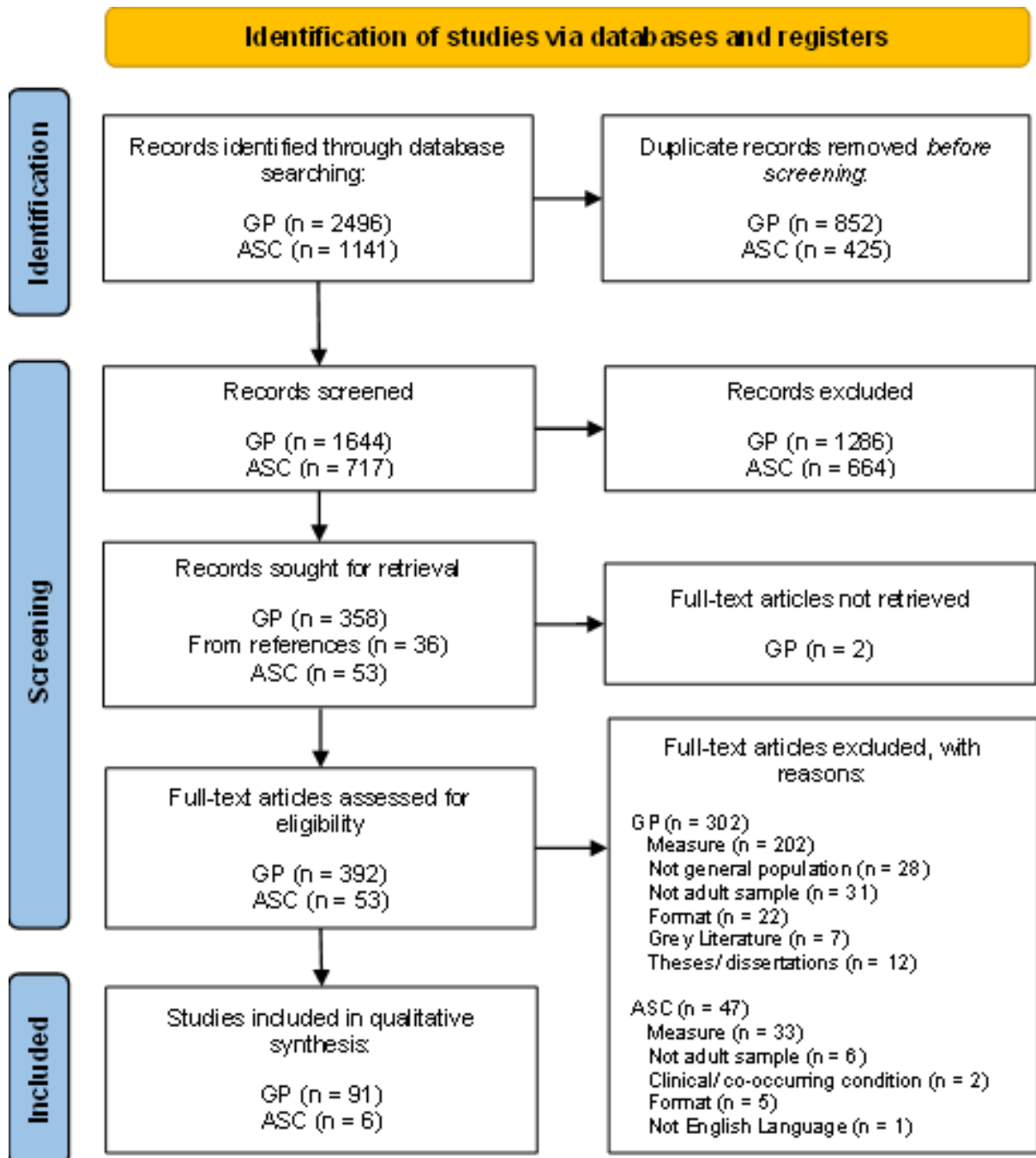
2.3. Results: Stage 1

2.3.1. Autistic Adults

The search for studies using tools to assess self-harm in autistic adults with or without co-occurring ID identified 717 articles which were screened, where six of these were retained for analysis (see Figure 2). These six studies all utilised a cross-sectional design to explore forms of self-harm (e.g., NSSI, SIB) in autistic adults and included between 42 and 314 autistic participants. Two tools were used to assess self-harm across the six studies: the NSSI-AT (Whitlock et al., 2014) and the Inventory for the Functional Assessment of Self-Injurious Behavior (IfES; Bienstein & Nußbeck, 2010). However, the IfES was not considered for stage 2 as it had only been used in one study of autistic adults with co-occurring ID, and the tool was not available in English.

Figure 2.

PRISMA flow diagram for the selection of articles for general and autistic population searches.



2.3.2. General Population Adults

The search for studies using tools to assess self-harm in general population adults identified 1644 articles which were screened, 91 of which were retained for analysis (see Figure 2). Most studies utilised a cross-sectional design ($k = 74$, 81.32%), and sample sizes ranged from 97 to 11,529 general population adults. Within these, fourteen different tools were used to assess self-harm. Self-report questionnaires included the: Body-focused Self-damaging Behavior Expectancies Questionnaire (BSBEQ; Forbes et al., 2022), Cardiff Self-Injury Inventory (CSII; Snowden et al., 2022), Deliberate Self-Harm Inventory (DSHI; Gratz, 2001), Functional Assessment of Self-Mutilation (FASM; Lloyd, 1997), Inventory of Statements about Self-Injury (ISAS; Klonsky & Glenn, 2009), Non-suicidal self-injury – Assessment tool (NSSI-AT; Whitlock et al., 2014), Questionnaire for Non-suicidal Self-Injury (Turner et al., 2012), Self-harm Inventory (SHI; Sansone et al., 1998), Self-Injury Questionnaire – Treatment Related (SIQ-TR; (Claes & Vandereycken, 2007b), Ottawa Self-Injury Inventory (OSI; Martin et al., 2013), Repetitive Non-Suicidal Self-Injury Questionnaire (R-NSSI-Q; Manca, 2009), and Self-Harm Behavior Questionnaire (SHBQ; Gutierrez, 1998). The search also identified two clinician interviews: the Clinician-Administered Non-suicidal Self-injury Disorder Index (CANDI; Gratz et al., 2015) and SITBI (Nock et al., 2007). Five of these tools (BSBEQ, CANDI, OSI, R-NSSI-Q, SHBQ) were only used in one study of general population adults without co-occurring conditions and were therefore not considered further.

2.3.3. *Summary*

Overall, nine tools were identified that had been used frequently in either the general population or autistic adults with some evidence of validity (CSII, DSHI, ISAS, FASM, NSSI-AT, QNSSI, SHI, SITBI, SIQ-TR). From the six studies with autistic adults, a single self-harm assessment tool (NSSI-AT) had been used frequently. However, the NSSI-AT had not been developed or validated for autistic people.

2.4. **Methods: Stage 2**

2.4.1. *Search Strategy*

This stage of the review searched specifically for evidence of the measurement properties of the tools identified in stage 1. Studies on measurement properties are recognised as difficult to find due to variations in terminology, along with poor indexing and reporting (Terwee et al., 2009). However, PubMed is the only database with a filter designed and validated to identify studies assessing the measurement properties of health outcome measures (Terwee et al., 2009). Consequently, a second comprehensive search was conducted (from inception to August 26, 2023) using the PubMed database and supplemented by handsearching references of analogous reviews. Similarly to stage 1, eligible studies needed to explore the measurement properties of these tools in adults (autistic or general population) and were only included if 50% or more of the total sample was over 18 years old or the mean age of the sample was 18 years and above. Whereas for stage 2, studies of adults with co-occurring conditions were also considered. This was because self-harm assessment tools used frequently in the general population may also be validated in clinical samples, and the retrieval of such studies could

highlight additional contexts where the tools would be useful. As in stage 1, 25% of papers at both title and abstract and full-text screen were checked by an independent reviewer (SC). Inter-rater reliability was almost perfect for the title and abstract screen (PABAK = .83, 91.7%) and substantial for the full-text screen (PABAK = .78, 88.9%). Any discrepancies were resolved through discussion, and the opinion of a third reviewer was sought if necessary (CR).

2.4.2. Data Extraction Method

The COSMIN risk of bias checklist was used to assess the methodological quality of each study identified from the search (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). COSMIN rates evidence against each of the following 9 measurement properties: 1) content validity – the degree to which the content of a tool is an adequate reflection of the construct to be measured; 2) structural validity – the degree to which the scores of a tool are an adequate reflection of a constructs' dimensionality; 3) internal consistency – the degree of interrelatedness among the items; 4) reliability – the proportion of total variance in a measurements' 'true' differences between participants; 5) measurement error – the systematic and random error of a participant's score not attributed to true changes in the construct; 6) hypothesis testing for construct validity¹ – the degree to which the scores of a tool are consistent with hypotheses²; 7) cross-cultural validity/ measurement invariance – the degree to which items on a translated or adapted (e.g., culturally, different groups) tool adequately reflect the performance of items from the original version; 8) criterion validity – the degree to which the scores of a tool are an adequate reflection

¹ Hypotheses to evaluate construct validity were formulated a-priori by the review team based on those in Prinsen et al., (2018). See Table A1 in Appendix A.

² For the hypothesis testing measurement property, (a) refers to convergent or divergent relationships with other instruments, and (b) to discriminant differences between relevant groups.

of a 'gold standard'; and 9) responsiveness – the ability of a tool to detect change over time in the construct measured (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). Each study was rated on these measurement properties using a 4-point system of 'very good', 'adequate', 'doubtful' or 'inadequate' quality. The overall quality for every measurement property was then determined from a "worst score counts" principle, taking the lowest score provided. For example, if any criteria for reliability were scored as 'inadequate', the overall methodological quality of reliability for that specific study would then be 'inadequate'. However, structural validity and internal consistency were not rated for behaviour-specific measures (CSII, ISASI I subscale, DSHI, SHI). As the presence or form of self-harm does not reflect an underlying latent construct, these measurement properties would hold little theoretical or empirical meaning.

The quantitative findings of each single study on a measurement property were also rated against the updated criteria for good measurement properties (see Table A2 in Appendix A) and scored as sufficient (+; in support of the measurement property), insufficient (-; evidence against the measurement property) or indeterminate (?; not possible to deduce whether the evidence is for or against the measurement property).

Checklists were completed by VN, and 20% of the articles were rated for risk of bias by an independent reviewer (SC) trained and experienced in using COSMIN (Cassidy et al., 2018b, 2018a). Inter-rater agreement was substantial for the risk of bias checklist (PABAK = .71, 85.7%), similar to that of previous COSMIN reviews (Cassidy et al., 2018b, 2018a). Any disagreements were resolved through discussion, and agreed ratings were utilised in the subsequent evidence synthesis. As recommended by COSMIN, data were extracted from the included studies and

corresponding self-harm assessment tools, including sample characteristics and the results for measurement properties. Information about the interpretability and feasibility of the score(s) of the eligible tools were also qualitatively summarised, where interpretability referred to how easily meaning can be derived from the tools' score(s), and feasibility denoted how easily the tool can be applied in its intended setting (Mokkink et al., 2018).

2.4.3. Evidence Synthesis

This step focused on the quality of each tool by qualitatively summarising the results of all available studies per measurement property (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). The summarised results were again compared against the criteria for good measurement properties to determine whether the overall measurement property of each tool was sufficient (+), insufficient (-), inconsistent (\pm) or indeterminate (?). To be classed as sufficient or insufficient, 75% of the results had to meet the corresponding criteria. For example, an overall rating of 'sufficient' for hypothesis testing would require at least 75% of the results to be in accordance with the hypotheses, while 75% not in accordance would mean an 'insufficient' rating. If the results of single studies were inconsistent and the inconsistency was unexplained, the overall result would be 'inconsistent'. Likewise, if the results per study were all indeterminate, the overall rating would also be 'indeterminate' (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018).

A modified version of the Grading of Recommendations Assessment, Development and Evaluation (GRADE; Schünemann et al., 2012) system was then used to evaluate the quality of the summarised evidence per measurement property per tool (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). Four factors

assessed this: 1) risk of bias – the methodological quality of studies; 2) inconsistency – unexplained inconsistency of results across studies; 3) imprecision – total sample size of the available studies; and 4) indirectness – evidence from different populations other than the defined population of interest. However, due to the stringent inclusion criteria, indirectness was not considered applicable to the current review and was not evaluated. Factors 1 to 3 were graded as high, moderate, low, or very low evidence to indicate the confidence in the true measurement property being reflected by that of the summarised result. As recommended by COSMIN, grading was completed by VN and independently by a second reviewer (SC), where the inter-rater agreement was substantial (PABAK = .61, 81.0%).

The final step of the COSMIN method involved formulating recommendations on the most suitable assessment tool for the construct of interest and study population (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). These were categorised as: A) assessment tools with evidence for sufficient content validity (any level) AND at least low-quality evidence for sufficient internal consistency; B) assessment tools categorised not in A) or C); or C) assessment tools with high-quality evidence for an insufficient measurement property. Those categorised as A can be recommended for use (or adaptation), B has the potential to be recommended for use but requires further research to assess quality, and C is not recommended for use (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018).

2.5. Results: Stage 2

The PubMed search for studies assessing the measurement properties of self-harm assessment tools identified 394 articles eligible for title and abstract

screening. Of these, 44 were screened in full, and 19 were retained for analysis (see Figure 3). No studies were identified that assessed the measurement properties of any self-harm assessment tools in autistic samples, nor the measurement properties of the FASM in adult samples. See Table 2 for an overview of sample demographics from the included studies and Table 3 for the characteristics of each evaluated self-harm assessment tool.

The methodological quality of the included studies was rated using the risk of bias checklist and criteria for good measurement properties. However, none had explored content validity, measurement error, cross-cultural validity/ measurement invariance, or responsiveness, so these properties could not be rated. The risk of bias for each measurement property of the included studies is presented in Table 4, and the collated evidence for the criteria for good measurement properties of each tool is presented in Table 5. Table 6 provides a qualitative summary of results, overall rating, and quality of evidence for each tool's measurement properties.

Figure 3.

PRISMA flow diagram for the selection of articles with evidence for measurement properties.

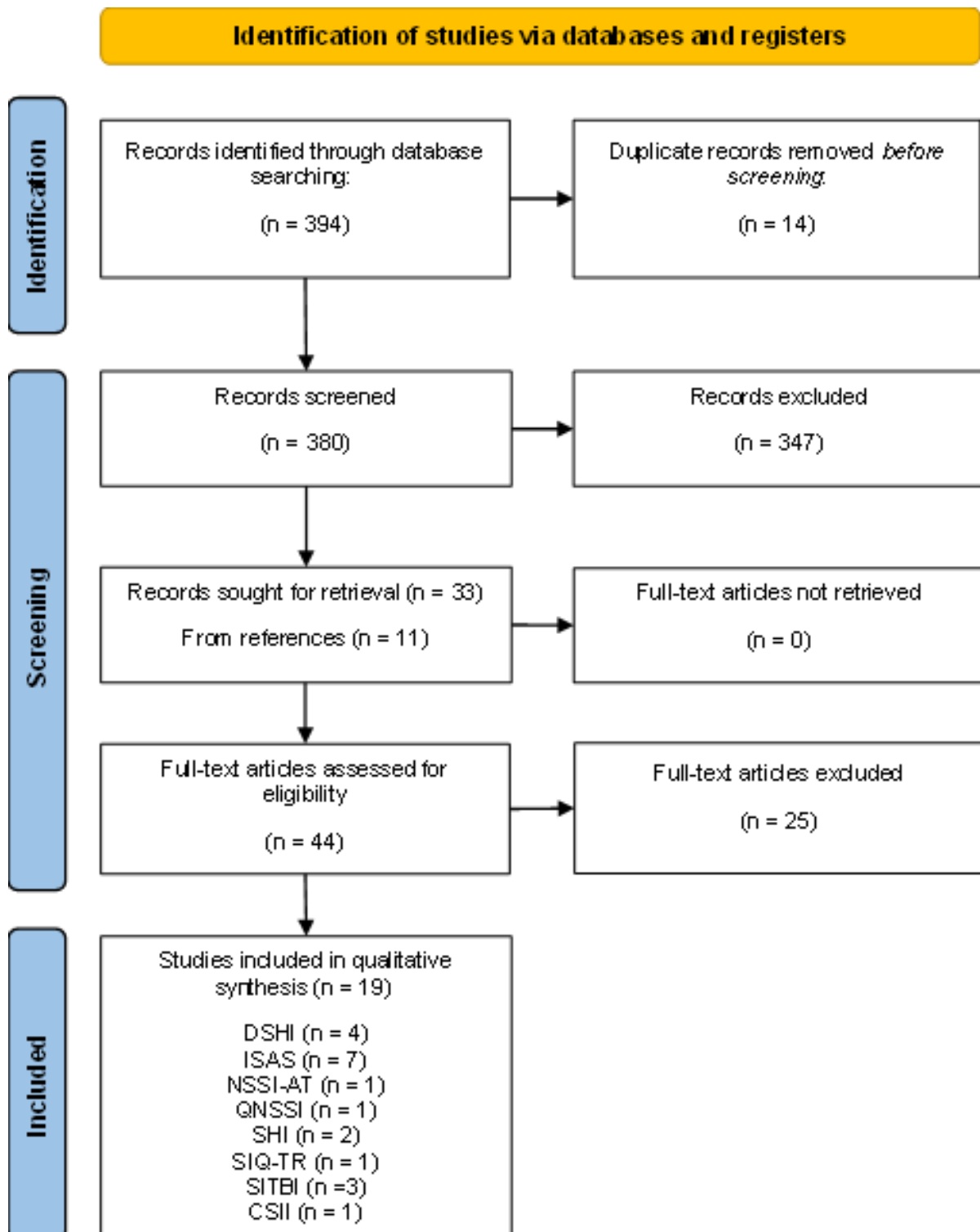


Table 2.*Demographics for the samples from included studies.*

Measure	Authors (Year)	Country	Language	Population	Sample size	Age	Male (m)/ Female (f)
					<i>n</i>	<i>M (SD)</i>	<i>n (%)</i>
CSII	Snowden et al., (2022)	UK	English	Student	184	19.9 (1.8) 18-29	m: 37 f: 137 non-binary/ not listed: 10
DSHI	Gratz (2001)	USA	English	Student	150	21.86 (3.16) 18-64	f: 68%
	Fliege et al., (2006)	Germany	German	Clinical	361	41.9 (14.9) 17-77	f: 242 (67%)
	Ohira et al., (2018)	Japan	Japanese	Community & Student	149 Community: 18 Student: 131	20.5 (2.3) 18-29	m: 58 f: 91
	Vigfusdottir et al., (2020)	Norway	Norwegian	Student	402	Under 25: 193 (48.4%) 16-35: 85 (21.1%) 36-45: 51 (12.7%) 46-55: 35 (8.7%) Over 55: 35 (8.7%)	f: 317 (78.9%)
ISAS	Glenn & Klonsky (2011)	USA	English	Student	51	19 (1.6)	f: 72.5%
	Kim et al., (2019)	Korea	Korean	Community (NSSI & Control)	539 NSSI: 343 Control: 196	19-22: 262 (48%) 23-26: 217 (40.2%) 27-30: 60 (11.2%)	f: 357 (66.2%) unspecified: 4 (0.7%)
	Klonsky & Glenn (2009)	USA	English	Student	235	18.5 (1.1)	f: 55%
	Klonsky & Olino (2008)	USA	English	Student	205	18.5 (1.2)	f: 57%
	Kortge et al., (2013)	USA	English	Community	201	23.77 (6.58) 18-50	f: 91%

	Pérez et al., (2020)	Spain	Spanish	Clinical	355	27.89 (13.31) 12-68	m: 40 (11.3%) f: 315 (88.7%)
	Vigfusdottir et al., (2020)	Norway	Norwegian	Student	402	Under 25: 193 (48.4%) 26-35: 85 (21.1%) 36-45: 51 (12.7%) 46-55: 35 (8.7%) Over 55: 35 (8.7%)	f: 317 (78.9%)
NSSI-AT	Whitlock et al., (2014)	USA	English	Student	11,529	20.31 (1.80) 18-25	m: 4,809 (41.7%) f: 6,639 (57.6%)
QNSSI	Turner et al., (2012)	Canada	English	Community	162	22.47 (7.14) 16 -57	f: 162 (100%)
SHI	Latimer et al., (2009)	Australia	English	Student	423	19.45 (2.14) 17-52	m: 81 f: 342
	Müller et al., (2016)	Germany	German	Population	2,507	48.79 (18.11) 14-94	m: 1,115 (44.5%) f: 1,392 (55.5%)
SIQ-TR	Claes & Vandereycken (2007)	Belgium	English	Clinical	273	24.8 (8.2)	f: 100%
SITBI	Fox et al., (2020)	USA	English	Community			
	Study 1				110	29.13 (12.8)	f: 69.2%
	Study 2				188	26.94 (6.54)	f: 58.5%
	García-Nieto et al., (2013)	Spain	Spanish	Clinical	150	43.30 (10.3)	f: 84 (56%)
	Lee et al., (2021)	Korea	Korean	Student	108	22.10 (3.33)	f: 91 (84.3%)

CSII = Cardiff Self-Injury Inventory; DSHI = Deliberate Self-Harm Inventory (DSHI); ISAS = Inventory of Statements about Self-Injury; NSSI-AT = Non-Suicidal Self-Injury – Assessment Tool; QNSSI = Questionnaire for Non-Suicidal Self-Injury; SHI = Self-Harm Inventory; SIQ-TR = Self-Injury Questionnaire – Treatment Related; SITBI = Self-injurious Thoughts and Behaviors Interview

Table 3.*Description of the included self-harm assessment tools.*

Measure	Original Authors (Year)	Aims to assess	Suicidal intent?	Mode of administration	Items	Subscales	Response format
CSII	Snowden et al., (2022)	Frequency	With and without	Self-report	8	2 sections (1) across whole life (2) in the past 3 months	5-point scale
DSHI	Gratz (2001)	Frequency, severity, duration, and type	Without	Self-report	17	n/a	Dichotomous (yes/no), open-ended
ISAS	Klonsky & Glenn, (2009)	Frequency, characteristics and functions	Without	Self-report	8 ISAS I: 7 ISAS II: 39	ISAS I ISAS II (2 subscales): (a) intra- and (b) interpersonal functions	Dichotomous (yes no), multiple choice, open-ended, 3-point scale
NSSI-AT	Whitlock et al., (2014)	Primary (form, frequency, and function) and secondary (habituation, context, life interference, treatment, and impacts) characteristics	Without	Self-report	39	12 modules: (a) NSSI behaviours; (b) functions; (c) recency and frequency (and age of cessation); (d) age of onset; (e) wound locations; (f) initial motivations; (g) severity; (h) practice patterns; (i) habituation and perceived life interference; (j) NSSI disclosure; (k) NSSI treatment experiences; and (l) personal reflections and advice	Dichotomous (yes/no, true/false), multiple choice, open-ended, 4- or 5-point scales

QNSSI	Kleindienst et al., (2008)	Frequency, methods, functions, expectations, and emotions	Without	Self-report	26 Functions: 17 + 22 SASII	Functions (5 subscales): (a) emotion relief; (b) feeling generation; (c) interpersonal communication; (d) interpersonal influence; and (e) self-punishment	Dichotomous (yes/no), multiple choice, open-ended, 4- or 5-point scales
SHI	Sansone et al., (1998)	Type	With (1 item) and without	Self-report	22	n/a	Dichotomous (yes/no)
SIQ-TR	Claes & Vandereycken, (2007a)	Characteristics, functions, and emotions	Without	Self-report	10 items per 5 NSSI behaviours (+ other)	Emotions (4 subscales): (a) Negative-before; (b) Positive-before; (c) Negative-after; (d) Positive-after Functions (3 subscales): (a) Social Positive Reinforcement; (b) Automatic Positive Reinforcement; (c) Automatic Negative Reinforcement	Multiple choice, 4- or 5-point scales
SITBI	Nock et al., (2007)	Presence, frequency, and characteristics	With and without	Structured interview	169	5 modules: (a) suicidal ideation; (b) suicide plans; (c) suicide gestures; (d) suicide attempts; (e) NSSI	Dichotomous (yes/no), multiple choice, open-ended, 5-point scale

CSII = Cardiff Self-Injury Inventory; DSHI = Deliberate Self-Harm Inventory (DSHI); ISAS = Inventory of Statements about Self-Injury; NSSI-AT = Non-Suicidal Self-Injury – Assessment Tool; QNSSI = Questionnaire for Non-Suicidal Self-Injury; SASII = Suicide Attempt Self-Injury Interview; SHI = Self-Harm Inventory; SIQ-TR = Self-Injury Questionnaire – Treatment Related; SITBI = Self-injurious Thoughts and Behaviors Interview

Table 4.

Risk of bias for the included studies of each self-harm assessment tool.

Measure	Study	Structural Validity	Internal Consistency	Reliability	Criterion Validity	Hypothesis testing	
						(a)	(b)
CSII	Snowden et al., (2022)			Doubtful	Very good	Very good	
DSHI	Gratz (2001)			Inadequate		Adequate	Doubtful
	Fliege et al., (2006)			Inadequate	Inadequate	Very good	Doubtful
	Ohira et al., (2018)			Inadequate		Adequate	Adequate
	Vigfusdottir et al., (2020)				Very good	Adequate	Doubtful
ISAS	Glenn & Klonsky (2011)			Inadequate		Adequate	
	Kim et al., (2019)	Very good	Very good	Doubtful	Very good	Adequate	
	Klonsky & Glenn (2009)	Adequate	Very good			Adequate	
	Klonsky & Olino (2008)			Doubtful		Adequate	Adequate
	Kortge et al., (2013)	Very good	Very good				Doubtful
	Pérez et al., (2020)	Very good	Very good	Inadequate		Very good	
	Vigfusdottir et al., (2020)	Inadequate	Very good		Very good	Adequate	Doubtful
NSSI-AT	Whitlock et al., (2014)	Adequate	Very good	Doubtful	Inadequate	Doubtful	
QNSSI	Turner et al., (2012)	Doubtful	Very good			Adequate	
SHI	Latimer et al., (2009)						Adequate
	Müller et al., (2016)					Adequate	Adequate
SIQ-TR	Claes & Vandereycken (2007b)	Inadequate	Doubtful			Adequate	
SITBI	Fox et al., (2020)			Adequate		Adequate	
	García-Nieto et al., (2013)			Inadequate		Doubtful	

CSII = Cardiff Self-Injury Inventory; DSHI = Deliberate Self-Harm Inventory; ISAS = Inventory of Statements about Self-Injury; NSSI-AT = Non-Suicidal Self-Injury – Assessment Tool; QNSSI = Questionnaire for Non-Suicidal Self-Injury; SHI = Self-Harm Inventory; SIQ-TR = Self-Injury Questionnaire – Treatment Related; SITBI = Self-injurious Thoughts and Behaviors Interview

Table 5.

Collated evidence of the criteria for good measurement properties for each self-harm assessment tool.

Measure	Structural Validity	Internal Consistency	Reliability	Criterion Validity	Hypothesis testing	
					(a)	(b)
CSII			?	+	+	
DSHI			???	+ ?	+++ + - -	++++
ISAS	++ - - -	+++++ -	???	++	+++++	+++
NSSI-AT	?	-	+	?	+	
QNSSI	+	+			+	
SHI					+	++
SIQ-TR	+	-			+ -	
SITBI			-	?	+++	

“+” = sufficient, “-” = insufficient, “?” = indeterminate

CSII = Cardiff Self-Injury Inventory; DSHI = Deliberate Self-Harm Inventory; ISAS = Inventory of Statements about Self-Injury; NSSI-AT = Non-Suicidal Self-Injury – Assessment Tool; QNSSI = Questionnaire for Non-Suicidal Self-Injury; SHI = Self-Harm Inventory; SIQ-TR = Self-Injury Questionnaire – Treatment Related; SITBI = Self-injurious Thoughts and Behaviors Interview

Table 6.

Qualitative summary of findings for the measurement properties of each self-harm assessment tool.

Measure		Structural Validity	Internal Consistency	Reliability	Criterion Validity	Hypothesis testing	
						(a)	(b)
CSII	<i>Summary result</i>			$r = .82; n = 58$	DSHI ($r = .82$)	1 out of 1 hypothesis confirmed (100%)	
	<i>Overall rating Quality of evidence</i>			Indeterminate (?) Very low	Sufficient (+) High	Sufficient (+) High	
DSHI	<i>Summary result</i>			r range = .84 - .92; \emptyset range = .49 - .73; $n = 176$	Clinician rating (ICC/ $k < .70$); ISAS ($r > .70$)	10 out of 13 hypotheses confirmed (76%)	4 out of 4 hypotheses confirmed (100%)
	<i>Overall rating Quality of evidence</i>			Indeterminate (?) Low	Inconsistent (\pm) Low	Sufficient (+) High	Sufficient (+) Moderate
ISAS	<i>Summary result</i>	EFA: 3+ item coefficients > .4 loading on each factor with some minor cross-loading	ISAS II: α range = .52 - .92 (one below > .70); $n = 973$	ISAS I: r range = .52 - .94 ISAS II: r range = .35 - .92; $n = 268$	DSHI (r range = .81 - .96); FASM (r range = .74 - .77)	8 out of 8 hypotheses confirmed (100%)	3 out of 3 hypotheses confirmed (100%)
	<i>Overall rating Quality of evidence</i>	Inconsistent (\pm) Low	Sufficient (+) High	Indeterminate (?) Low	Sufficient (+) High	Sufficient (+) High	Sufficient (+) Moderate

NSSI-AT	<i>Summary result</i>	EFA: Unable to determine	α all < .70; $n = 1,773$	$k = .74 - .85$; ICC = .63 - .91; $n = 25$	FASM ($k > .77$)	3 out of 3 hypotheses confirmed (100%)	
	<i>Overall rating</i>	Indeterminate (?)	Insufficient (-)	Sufficient (+)	Indeterminate (?)	Sufficient (+)	
	<i>Quality of evidence</i>	Moderate	High	Very low	Very low	Low	
QNSSI	<i>Summary result</i>	EFA: 3+ item coefficients > .4 on each factor and no cross-loadings	$\alpha = .66 - .85$ (one below > .70); $n = 162$			3 out of 3 hypotheses confirmed (100%)	
	<i>Overall rating</i>	Sufficient (+)	Sufficient (+)			Sufficient (+)	
	<i>Quality of evidence</i>	Low	High			Moderate	
SHI	<i>Summary result</i>					1 out of 1 hypothesis confirmed (100%)	2 out of 2 hypotheses confirmed (100%)
	<i>Overall rating</i>					Sufficient (+)	Sufficient (+)
	<i>Quality of evidence</i>					Moderate	High
SIQ-TR	<i>Summary result</i>	EFA: 3+ item coefficients > .4 on each factor and no cross-loadings	$\alpha = .51 - .89$; $n = 83$			1 out of 3 hypotheses confirmed (100%)	
	<i>Overall rating</i>	Sufficient (+)	Insufficient (-)			Insufficient (-)	
	<i>Quality of evidence</i>	Very low	Very low			Moderate	
SITBI	<i>Summary result</i>			$k = .33 - 1$; ICC = .15 - .91; $n = 212$	DSM-5 diagnoses: SBD ($k = 1.0$); NSSI ($k = .94$)	5 out of 5 hypotheses confirmed (100%)	

Overall rating
Quality of
evidence

Insufficient (-)
Low

Indeterminate (?)
Very low

Sufficient (+)
High

n = total sample size

CSII = Cardiff Self-Injury Inventory; DSHI = Deliberate Self-Harm Inventory (DSHI); FASM = Functional Assessment of Self-Mutilation; ISAS = Inventory of Statements about Self-Injury; NSSI = Non-Suicidal Self-Injury; NSSI-AT = Non-Suicidal Self-Injury – Assessment Tool; QNSSI = Questionnaire for Non-Suicidal Self-Injury; SBD = Suicidal Behavior Disorder; SHI = Self-Harm Inventory; SIQ-TR = Self-Injury Questionnaire – Treatment Related; SITBI = Self-injurious Thoughts and Behaviors Interview

2.5.1. *Cardiff Self-Injury Inventory (CSII)*

One study assessed the measurement properties of the CSII in general population adults (Snowden et al., 2022). Reliability was indeterminate, reported using r values, not the intraclass correlation coefficient (ICC) as required by COSMIN, and of very low quality due to a doubtful rating and small sample size ($n = 48$). On the other hand, evidence for criterion validity was sufficient and of high quality, where the CSII demonstrated an acceptable correlation with the DSHI ($r = .81$). Hypothesis testing (a) was also sufficient and of high quality, showing an acceptable correlation with an instrument measuring a similar construct (Suicidal Behaviors Questionnaire-Revised [SBQ-R]; Osman et al., 2001).

2.5.2. *Deliberate Self-Harm Inventory (DSHI)*

Four studies assessed the measurement properties of the DSHI in clinical and general population adults (Fliege et al., 2006; Gratz et al., 2015; Ohira et al., 2018; Vigfusdottir et al., 2020). Three studies used versions translated into either German (Fliege et al., 2006), Japanese (Ohira et al., 2018) or Norwegian (Vigfusdottir et al., 2020). One of the included studies consisted of a clinical sample of psychosomatic inpatients (Fliege et al., 2006) and three of general population adults. The DSHI demonstrated indeterminate evidence for reliability, which was of low quality due to multiple inadequate ratings and inappropriate reporting of statistics (r and omega values instead of ICC and weighted Kappa). Evidence for criterion validity was inconsistent and of low quality, where the DSHI demonstrated sufficient coefficients with the ISAS ($r > .70$) but not with clinician rating (ICC/ $k < .70$). Evidence for hypothesis testing (a) was sufficient and of high quality, with acceptable correlations for similar measures (e.g., SHBQ; Gutierrez et al., 2001), related but dissimilar

measures (e.g., Difficulties in Emotion Regulation Scale; Gratz & Roemer, 2004), and unrelated measures (e.g., Marlowe-Crowne Social Desirability Scale [MCSDS]; Crowne & Marlowe, 1960). Evidence for hypothesis testing (b) was also sufficient but of moderate quality, with expected differences between groups (e.g., similar rates of self-harm in women vs men).

2.5.3. Inventory of Statements about Self-Injury (ISAS)

Seven studies assessed the measurement properties of the ISAS in general population adults (Glenn & Klonsky, 2011; S. Kim et al., 2019; Klonsky & Glenn, 2009; Klonsky & Olino, 2008; Kortge et al., 2013; Pérez et al., 2020; Vigfusdottir et al., 2020). Three studies used versions translated into either Korean (Kim et al., 2019), Spanish (Pérez et al., 2020) or Norwegian (Vigfusdottir et al., 2020). The ISAS consists of two sections, where two studies examined the measurement properties of ISAS I only (Klonsky & Olino, 2008; Vigfusdottir et al., 2020), three ISAS II only (Klonsky & Glenn, 2009; Kortge et al., 2013; Pérez et al., 2020), and two both ISAS I and II (Glenn & Klonsky, 2011). One of the seven studies included a clinical sample of participants diagnosed with an eating or cluster B personality disorder (Pérez et al., 2020).

For the ISAS II subscale, evidence for structural validity was inconsistent, and the subsequent quality was low. Four studies conducted exploratory factor analysis only (EFA), two conducted confirmatory factor analysis (CFA), and one used a Rasch model. EFA indicated a two-factor solution (interpersonal and intrapersonal) across respective studies, with three or more coefficients of $\geq .4$ loading on each factor (although there was evidence of minor cross-loading in two studies; Kortge et al., 2013; Vigfusdottir et al., 2020). Only one CFA supported the two-factor solution with

an acceptable model fit, and this was in the clinical sample (Pérez et al., 2020). The Rasch model met the assumptions for dimensionality and independence but did not report the appropriate fit statistics specified for a sufficient rating by COSMIN (Kortge et al., 2013). Conversely, evidence for internal consistency of the ISAS II subscale was sufficient and of high quality, where all studies reporting on this had very good ratings. Three of the four studies reported an acceptable level for Cronbach's alpha ($\alpha \geq .70$), and the one study that had an insufficient rating was only below acceptable on the intrapersonal factor (Kortge et al., 2013; $\alpha = .52$).

There was indeterminate evidence for the reliability of both ISAS I and ISAS II subscales, which were of low quality. Similarly to the CSII and DSHI, the four studies reporting this only used r values rather than ICC, along with doubtful or inadequate ratings. Evidence for criterion validity was sufficient and of high quality, where the ISAS demonstrated acceptable correlations ($r > .70$) with both the FASM and the DSHI. Evidence for hypothesis testing (a) was sufficient and of high quality, where correlations were demonstrated with related but dissimilar measures (e.g., suicidality items on the Youth Risk Behaviors Survey; Kann, 2001) and unrelated measures (e.g., MCSDS; Crowne & Marlowe, 1960). Hypothesis testing (b) was also sufficient but of moderate quality, showing expected differences between groups (e.g., higher scores on ISAS II corresponding to borderline personality disorder diagnosis).

2.5.4. Non-Suicidal Self-Injury-Assessment Tool (NSSI-AT)

One study assessed the measurement properties of the NSSI-AT in general population adults (Whitlock et al., 2014). Evidence in support of structural validity was indeterminate but of moderate quality. EFA was conducted on suitable modules (NSSI functions, NSSI practice patterns and NSSI personal reflections and advice).

However, no coefficients were provided for any of these. Evidence for internal consistency was insufficient yet of high quality. Cronbach's alpha ($\alpha \geq .70$) was below the acceptable level for each module but rated as very good for risk of bias. Conversely, reliability was sufficient, with acceptable Kappa ($k > .70$) and ICC reported for all but one of the corresponding variables (number of wound locations), which was not downgraded on this occasion due to the possibility of real change occurring. Criterion validity was indeterminate when establishing NSSI-AT scores as an adequate reflection of the FASM, as no correlation or AUC was reported. However, evidence for reliability and criterion validity were of very low quality due to the risk of bias from missing necessary information or a small sample size ($n = 25$). There was sufficient evidence for hypothesis testing (a) with acceptable correlations for related but dissimilar constructs (e.g., suicidal thoughts and behaviours) and unrelated constructs (e.g., number of sexual partners in the last year). However, this was of low quality due to a lack of evidence for the validity of how these constructs were measured.

2.5.5. Questionnaire for Non-Suicidal Self-Injury (QNSSI)

One study assessed the measurement properties of the QNSSI in general population adults (Turner et al., 2012). Evidence in support of structural validity was sufficient but of low quality. EFA indicated a five-factor solution (emotion relief, feeling generation, interpersonal influence, interpersonal communication, and self-punishment) with three or more coefficients of $\geq .4$ loading on each factor. However, the sample size was inadequate, with less than 5 participants per item. On the other hand, internal consistency was sufficient and of high quality. Cronbach's alpha was above acceptable for four of the five factors ($\alpha \geq .70$), but self-punishment ($\alpha = .66$) was considered close enough to be of an acceptable level. Evidence for hypothesis

testing (a) was sufficient and of moderate quality. Acceptable correlations were demonstrated between factors with related but dissimilar items on other measures (e.g., emotion relief with affective intensity, expressive suppression, and difficulties in emotion regulation) and unrelated items (e.g., feeling generation with affective reactivity or expressive suppression).

2.5.6. Self-Harm Inventory (SHI)

Two studies assessed the measurement properties of the SHI in general population adults (Latimer et al., 2009; Müller et al., 2016). One study used a version translated into German (Müller et al., 2016). As the SHI is behaviour-specific, hypothesis testing was the only relevant measurement property. The evidence in support of hypothesis testing (a) was sufficient and of moderate quality, where the SHI demonstrated acceptable correlations with related but dissimilar measures (e.g., Patient Health Questionnaire for Depression and Anxiety; Kroenke et al., 2009). Similarly, hypothesis testing (b) was sufficient and of high quality, with expected differences found between groups (e.g., depression and anxiety scores differed across severity levels of the SHI).

2.5.7. Self-Injury Questionnaire – Treatment Related (SIQ-TR)

One study assessed the measurement properties of the SIQ-TR in a clinical sample of inpatients with an eating disorder (Claes & Vandereycken, 2007b). Evidence for structural validity was sufficient, where EFA indicated a two-factor solution on the emotion subscale (preceding feelings and consequent feelings) and a three-factor solution on the function subscale (social positive reinforcement, automatic positive reinforcement and automatic negative reinforcement). Both scales had three or more coefficients of $\geq .4$ loading on each factor. Conversely, the

evidence for internal consistency was insufficient; there was no overall Cronbach's alpha for any of the subscale's factors, and individual alphas ranged below the acceptable level on each subscale ($\alpha < .70$). Quality of evidence was very low for both structural validity and internal consistency due to unclear and flawed reporting on these measurement properties which increased risk of bias. There was also insufficient evidence for hypothesis testing (a). However, this was of moderate quality, where the SIQ-TR demonstrated inconsistent relationships across subscales with related but dissimilar measures (e.g., Self-Expression and Control Scale; van Elderen et al., 1996).

2.5.8. Self-injurious Thoughts and Behaviours Interview (SITBI)

Three studies assessed the measurement properties of the SITBI in general population adults (Fox et al., 2020; García-Nieto et al., 2013; Lee et al., 2021). One study used a revised version of the SITBI (SITBI-R; Fox et al., 2020), and two studies used versions either translated into Spanish (García-Nieto et al., 2013) or Korean (Lee et al., 2021). One study included a clinical sample of psychiatric inpatients admitted for self-harmful (with or without suicidal intent) ideation and behaviour (García-Nieto et al., 2013). Despite the SITBI not being a wholly behaviour-specific tool, the authors argue that structural validity and internal consistency are not meaningful, as the tool uses various item formats to measure a wide range of constructs. Consequently, these measurement properties were not reported by any of the studies. Evidence in support of reliability was insufficient and of low quality. ICC and k values reported within all three studies ranged below the acceptable level ($< .70$) and were at risk of bias due to inappropriate time intervals, inconsistent types of administration or small sample sizes. Similarly, criterion validity was indeterminate and of very low quality due to missing necessary information.

Nonetheless, there was sufficient evidence for hypothesis testing (a) that was of high quality, with acceptable correlations of the SITBI with similar (e.g., Scale for Suicidal Ideation; Beck et al., 1979) and related but dissimilar measures and items (e.g., Survival and Coping Beliefs of the Reason for Living; Linehan et al., 1983).

2.5.9. Interpretability and Feasibility

For interpretability, the distribution of the overall or subscale score of each tool (i.e., mean and standard deviation or equivalent) was provided in all studies. This was less relevant in behaviour-specific measures (CSII, DSHI, SHI), where the proportion of self-harm behaviours endorsed or frequency of behaviours was given instead. Eight studies reported exclusion of participants due to missing data or addressed how missing data was/ would be handled. However, it was not necessarily clear whether this was specific to data from the self-harm assessment tool or the broader study. Only one study included the response rate for each item and subscale on the NSSI-AT (Whitlock et al., 2014). Two studies explicitly identified a floor effect, which was present at the more severe end of self-harm on the DSHI (Latimer et al., 2009), and for the interpersonal factor on the ISAS (Kortge et al., 2013). None of the studies reported scores and change scores for relevant (sub)groups, minimal important change, or information on response shift.

In terms of feasibility, there was no evidence of content validity for any of the self-harm assessment tools in the population of interest, so neither patient nor clinician comprehensibility could be evaluated. The length of the tools varied from 8 items (CSII) to 169 items (SITBI) and took 1 to 30 minutes to complete, depending on the measure. It was assumed that respondents would require at least an average IQ (> 70) to complete the tools, as there was no evidence to suggest otherwise. In

general, the availability of guidance or instructions for administering and scoring the self-harm assessment tools was inconsistent, although somewhat self-explanatory. Copyright information was provided for the CSII and SHI, and only one tool was not freely available online but was accessed at no cost with permission from the authors (QNSSI; Turner et al., 2012).

2.5.10. *Formulated Recommendations*

Based on the COSMIN checklist for formulating recommendations, seven of the eight self-harm assessment tools were classified as B (potential to be recommended for use but require further research to assess quality). However, the NSSI-AT was classified as C (not recommended for use) due to high-quality evidence for insufficient internal consistency. The ISAS and QNSSI were the only assessment tools with sufficient internal consistency, in line with classification A (recommended for use), but did not assess content validity, which was necessary to meet the full requirements. Moreover, the ISAS had the most evidence overall for its measurement properties in general and clinical population adults ($k = 7$), compared to the single study for the QNSSI. Thus, as no evidence was available for autistic adults, either the ISAS or QNSSI would likely be the most suitable tool to recommend for use with general population adults, but both need further research to assess content validity.

2.6. Discussion

Before this review, it was unknown which tools, if any, had been used frequently to assess self-harm in autistic versus general population adults. Results revealed a small number of studies with autistic adults that had used a validated tool to assess self-harm ($k = 6$) compared to general population adults ($k = 91$).

Moreover, only one frequently used self-harm assessment tool had been utilised with autistic adults (NSSI-AT). While the NSSI-AT has been used in the general population with some evidence of validity, it has not been developed or validated specifically for autistic individuals. These findings correspond with previous COSMIN reviews, highlighting a distinct lack of robust health outcome measures for autistic people (Cassidy et al., 2018b, 2018a; Thoen et al., 2023). Therefore, the current review emphasises the urgent need for self-harm assessment tools that are developed and validated for autistic people to improve the conceptualisation of self-harm and its measurement in research and clinical practice.

Studies identified in the first stage of the review commonly assessed self-harm in autistic individuals using singular items or subscales within broader tools rather than dedicated self-harm measures. Many also assessed SIB in this manner as a “challenging” and/ or “restrictive and repetitive” behaviour (e.g., Behaviour Problems Inventory; Rojahn et al., 2001). This was mainly the case in samples of autistic children or those with co-occurring ID, although a small number of studies used such subscales for autistic adults without co-occurring ID (e.g., Challenging Behaviour Questionnaire; Licence et al., 2020). The IfES was the only tool in the current review focusing specifically on the SIB conceptualisation of self-harm (IfES; Bienstein & Nußbeck, 2010), it was not considered for the second stage as it had only been used in one study, and the tool was not available in English. Furthermore, some studies used items that did not distinguish between self-harm and suicidality (e.g., “Thoughts you would be better off dead or hurting yourself” Patient Health Questionnaire-9 [PHQ-9]; Kroenke et al., 2001), despite not knowing enough about self-harm in autistic people to assess its function as commensurate to suicidal ideation (Cassidy et al., 2020). Thus, based on a synthesis of the available evidence

and the outcomes of the COSMIN checklist, recommendations are made for the use of self-harm assessment tools in autism research.

The second stage of the review found nineteen studies exploring the measurement properties of eight validated self-harm assessment tools in general and clinical population adults (CSII, DSHI, ISAS, NSSI-AT, QNSSI, SHI, SITBI and SIQ-TR). However, no studies were identified that assessed the measurement properties of these tools in autistic adults. Of the included measures, some focused solely on self-harm behaviours, measuring aspects such as type, frequency, and severity (CSII, DSHI, SHI). However, while this is valuable for epidemiological research, such tools provide limited insight into the underlying functions of self-harm, which is key to providing effective support (Edmondson et al., 2016). Moreover, the SITBI focuses more on suicidality, and the Suicidal Behaviours Questionnaire – Autism Spectrum Conditions (SBQ-ASC; Cassidy, Bradley, et al., 2021) has already been successfully adapted to measure this construct in autistic people. Given the paucity of research on self-harm in autism, tools which measure the underlying latent construct (e.g., functions) are more likely to be beneficial to clinical and research contexts.

Overall, evidence for the measurement properties of the other assessment tools was mixed. The ISAS had the most studies exploring its measurement properties ($k = 7$) with generally favourable evidence, though some concerns remained regarding its structural validity and reliability. Some tools had stronger evidence for their internal structure (ISAS, QNSSI), while others demonstrated adequate criterion and construct validity (ISAS, NSSI-AT), suggesting they better reflect the underlying latent construct or interrelatedness among items (Mokkink et al., 2010). Moreover, the ISAS and the QNSSI had at least low-quality evidence for

sufficient internal consistency, meeting one of the two COSMIN criteria for recommended use. Although the NSSI-AT was the only tool used with autistic individuals, its inadequate internal consistency was of concern. However, the authors recognise this may result from small subscales (3-4 items), that the items were not originally designed as scales, and the mostly dichotomous scoring (Whitlock et al., 2014). Consequently, the ISAS appears to be the strongest candidate for future research, while the QNSSI also demonstrates promising evidence, and the NSSI-AT remains the only tool previously used with autistic adults.

The review also highlighted that none of the studies explored measurement error, cross-cultural validity, measurement invariance, or responsiveness for any self-harm assessment tools identified. Many tools lacked sufficient test-retest reliability, with reported statistics below the recommended threshold of .70 or where time intervals were inadequate (e.g., more than four weeks between administrations). However, antecedent factors and the temporal proximity of these to an episode of self-harm are complex (Townsend et al., 2016), and the predictive utility of such assessments for future behaviour is generally poor (Quinlivan et al., 2016, 2017). Therefore, it is unsurprising that reports of self-harm frequency and function do not appear to be stable between repeated measurements. Consequently, studies should also aim to include tests of responsiveness to change to address the nature or assessment of changes in self-harm over time.

2.6.1. Strengths and Limitations

A key strength of the current review was the use of COSMIN, which provided a rigorous approach to identify studies and evaluate the measurement properties of assessment tools. However, this rigour may have also inadvertently led to the

exclusion of relevant data from self-harm subscales or single items, where SIB was mainly assessed this way. Nevertheless, subscales frequently have narrower definitions and fewer items to aid a holistic understanding of a construct, and it was considered more important to focus on assessment tools specific to self-harm. Additionally, the strict nature of the COSMIN criteria may have resulted in more negative ratings of measurement properties due to the requirement of very specific or high statistical thresholds (Modini et al., 2015). For example, structural validity criteria were adapted within the current review to account for EFA results that would be considered well-adjusted according to best practice (Costello & Osborne, 2005). Additionally, searches were limited to studies published and available in English, potentially omitting relevant evidence for tools originally developed in other languages, such as the QNSSI (Kleindienst et al., 2008).

2.6.2. Next Steps

Building on the findings of this review, Chapter 3 will aim to assess the content validity of existing self-harm assessments in that they are relevant, clear and comprehensive for autistic populations. If not, new tools will need to be adapted or developed following COSMIN guidelines (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018), utilising focus groups and cognitive interviews with autistic individuals. While the ISAS appears to be the strongest candidate, the QNSSI also demonstrated promising measurement properties. However, the NSSI-AT remains the only tool previously used with autistic adults, highlighting its potential despite some concerns about measurement properties. Previous adaptations of depression and suicidality assessment tools for autistic adults have demonstrated that improving clarity and relevance increases sensitivity in detecting these constructs (Cassidy,

Bradley, et al., 2021; Cassidy, Cogger-Ward, et al., 2021), suggesting that similar adaptations for self-harm measures may also be effective.

2.7. Conclusion

This chapter provided the first systematic review to use COSMIN as a robust research tool to identify, evaluate, and synthesise the evidence for the assessment of self-harm in autistic and general population adults. Eight validated self-harm assessment tools were identified, but only one of these had been used with autistic adults, and none had been developed or validated to assess self-harm in this group. Subsequently, Chapter 3 will explore whether self-harm assessment tools designed for the general population are appropriate and acceptable to use with autistic adults. This will determine whether either an existing measure can be adapted or if a new one needs to be developed in order to accurately assess self-harm in autism.

Chapter 3. “Picking the Best of a Bad Bunch”: Exploring Stakeholder Perspectives of Self-harm Assessment Tools for Autistic Adults.

iii. Preface

Chapter 2 highlighted the lack of self-harm assessment tools specifically developed or validated for autistic individuals and identified several potential candidates for further investigation. To ensure autistic perspectives guide this process, Chapter 3 utilises focus groups to explore the views of autistic individuals with lived experience of self-harm and professionals who support them regarding three existing self-harm assessment tools (ISAS, NSSI-AT, QNSSI). Reflexive thematic analysis is then used to identify themes in line with the appropriateness and acceptability of these tools for use with autistic adults.

The research presented in Chapter 3 accepted for publication in:

Newell, V., Richards, C., & Cassidy, S. (2025). “Picking the best of a bad bunch”: exploring stakeholder perspectives of self-harm assessment tools for autistic adults. *Autism*.

3.1. Introduction

Research indicates worryingly high rates of self-harm among autistic individuals (Figueiredo et al., 2023; Steinfeldt-Kristensen et al., 2020), who are also at a greater risk compared to non-autistic individuals (Blanchard et al., 2021; Stark et al., 2022). Likewise, self-harm is more prevalent in adults with high autistic traits than in those with lower autistic traits (Stewart et al., 2023; Wang & Wang, 2023). In the general population, self-harm is associated with adverse outcomes such as mental health difficulties and suicidality (Beckman et al., 2019; Moran et al., 2015; Ohlis et al., 2020), which autistic people are already more likely to experience (Lai et al., 2019; Newell et al., 2023), and may contribute to self-harm in this group (e.g., (Kim et al., 2024; Lopez-Arvizu et al., 2025; Moseley et al., 2022a). However, a significant barrier to understanding and preventing self-harm in autism is the lack of validated and appropriate assessment tools.

Therefore, Chapter 2 described a systematic review using COSMIN (the COnsensus-based Standards for the selection of health Measurement INstruments; Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018), which highlighted the absence of instruments specifically to assess self-harm in autism (see Chapter 2; Newell et al., 2024). Of the eight self-harm assessment tools identified, only one had been used in studies involving autistic adults, the Non-Suicidal Self-Injury - Assessment Tool (NSSI-AT; Whitlock et al., 2014). Two other tools, the Inventory of Statements About Self-injury (ISAS; Klonsky & Glenn, 2009) and the Questionnaire for Non-Suicidal Self-Injury (QNSSI; Turner et al., 2012), demonstrated promising measurement properties in the general population. However, none of the tools had been developed or validated for autistic individuals, leaving uncertainty about their use in research or clinical contexts and the potential need for adaptation.

Existing self-harm assessment tools may pose difficulties for autistic individuals in terms of identifying and describing emotions (i.e., alexithymia; Kinnaird et al., 2019), episodic memory and future thinking (Lind et al., 2014; Lind & Bowler, 2010), literal interpretation of information (Vicente & Falkum, 2023), and unique presentations of self-harm in relation to sensory processing differences, meltdowns or stimming (Marsden et al., 2024; Moseley et al., 2019). To ensure that self-harm assessment tools are reliable, valid, and suitable for this population, it is crucial that researchers collaborate with autistic individuals in the development and evaluation of such tools (Nicolaidis et al., 2020). Evidence suggests that measures can be successfully adapted with and for autistic people, as shown by the Suicidal Behaviours Questionnaire – Autism Spectrum Conditions (SBQ-ASC; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021) and the Autistic Depression Assessment Tool – Adult (ADAT-A; Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021). Despite the urgent need for instruments to assess self-harm in autism, no research has yet investigated the perspectives of key stakeholders on the appropriateness and acceptability of existing tools.

Consequently, this study explores the views of autistic individuals with lived experience of self-harm and professionals who work with them regarding three self-harm assessment tools (ISAS, NSSI-AT, QNSSI) identified in the prior COSMIN review (see Chapter 2; Newell et al., 2024). Specifically, this study aims to determine 1) which, if any, of these tools would be most appropriate to use with autistic adults in the subsequent research stages; and 2) whether the tools are clear, relevant, and representative of autism-specific items.

3.2. Methods

3.2.1. Participants

Nine participants took part in two separate focus groups: one with autistic adults with lived experience of self-harm ($n = 5$) and one with professionals who have worked with autistic people who self-harm ($n = 4$). See Table 7 for participant demographics by focus group.

Table 7.

Participant demographics for each focus group.

Demographics	Autistic adults ($n = 5$) n (%) / M (SD)	Professionals ($n = 4$)
Age*	37.20 (5.85)	30.33 (11.85)
Gender identity		
Male	0	1 (25)
Female	3 (60)	3 (75)
Non-binary	1 (20)	0
Questioning	1 (20)	0
Autism		
Formal diagnosis	5 (100)	1 (25)
Self-identified	0	1 (25)
Not autistic	0	2 (50)

*Missing data for one participant.

Participants for both groups were recruited using purposive sampling via social media (e.g., X), as well as professionals from a local third-sector organisation with which the researchers already had existing connections. The professional group included early career professionals and those with experience supporting autistic individuals with co-occurring ID, across one or more roles such as team leader ($n = 2$), clinical support worker ($n = 2$) and specialist mentor ($n = 1$). Due to the sensitive research topic, participants were required to be over 18 years old and live in the

United Kingdom for safeguarding purposes. As these findings would directly inform subsequent research stages, participants were compensated following the National Institute for Health and Care Research (NIHR, 2022) guidance, which outlines recommended payment rates for public involvement (<https://www.nihr.ac.uk/payment-guidance-researchers-and-professionals>). To fairly recognise individuals' time, expertise, and contribution, this equated to £90, covering preparation and a half-day activity.

3.2.2. *Materials and Measures*

Participants were provided with the three self-harm assessment tools identified in a COSMIN systematic review (see Chapter 2; Newell et al., 2024): the ISAS (Klonsky & Glenn, 2009), NSSI-AT (Whitlock et al., 2014), and QNSSI (Turner et al., 2012). Descriptions of these measures are presented in Table 8. An agenda was developed for each group (autistic and professional), outlining the focus-group aims, schedule, and questions for discussion (see Appendix B for the interview schedule). Questions were based on the COSMIN methodology for evaluating content validity (Terwee et al., 2018), covering comprehensibility (i.e., are the items understood as intended?), relevance (i.e., are all items relevant for the construct of interest within a specific population and context of use?) and comprehensiveness (i.e., are any key aspects of the construct missing?). Participants were also asked which tool they would be most and least likely to recommend for use with autistic people who self-harm and why.

Table 8.*Description of self-harm assessment tools presented to focus groups.*

Measure	Authors	Items	Description	Response format
ISAS	Klonsky & Glenn (2009)	8	2 subscales ISAS I: lifetime frequency of 12 NSSI behaviours, age of onset, physical pain, whether alone, the time between the urge and act, and desire to stop. ISAS II: 13 potential intra- and interpersonal functions of NSSI across 39 statements (3 per function)	ISAS I: dichotomous (yes no), multiple choice, open-ended ISAS II: 3-point scale (not relevant to very relevant)
NSSI-AT	Whitlock et al., (2014)	39	12 modules (a) NSSI behaviours; (b) functions; (c) recency and frequency (and age of cessation); (d) age of onset; (e) wound locations; (f) initial motivations; (g) severity; (h) practice patterns; (i) habituation and perceived life interference; (j) NSSI disclosure; (k) NSSI treatment experiences; and (l) personal reflections and advice	Dichotomous (yes/no, true/false), multiple choice, open-ended, 4- or 5-point scales (strongly disagree to strongly agree)
QNSSI	Turner et al., (2012)	26	Frequency, NSSI behaviours, time between the urge and act, pain, severity, functions, expectations, emotions before and after, antecedents, and consequences. Functions: 39 statements (17 + 22 SASII) across emotion relief, feeling generation, interpersonal communication, interpersonal influence and self-punishment.	Dichotomous (yes no), multiple choice, open-ended, 4- or 5-point scales (never to always); ranking

ISAS = Inventory of Statements about Self-Injury; NSSI = Non-Suicidal Self-Injury; NSSI-AT = Non-Suicidal Self-Injury - Assessment Tool; QNSSI = Questionnaire for Non-Suicidal Self-Injury; SASII = Suicide Attempt Self-Injury Interview

3.2.3. *Procedure*

Participants expressed their interest by contacting the research team, who then provided further information about the research and responded to any questions. Autistic adults were required to have an online introductory meeting with the lead researcher to fill in a wellbeing plan adapted from previous self-harm and suicide research (Goodwin et al., 2024; Pelton et al., 2025; see Appendix B), which included emergency contact information, accessibility needs, and how best to support the participant should they become distressed. This plan was password-protected, shared with the participant, stored securely, and deleted two weeks after participation. The introductory meeting was optional for professionals who already had access to safeguarding procedures due to their line of work. Participants provided informed consent via an electronic form on Qualtrics, and study materials were shared a week before the focus groups to allow preparation time (see Appendix B for interview schedules).

Two focus groups were conducted in line with guidance on saturation and sample size parameters for qualitative research, suggesting one group per demographic of interest (autistic adults and professionals) to identify key issues in the data, and 2-3 groups in total to achieve approximately 80% thematic saturation. This saturation threshold is considered acceptable for capturing the most prevalent themes, where any additional discoveries are unlikely to add further insights, and complete saturation is rarely possible (Hennink et al., 2019). Owing to the sensitive research topic, group size was also limited to 4-5 participants to encourage in-depth discussions and facilitate easier safeguarding if required (Barbour, 2018). Focus groups were run using a semi-structured format, facilitated by two researchers who followed the agenda. Several measures were implemented to support participant

wellbeing (e.g., mood checks before and after, a virtual breakout room) and improve accessibility (verbal or typed communication, frequent breaks).

All introductory meetings and focus groups were held online via Microsoft Teams to enable greater geographical reach and convenience. Sessions were recorded, transcribed verbatim, and anonymised for analysis.

3.2.4. Data Management and Analysis

Reflexive thematic analysis was conducted using Braun & Clarke's (2006) six-phase framework, which consisted of: 1) familiarising yourself with your data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report. This method was selected to identify patterns of information and perspectives on the underexplored topic of assessments for self-harm in autism. To ensure rigour and transparency, Braun & Clarke's (2021) tool for evaluating thematic analysis quality informed the methodological approach and analytic process.

Data was analysed from an essentialist theoretical standpoint, with participants' experiences understood as direct expressions of their lived reality. A primarily deductive approach was taken, where data was 'open coded' but also guided by the COSMIN methodology for evaluating content validity (Terwee et al., 2018) to ensure themes were meaningful to the research question. Codes were identified at the semantic level, reflecting the data's explicit or surface meanings. The authors brought a range of lived and professional experiences to the study and acknowledged the potential influence of personal biases on knowledge production. Reflexivity was embedded throughout the research process via notetaking and team

discussions, to critically reflect on how our identities, assumptions, and disciplinary backgrounds may have shaped interpretation of the data and theme development.

VN transcribed each focus group verbatim and summarised initial thoughts on the content. Following this, VN familiarised themselves with the data and generated initial codes. These initial codes were then reflected on by revisiting the data to refine or add new ones as needed. Codes were then collated into groups describing similar concepts, forming the basis for potential themes and subthemes, which were reviewed and refined against the codes and original data. Lastly, clear definitions and names for the final themes were generated. VN discussed themes with independent members of the team (SC, CR), who offered feedback and helped ensure an accurate interpretation of the data (Braun & Clarke, 2006, 2021).

Both focus groups were analysed together to triangulate viewpoints due to similarities in participant perspectives. This approach has been taken by previous research that found uniformity in themes across stakeholder groups (French & Cassidy, 2024; Goodwin et al., 2024). Likewise, quotes are presented both verbatim and as excerpts integrated throughout the text (Bradley et al., 2021; Camm-Crosbie et al., 2019), with square brackets used to add context where needed. To maintain anonymity, participants are identified by group (autistic adult [A], professional [P]) and participant number (e.g., A1, P2).

3.3. Results

There was no significant difference in self-reported mood using the visual analogue scale ($t(8) = -.936, p = .377$) before versus after the focus group across

autistic adults and professionals³. The reflexive thematic analysis generated one overarching theme: “picking the best of a bad bunch”. This theme included seven subthemes which explored the perspectives of both autistic adults and professionals on the three self-harm assessment tools. See Figure 4 for a thematic map.

Figure 4.

Thematic map of themes and subthemes.



3.3.1. *Picking the best of a bad bunch*

The overarching theme centred on the consensus that none of the three self-harm assessment tools were considered “fit for purpose” (P4), and as a result, participants felt they had to “pick the best of a bad bunch” (A3). This was reflected in the acknowledgement that the tools had some strengths, but many limitations outweighed these. The nuances of this theme are discussed within the relevant subthemes below.

³ Groups were combined for this analysis due to the small sample size (n = 9).

“At this moment of time, all three [tools] are so off on its own thing, that I don't think there's one that can be really used.” (P3)

3.3.1.1. Strengths

Participants highlighted that within the tools, there were “one or two elements that you think, you know, that's quite well laid out, it could be adapted” (P4) or “something you can take from each [tool]” (P3). For example, the NSSI-AT and QNSSI were described as more comprehensive and relevant. The NSSI-AT included extra “detail and options to select” and “granularity” (A3), along with self-harm behaviours and functions that were “inclusive” (A4) or that “autistic people may not have thought were self-harm” (P4).

“This [NSSI-AT] had things on it that the others didn't, such as a friend suggesting it and seeing it on TV and things like that. I just think it adds more situation.” (A4)

The QNSSI also “recognise[s] there are some benefits to self-harm behaviours” (A5) and included response options relevant to autistic people’s experiences of self-harm, such as “decreasing tension” (A5) or “head-banging and scratching” (P2).

“It [QNSSI] was the only one that looked at kind of head banging and scratching as methods of self-harm, and from just my own client base, those are the methods I've seen the most commonly with autistic people.” (P2)

Several participants reported on what made the tools more user-friendly. The NSSI-AT provided “guidance” (A2) on how to answer questions, and the “strongly agree, somewhat disagree [etc.]” Likert scaling was “easier to fill out” and “less overwhelming” (A2). The ISAS was generally favoured in terms of its “layout” (P3),

“presentation” (A2), and “shortness” (P4). It also provided references, where this “basis in fact” was “reassuring” (P4). Moreover, participants appreciated having lists of response options, which were common across all three tools.

“I think often, I find it difficult to locate the answer, but if I have a menu, I can often see what I agree with or what I don't agree with.” (A1)

3.3.1.2. Cognitive considerations

Conversely, participants found the tools to be “really long” (A3), “overcomplicated” (P2) and “overwhelming” (P3), especially the NSSI-AT and QNSSI. Scale explanations were “wordy and high-minded” (P4), which resulted in participants feeling “agitated” (P1) or “frustrated” (A2) with having to go back and forth to make sense of things. Multiple autistic participants said they would struggle to complete the tools on their own, but “it would be okay” (A3), or they would “stick with it” (A4) and “ask more” (A2) if they were being supported. However, they also acknowledged that if a professional made a mistake when using a complex tool with someone in crisis, it could have harmful consequences – “does that person just go, yeah, this [professional] doesn't know what they're doing. I'm not trusting them or telling them that I'm feeling a certain way” (P4).

“You know, you go through this list that keeps saying this, and how do you feel about this? How do you feel about that? And it is a process where they have to really think about what's going on, where they are.” (P3)

Consequently, participants thought it was important that the tools had “considered and quality formatting that's well spaced and clear” (A1), “a balance between including relevant items, but then not having a list that's longer than it needs

to be” (P1), and that “things go in quite a logical order, and they make sense for someone to follow” (P2).

“Short, simple, you know, layout. Good font, easy to read. You know, those sorts of things are really, really important, aren’t they? And quite often overlooked when we’re looking at clinical tools, you know, that actually, is it just an easy read?” (P4)

Furthermore, problems with Likert scales were flagged by multiple participants. “Each of the measures had loads of different types of scales” (P2), and scale options were considered “really hard to differentiate [often vs seldom]” (A4) or inappropriate where “it doesn’t feel like agreeing or disagreeing really captures what it’s [the question] asking about” (A4). Other participants found “numerical scales really difficult to respond to” (A1), leading to a preoccupation with how to answer the question and wanting to “get it right even though it’s not necessarily a right or wrong thing” (P1).

“I’d be sitting there for ages trying to think what number it [response] would fit in. Like, how I would quantify that in my head is quite confusing.” (A4)

It was suggested that Likert scales could be improved by providing “something that is more illustrative” (A1) or “another kind of scale next to it” (A4). Other participants reported that a neutral option would help them “move on [from the question] in a way that might not have been possible otherwise” (A1) and reducing the number of options to something like “never, sometimes, always... might be a bit more approachable.” (P1).

Participants also described challenges when estimating over a time period or determining how much time has passed. For example, the ISAS item regarding how many times a person engaged in different self-harm behaviours over their lifetime

was highlighted as particularly “difficult” (P1). Autistic participants spoke of being “time blind” (A1) and the impact of one’s emotional state or not being in your “wise mind” (A4) on their ability to remember. These questions also did not give space for variability in self-harm, where an individual may have “periods where it is quite intense and then periods where it’s, kind of, not present at all” (A1).

“I would struggle to remember how many occasions because something blocks it out, and I’m not really, like my awareness and my memory of it is not good, because like you say, the distress and the kind of, not being as aware or as in control at the time. Which then makes it difficult to estimate things like that, doesn’t it?” (A3)

Additionally, the tools had high demands on working memory. For Likert scales, “holding that information [scale options] and processing the question is really challenging” (A1). Multiple participants also noted that the QNSSI items that required ranking statements were “really hard” (A1) and “almost impossible” (A3) as a result of “the cognitive load of trying to deal with that [long list] and make those decisions [ranking]” (P2).

“Working memory is a problem that I think would affect my answering of a lot of these questionnaires, having to remember different responses and manipulate them and work out and compare them in my head.” (A3)

There were shared concerns that the language used across tools was not appropriate or clear. Participants described ambiguous phrasing such as “creating a boundary between yourself and others [ISAS]” (A3), wanting clarity on “occasions” vs “times” (A3), and what type of “therapy” and “medical care” (A3) was relevant. Some questions were confusing (e.g., Who knows/ suspects about it [self-harm] and has not talked with you about it? [NSSI-AT]) – “How would I know that?” (A1). Others

could be answered in multiple different ways (e.g., Do or did you want to stop self-harming? [ISAS]) where “do you, and did you, are two different questions” (A3) and the answer could be “both [yes and no]” (A1). Similarly, participants might interpret things literally, such as “bloodletting” [QNSSI] as “some medieval practice, and not really understand that it meant cutting” (P4), or “as a way to practice suicide” [NSSI-AT] in that “the more I practice self-harm, is that gonna make me more likely to “be successful” dying by suicide?” (P1). The language was also described as “outdated and probably quite complex for people who aren't academic or clinical staff” (P4).

“They [the tools] need definitions or explanations so it’s clear how to answer them. Also, a few questions I can read too literally and answer differently than reading the question again, which suggests they’re actually wanting.” (A5)

Moreover, all three tools require a level of introspection, such as on one’s emotional state or perception of pain. The NSSI-AT module on personal reflections was confusingly “weighted towards the impact of scars.” (A1) and required “an understanding of myself or autism to make this information meaningful” (A2). Participants also described having “a really terrible range of emotions” (A2) or “alexithymia” (A4), which made it challenging to identify the reason for their progression from “reasonably okay, to just can't cope, need to let it out.” (A5). This was complicated further by tools including emotional states that become “more and more nuanced as you go along”, such as “euphoric”, “relieved”, and “positively aroused” (P4). Participants reported similar issues for questions about physical pain, where they “might feel pain (or not) differently” (A3) and that “the idea of pain itself can be relatively abstract” (P4).

"I don't really know how I feel a lot of the time. Especially in heightened distress, like I'll just describe it as URGHH I feel awful, but I can't actually say whether that's sadness, anxiety, disappointment." (A4)

3.3.1.3. Missing elements

Participants discussed a variety of elements they felt were missing from the tools. A broader range of behaviours "not normally considered self-harm" (A3) were highlighted, such as "smoking and drinking" and "using substances" or "medication" (A3), "putting yourself in an unsafe situation" (A4), "self-neglect" (A4), "intentionally ingesting or exposing yourself" to something you are allergic/ have a reaction to (A3), and "looping thoughts and rumination" (A4).

"Self-neglect probably is my biggest form of self-harm. I won't eat or eat the wrong things knowing it's bad for me, and none of these measures really address this." (A5)

Likewise, self-harm was reported as having additional functions to "block other uncomfortable feelings" (A3) and "regulate distress or to address dysregulation" (A3), which could result from "sensory or social overload" (A1). Some participants also described an element of self-harm "management" (A1), where they reported doing "less than [usual]" (A1) or a behaviour they "wouldn't usually engage in" (A4) if they wanted to self-harm but avoid involving or dealing with medical services. Moreover, none of the tools included "sensory seeking" (P2) or being "under-stimulated" (P4) as a reason for self-harm.

Understanding contextual and environmental factors was considered essential to "capturing the real reason why" (A5) someone self-harms, helping to identify "patterns" and "stop it [self-harm] in the future" (A5). Participants described their own

experiences as “extremely situational” (A4), where “things stack on top of each other” (A4), and it depends on “what the trigger was to begin with; was it sensory, was it something someone said, is it you’re just having a bad day, and you don’t feel well cause it’s a time of the month?” (A5). This should also include “outside challenges that people might be experiencing”, such as “sexual abuse, sexual assault” (A1) that are not covered by the tools.

“I think a questionnaire that focuses on the situational motivations would be beneficial for me, because it would allow me to go, oh okay, in this situation, I self-harmed because of this. In future, when I’m in this situation, maybe I could do this instead of self-harming, and I think that’s a good thing to focus on.” (A4)

Additionally, participants suggested a need for items like “Have you put any adjustments in place to support yourself?” (A2) or “What have you tried before or what do you try to stop self-harming” (A5), which could indicate “potentially why doesn’t it [the adjustment] always work” (A2).

“If you’re autistic and you’ve tried to talk to somebody, or you have ADHD and they’ve rejected you or they don’t understand you, because the double empathy problem or whatever. Then that’s another layer of additional challenge and complication to get around.” (A3)

3.3.1.4. Conceptualising self-harm is not straightforward

Participants found it challenging to identify certain behaviours as self-harm. The “issue of intentionality” (A3) was key to this, particularly with stimming behaviours (e.g., skin picking, biting nails, hitting oneself) where an individual is “not doing it intentionally to cause harm” (A3) or “it doesn’t necessarily feel like that [self-

harm]" (A4). Instead, the purpose of the behaviour is to "ground or put something back in" (P4) and "regulate [my] feelings" (A4). This distinction was important to participants who reflected that you do not want to "take something away from somebody that actually is really helpful for them, their wellbeing, and their mental health" (P4).

"Like picking skin or biting nails, you know, for some people that could be self-harm because you're literally destroying the nail, but for others, it could be stimming." (A2)

Additionally, self-harm was discussed in a stratified manner. Participants distinguished acute episodes (e.g., cutting) as "you do something in the moment, it happens at that time" (A3) versus chronic (e.g., neglecting self-care, not eating properly) where "the cumulative effect of all of that is really bad for your health" (A3). This was similarly referred to as "impulsive active self-harm and then more long-term passive self-harm" (A4).

It was also important to acknowledge the complexity of self-harm as having both "positives and negatives" (A1). Participants reported that the tools missed how self-harm "helps you cope, and it helps you survive a rough time" (A3), which may be especially relevant for those hurting themselves if it "is not the place where we're experiencing the most harm" (A1).

"The positives are particularly around like, you know, it supported me to survive, it enabled me to process difficult things, it supported me to stay grounded, it supported me to avoid other things." (A1)

3.3.1.5. *Perpetuating and addressing stigma*

The use of stigmatising language was common across all three tools. In particular, the word “mutilated” [NSSI-AT] was described as “harsh”, “aggressive” (P2), “offensive” and “uncomfortable” (A1). Certain items and response options also “didn’t sit right” (A4) with participants, such as “because my friends hurt themselves” [NSSI-AT], which made them “feel quite infantilised as if, like, oh my pal’s doing it. So, I’m just gonna give it a go” (A4).

Participants reported that some language could also be misinterpreted with potentially harmful implications. For example, the response options [NSSI-AT] “as a way to practice suicide” and “as an attempt to commit suicide” where “we know self-harm isn’t suicidal behaviour, they’re not the same thing, but that implies that they are” (P2). Likewise, self-harm is described in the QNSSI as a “commonly occurring symptom among (female) patients with borderline personality disorder”, which perpetuates “the stigma around personality disorders” (P1) and self-harm “being a symptom and not a coping mechanism” (P1).

Instead, self-harm and the language used should be approached from a position of “kind curiosity rather than feeling that it’s like bad or wrong” (A1). Tools should also provide an explicit and supportive place for specific self-harm (i.e., genital), which may otherwise have “associations of different kinds of shame and unspeakability” (A1).

“I think these [tools] could be much more, gently reframed in a way that feels less judgmental and more, like even neutral would be welcome. I think for me, it would impact how open I felt able to be.” (A1).

3.3.1.6. *The role of co-occurring conditions*

A shared narrative was that using the same tool for everyone does not work. Co-occurring conditions “may be playing a role in the way that you answer questions or your ability to interact with what's going on” (A2). For example, one participant with Attention Deficit Hyperactivity Disorder (ADHD) described “having the attention span of a gnat” and “reading every other word” (A2).

“The majority of autistic people also have additional neurodivergence where they may be dyslexic, there may be kind of visual processing or something, or you know, ADHD, where somebody might just get bored half the way through that and just not really do it.”

(P4)

Moreover, for those with an intellectual disability (ID) or learning difficulty, “completing it [the tool] and understanding what it's asking would be a huge barrier” (A3), which then “changes the tools that we've got to use, the language that we use, the words that we use” (P4) to get the same information. Participants noted other clinical tools which have short versions, such as the “Clinical Outcomes in Routine Evaluation” (P4) and “Autism Quotient” (P2), and the utility of these, even “for somebody without a learning difficulty, who was just maybe in a space of being completely overwhelmed” (P4). Demand avoidance may also complicate things further due to “the amount of demand that questions are placing on people” (P2) or that “the minute you're scoring anything, it starts to feel like it's a performative task” (P4), where “the majority of autistic people probably wouldn't do it [the tool], especially if there's a PDA [Pathological Demand Avoidance] element or profile” (P4).

3.3.1.7. *Duty of care*

Lastly, the content of the tools was described as “so overwhelming to sort of sit with and then have nothing afterwards” (P1) and that there was not “really anything around gentleness or self-care in relation to the questions” (A1). Consequently, participants stressed that researchers in this area have “a degree of responsibility to check that people are safe” (A1).

“It does concern me a little bit if someone’s doing this on their own, dredging through those [questions] and not being supported properly. That’s something I might do with a client over the course of three weeks, exploring those kinds of things, and then it’s boiled down to quite a small questionnaire. I think it could lead to some really interesting answers and knowledge, but I think from my perspective, it concerns me about them being properly cared for within that.” (P2)

It was suggested that the tools also need to be explicit around confidentiality so individuals can “either be honest” or “know that I don’t want to answer” (A1). This should also include an opportunity to check if they need help “to take a different action and to be safe in other ways” (A1), which can be followed up with appropriate support and validation.

“Like, you know, an encouragement to take a break, to look after yourself, to complete it with someone else if you need to, to not complete it if that’s what feels best. Um, I think some like, acknowledgement of how challenging this is, and that it can be like, triggering or distressing for people to think about and talk about, could be really validating and supportive.” (A1)

3.4. Discussion

This study explored the views of autistic individuals with lived experience of self-harm and professionals who support them of three existing self-harm assessment tools (ISAS, NSSI-AT, QNSSI). While some strengths of the tools were acknowledged, these were largely overshadowed by concerns, with participants describing the process as “picking the best of a bad bunch”. Subthemes explored a variety of cognitive considerations (e.g., complexity, length, working memory demands, introspection) and missing elements such as broader self-harm behaviours, additional functions, contextual and environmental factors, and support. Further challenges arose around how self-harm was conceptualised, particularly regarding intentionality and stimming, as well as the need to address stigma. Participants also highlighted the role of co-occurring conditions (e.g., ADHD, ID) and the importance of duty of care. Ultimately, none of the tools were considered appropriate or acceptable for autistic adults who self-harm. This is significant given the high prevalence of self-harm in autism and the current lack of suitable assessment tools (Newell et al., 2024), indicating there is a need for the development of a new tool.

The findings align with previous research highlighting accessibility issues in instruments for autistic individuals (Nicolaidis et al., 2020) and the importance of co-developing measures with the autistic community (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021). Participants reported similar difficulties to those found in earlier studies, including concerns about Likert scales, complex language, vague response options, and identifying and describing emotions (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021; Nicolaidis et al., 2020).

Additional feedback for items reflected known challenges that autistic individuals face regarding time perception (Casassus et al., 2019) and working memory demands (Wang et al., 2017). Moreover, participants highlighted missing elements (e.g., sensory sensitivities) which contribute to NSSI in autism (Marsden et al., 2024; Moseley et al., 2019), as well as broader forms of non-recreational risk-taking (Hawton et al., 2012) or self-damaging behaviours (Nock, 2010), and factors that precede a self-harm episode (Pelton et al., 2025). These findings align with what autistic individuals who self-harm consider essential to understanding and supporting them, such as reasons for self-harm, challenging assumptions and responding appropriately (Moseley et al., 2019). Moving forward, collaboration with autistic people is therefore key to improving the clarity and relevance of measurement tools, a process shown to enhance both accessibility and construct sensitivity (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021). Such efforts must carefully balance the inclusion of diverse self-harm experiences with the potential need for individualisation (e.g., for co-occurring conditions), while ensuring tools remain practical and accessible to users and professionals alike.

Moreover, another key limitation of the tools involved how self-harm was defined and assessed in autistic individuals, particularly concerning stimming and intentionality. Participants raised concerns that although stimming is a helpful self-regulatory mechanism (Kapp et al., 2019), harm is sometimes caused as an indirect consequence (e.g., skin picking, hitting self). Consistent with this, a qualitative study of online forum posts revealed that a significant portion of self-harm among autistic individuals was related to stimming, often performed unconsciously to relieve anxiety or sensory overload (Marsden et al., 2024). However, current assessment tools do

not account for harmful stimming in autistic adults without co-occurring IDs, leading to potential misclassification or under-recognition of this behaviour as self-harm (Goldfarb et al., 2021; Matson & Turygin, 2012). Therefore, self-harm assessment tools for autistic individuals should incorporate harmful stimming behaviours to better identify and understand self-harm in this population.

3.4.1. Strengths and Limitations

This study is the first to examine self-harm assessment tools from the perspectives of both autistic individuals with lived experience of self-harm and the professionals who support them. A key strength lies in the involvement of multiple stakeholders to address a community priority in autism research (Cassidy, Cogger-Ward, Robertson, et al., 2021; Roche et al., 2021). This approach allowed for the triangulation of viewpoints and revealed shared perspectives across groups (French & Cassidy, 2024; Goodwin et al., 2024). However, it is also possible that the professional group was more neuro-affirming than the norm, given that many autistic individuals report a lack of autism-specific knowledge among professionals as a barrier to mental health support (Adams & Young, 2021).

Moreover, the autistic group was limited in generalisability, being predominantly composed of female-identifying, cognitively able individuals. Autism in females, particularly those without co-occurring ID, is often under-recognised or misdiagnosed, resulting in inadequate support (Kirkovski et al., 2013; Loomes et al., 2017; Mandy & Lai, 2017). Likewise, females in the general population are also found to be more likely to engage in NSSI than males (Bresin & Schoenleber, 2015). While it is unclear whether these gender differences extend to autism, autistic females may face unique challenges that contribute to a qualitatively different

experience of self-harm. Nonetheless, the small sample overall and lack of demographic data (e.g., ethnicity, co-occurring conditions) limit the generalisability of the findings, suggesting future research should aim for a more representative sample in the development of new self-harm assessment tools.

3.4.2. Next Steps

Given the lack of consensus on existing self-harm assessment tools, the next step would be to develop a new autism-specific tool that aligns with the needs and experiences of autistic individuals who self-harm, which will be addressed in Chapter 4. First, content validity needs to be established, as it is regarded as the most important measurement property, providing the foundation for all others (Mokkink et al., 2010). COSMIN guidelines highlight cognitive interviews as a method to ensure that items of an outcome measure are interpreted and responded to as intended by the target population (Terwee et al., 2018). Previous research adapting measures of depression and suicidality with autistic adults has incorporated cognitive interviews as part of the process, contributing to increased sensitivity to detect the intended constructs (Cassidy, Bradley, et al., 2021; Cassidy, Cogger-Ward, et al., 2021). Involving autistic individuals in the development of this new self-harm assessment tool should enhance its validity, reliability, and overall suitability for this population (Nicolaidis et al., 2020).

3.5. Conclusion

The findings from this chapter indicate that assessment tools identified in Chapter 2 (ISAS, NSSI-AT, QNSSI) are not appropriate or acceptable for use with autistic adults who self-harm. Participants emphasised the need for tools that address various cognitive considerations, include autism-specific content, and adopt

a broader, more inclusive definition of self-harm. They also highlighted the importance of tackling stigma, recognising the role of co-occurring conditions, and that researchers in this area have a duty of care. While issues of clarity, relevance, and lack of autism-specific items are common in tools not validated for autistic populations, evidence suggests these can be adapted successfully. Consequently, Chapter 4 will address the urgent need for a new self-harm assessment tool specifically developed with and for autistic individuals.

3.6. Reflexive Statement

3.6.1. Adapting vs Developing a New Tool

My initial plan for the thesis was to adapt an existing self-harm assessment tool with and for autistic adults. The approach I took was similar to previous research, beginning with a COSMIN review to identify a candidate measure with the most support for its measurement properties, and then adapting this for the target population. Much like the SBQ-R (Osman et al., 2001) into the SBQ-ASC (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021) and the PHQ-9 (Kroenke et al., 2001) into the ADAT-A (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021). However, the findings of my COSMIN review in Chapter 2 (Newell et al., 2024) revealed mixed evidence regarding the measurement properties of existing self-harm assessment tools in the general population. This made it difficult to justify taking forward a single measure to adapt with and for autistic people, and instead, three tools were selected as potential candidates for adaptation.

Subsequently, in this chapter, I consulted focus groups with autistic individuals and professionals to decide which of the three tools should be adapted in the next stage of the research. However, it became clear from the findings that neither group

approved of any of the tools, and there were many limitations across these.

Ultimately, based on the outcomes from the COSMIN review and focus groups, I decided to develop a new self-harm assessment tool instead of adapting an existing one. The draft of the new tool was directly informed by feedback collected from the focus groups, incorporating the strengths of existing tools and addressing key issues while also being guided by relevant literature and theoretical models of self-harm.

This decision somewhat shifted the research direction for the following chapters but reinforced the value of co-production. As a result, I gained more appreciation for the complexities of measurement development and the importance of involving autistic individuals in this process.

Chapter 4. Using Cognitive Interviews with Autistic Adults to Inform the Development of a New Self-harm Assessment Tool.

iv. Preface

Chapter 3 explored the perspectives of autistic adults with lived experience of self-harm and the professionals who support them regarding the self-harm assessment tools identified from the COSMIN review in Chapter 2 (ISAS, QNSSI, NSSI-AT). The findings revealed that none of these tools were considered appropriate or acceptable for autistic individuals who self-harm. As a result, the decision was made to develop a new autism-specific assessment tool for self-harm informed directly by insights from the focus groups, guided by existing tools, literature and theoretical models. Building on this, Chapter 4 details the iterative development of the new tool through two rounds of cognitive interviews with autistic adults who have lived experience of self-harm.

4.1. Introduction

Autistic individuals and those with high autistic traits experience high prevalence rates of self-harm, as well as being at an increased risk compared to their non-autistic counterparts (Blanchard et al., 2021; Figueiredo et al., 2023; Stark et al., 2022; Steinfeldt-Kristensen et al., 2020). They are also more likely to experience both the contributing factors and adverse consequences associated with self-harm, such as mental health difficulties and suicidality (e.g., Kim et al., 2024; Lai et al., 2019; Moseley et al., 2022; Newell et al., 2023). However, previous chapters established a lack of instruments designed specifically to assess self-harm in this population (see Chapter 2; Newell et al., 2024), and that existing tools are not considered acceptable or appropriate for use with autistic adults (see Chapter 3). To accurately identify, understand and prevent self-harm in autism, a new self-harm assessment tool developed with and for autistic adults is urgently needed.

While the primary focus of the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) is the evaluation of the measurement properties for patient-reported outcome measures and the studies which utilise these (Mokkink et al., 2018; Prinsen et al., 2018), its taxonomy can also serve as a valuable framework for developing new tools. COSMIN outlines a sequential evaluation process, beginning with content validity, which is emphasised as the most important measurement property that provides the foundation for all others (Mokkink et al., 2018). Content validity refers to the extent to which an instrument's items are clear, relevant, and representative of the construct they intend to measure in the target population (Mokkink et al., 2010). Weaknesses in content validity can compromise the overall validity and reliability of a tool (Terwee et al., 2018), making it a crucial step in both the evaluation and development of assessment instruments

(Almanasreh et al., 2019; Prinsen et al., 2018). Despite its significance, content validity is often overlooked in tool development. Previous COSMIN reviews have demonstrated evidence of content validity for one measure of depression (Cassidy et al., 2018a), but not for suicidality or self-harm (Cassidy et al., 2018b; Newell et al., 2023). Consequently, it is necessary to establish content validity as the first step in developing a new self-harm assessment tool for autistic adults.

Cognitive interviewing is a key method recommended by COSMIN for establishing content validity in tool development (Terwee et al., 2018). It ensures that items are understood, both consistently across participants and in the way the researchers intend (Collins, 2015). This method is particularly relevant for autistic individuals, who may experience differences in language processing or introspection (Kinnaird et al., 2019; Vicente & Falkum, 2023), which can lead to difficulties in interpreting and responding to assessment tools designed for the general population (Cassidy et al., 2020). Thus, cognitive interviews provide a valuable tool for refining and validating instruments for autistic individuals.

Moreover, active input from service users in measure development can increase the acceptability, relevance, and overall quality of a tool, as well as strengthen subsequent research (Groene, 2012; Rose et al., 2011; Wiering et al., 2017). Similarly, collaborating with autistic individuals ensures that tools are developed to be valid, reliable, and appropriate for the population they will be used for (Nicolaidis et al., 2020). Consistent with this, previous research using cognitive interviews to adapt measures of depression and suicidality for autistic adults has shown that improving item clarity and relevance enhances a tool's ability to capture the intended construct (Cassidy, Bradley, et al., 2021; Cassidy, Cogger-Ward, et al., 2021). Involving autistic individuals in the development process should not only

ensure that the new tool is meaningful but also lead to improved measurement properties.

Therefore, this study aims to use cognitive interviews to identify potential issues with item clarity, relevance, and representativeness in a new self-harm assessment tool for autistic adults. Findings from two rounds of interviews will inform iterative revisions to the tool to improve content validity and ensure that the final version is appropriate and accessible for autistic individuals.

4.2. Methods

4.2.1. Participants

Purposive sampling was used to recruit participants through various channels, including the Autistica and Cambridge Autism Research Database mailing lists, social media platforms, and the University of Nottingham's Autism Social Network. The sample consisted of 10 participants who self-reported either a formal diagnosis of autism or suspected they were autistic but had not yet been diagnosed (i.e., self-identifying) with lived experience of self-harm and/ or self-injury⁴. Autistic adults with and without mild co-occurring intellectual disability (ID) were eligible to take part (see reflexive statement, Chapter 4). Given the sensitivity of the topic, participants had to be over 18 and reside in the United Kingdom for safeguarding purposes. See Table 9 for participant demographics.

⁴ The sample size is consistent with recommendations that 5 to 15 participants are sufficient to capture problems with instrument design, after which the rate of new problem identification per interview declines (Peterson et al., 2017; Willis, 2005).

Table 9.*Participant demographics for each cognitive interview.*

Demographics	Interview 1 (<i>n</i> = 10) <i>n</i> (%) / <i>M</i> (<i>SD</i>)	Interview 2 (<i>n</i> = 8)
<i>Autism</i>		
Formal diagnosis	7 (70)	5 (62.5)
Self-identified	3 (30)	3 (37.5)
<i>Age</i>	30.00 (9.42)	30.38 (10.56)
<i>Gender identity</i>		
Male	3 (30)	3 (37.5)
Female	5 (50)	3 (37.5)
Non-binary	2 (20)	2 (25)
<i>Mild co-occurring ID</i>	1 (10)	0

4.2.2. *Materials and Measures*

An initial version of the new self-harm assessment tool (see C1 in Appendix C) was created using feedback from focus groups on the tools reviewed in Chapter 3: the Inventory of Statements about Self-Injury (ISAS; Klonsky & Glenn, 2009), Non-suicidal self-injury – Assessment tool (NSSI-AT; Whitlock et al., 2014), and Questionnaire for Non-suicidal Self-Injury (QNSSI; Turner et al., 2012). This version incorporated the strengths of these tools (e.g., layout, guidance, relevant response options) and common items across all three (e.g., behaviours, functions), guided by the literature and theoretical models of self-harm (e.g., Nock, 2009; Nock & Prinstein, 2004). This resulted in 9 items assessing: 1) presence of self-harm; 2) behaviours; 3) frequency; 4) age of first self-harm; 5) severity; 6) body areas; 7) functions; 8) antecedents; and 9) support. Firstly, the presence of self-harm item (yes/no) was adapted from the QNSSI. For self-harm behaviours (20 response options), “past 3 months” was used as the indicator of recent self-harm, consistent with the QNSSI. Response options were collated from the three tools alongside suggestions from the

focus groups. Frequency of self-harm (“Never” to “1 or more times a day”) was adapted from the QNSSI but used the response format of the Suicidal Behaviours Questionnaire – Autism Spectrum Conditions (SBQ-ASC; Cassidy, Bradley, et al., 2021). Age of first self-harm (open response) was adapted from the NSSI-AT and ISAS, while ever self-harming more severely than expected (yes/no) and body areas self-harmed (21 response options) were adapted from the NSSI-AT. For functions of self-harm (36 response options), the actual question was adapted from the QNSSI, then supplemented with items from the three tools, the Card sort Task for Self-harm – Autism (CaTS- A; Pelton et al., 2025) and focus group suggestions. This provided a subscale of functions measured on a four-point Likert scale (0 = “strongly disagree” to 3 = “strongly agree”), mirroring the response format of the Autism Quotient (AQ; Baron-Cohen et al., 2001), which is frequently used with autistic people. Antecedents of self-harm (39 response options) were similarly adapted from the QNSSI and supplemented with items from the Vulnerable Experiences Quotient (Griffiths et al., 2019), CaTS- A (Pelton et al., 2025) and focus group suggestions. Finally, a three-part question on support (yes/no and open response) was developed based on focus group feedback, aligning with a similar item in the ISAS on the desire to stop self-harm.

4.2.3. Procedure

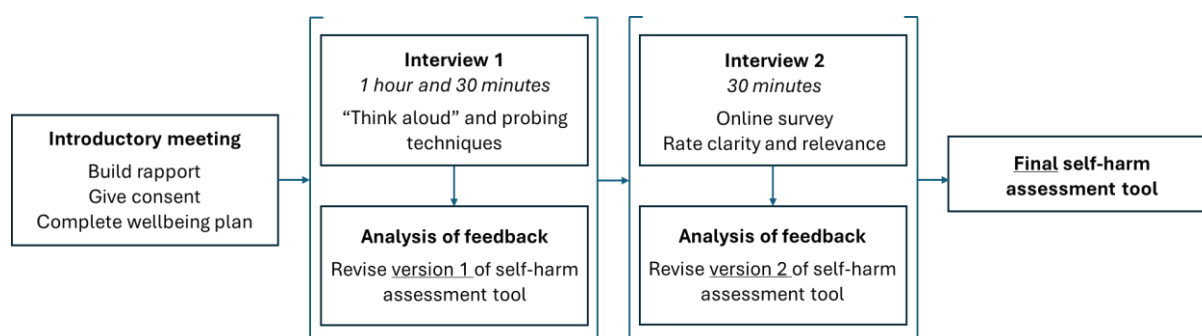
Potential participants either completed a screening questionnaire on Qualtrics to confirm their eligibility or contacted the researchers to express interest. They were provided with information about the study and attended an online introductory meeting with the lead researcher (VN) to build rapport, complete an electronic

consent form, and fill in a wellbeing plan⁵. They received a copy of the new self-harm assessment tool and the interview schedule (for questions and scripted probes, see C2 in Appendix C) immediately following the introductory meeting to allow preparation time.

They then took part in two rounds of cognitive interviews, both of which were online with the researcher, to develop and refine a new self-harm assessment tool. These interviews explored the cognitive processes involved in responding to each item and identified potential issues with validity and measurement (Collins, 2015). The same measures used in the focus groups (Chapter 3) were implemented during the interviews to ensure participant wellbeing (e.g., mood checks before and after, a virtual breakout room available throughout) and improve accessibility (verbal or typed communication, frequent breaks). Figure 4 shows an overview of the cognitive interview procedure.

Figure 5.

Stages of the cognitive interview procedure.



For the first cognitive interview, “think aloud” and probing techniques were used to elicit participants' thoughts and interpretations of the tool (Priede & Farrall,

⁵ The wellbeing plan format and procedure is the same as Chapter 3 (adapted from Goodwin et al., 2024; Pelton et al., 2025). See B2 in Appendix B.

2011). “Think aloud” involved asking participants to verbalise their thought process regarding how they would respond to items on the new self-harm assessment tool and what they are thinking about in order to do this (Collins, 2015; Ericsson & Simon, 1980). First, participants engaged in a practice “windows example” (Willis, 2005), where they were asked to count how many windows they have in their home (e.g., “Think about how many windows there are in your house. As you count up the windows, tell me what you are seeing and thinking about”). The “think aloud” technique was followed by scripted or spontaneous verbal probes to further gauge understanding and interpretation of items. If additional clarification was needed, probes were used either immediately after the “think aloud” for each item (concurrent) or at the end of the interview (retrospective; Collins, 2015). Scripted probes were determined in advance using the theoretical framework for Tourangeau's (1984) four-stage model of survey response. This model proposes that participants engage in four cognitive operations as potential sources of error – comprehension (e.g., what does the term “X” mean to you?), retrieval (e.g., how easy or difficult was it to remember “X”?), judgement (e.g., how did you work out your answer to this question?) and response (e.g., is there anything missing from the options provided?). Spontaneous probes were also used where it was not possible to anticipate sources of confusion. All probes were neutrally phrased (e.g., how did you find that?) and balanced (e.g., did you find it easy or difficult?) to ensure unbiased responses. Each interview was recorded, transcribed verbatim and anonymised for analysis.

Following analysis and revisions from the first interview, participants were invited back to review the updated self-harm assessment tool in a second interview. They tested an online version of the tool in Qualtrics, reflecting the intended format

for the following research stage. During the meeting, participants accessed the survey via a link shared by the researcher and rated each item for clarity (yes/no) and relevance (on a scale of 0–10). They could also provide optional comments through open-text boxes or offer feedback verbally, which the researcher documented and collated with the former for analysis. This interview was not recorded, as responses were mainly collected directly through Qualtrics.

Participants were not required to complete the self-harm assessment tool, only to provide feedback on the items. As in the focus groups (Chapter 3), all introductory meetings and both interviews were held via Microsoft Teams to enable greater geographical reach and convenience. All participants were compensated for their time in line with the University of Nottingham's guidance of £10 per hour. Ethical approval was received for this study from the University of Nottingham's School of Psychology (ref: S1508).

4.2.4. Data Management and Analysis

There is no agreed-upon method in the literature for analysing data from cognitive interviews for scale development (Peterson et al., 2017). Therefore, Collins's (2015) comprehensive guidance was followed for analysis, interpretation and application of findings, incorporating best practice and theoretical frameworks. Data analysis was completed iteratively after both interviews, providing an updated version of the self-harm assessment tool. Each version was shared with participants, highlighting any changes made due to the analysis and why (see C1, C3 and C4 in Appendix C for the different iterations of the self-harm assessment tool).

For the first interviews, VN reviewed all recordings and transcriptions before using a standardised template to summarise key findings per participant for each

item tested (Collins, 2015)⁶. For both interviews, findings from all participants were combined into a summary matrix using the Framework Approach (Miles & Huberman, 1994; Spencer et al., 2003). A matrix was created for each item of the self-harm assessment tool, with participants listed in rows and findings organised in columns. For the first interviews, columns were separated into “think-aloud” and probe responses (comprehension, retrieval, judgment, response), then clarity, relevance, and additional comments for the second. This process is also known as “charting”, where the goal is to collate and reduce findings across interviews into a coherent structure for formal analysis (Collins, 2015).

Data were then analysed using descriptive and explanatory methods (Collins, 2015). Descriptive analysis categorised differences in item interpretation and response behaviours (e.g., answering strategies), highlighting potential issues with the original measurement aims. Explanatory analysis built on this by identifying patterns across these categories, exploring underlying explanations, and evaluating the implications for data quality. Lastly, overall findings were reviewed in relation to the original measurement aims, evidence of item performance, and possible constraints (e.g., mode of administration, interview length). Based on this, recommendations were made for item revision (e.g., wording, answer options or layout changes), deletion (e.g., dropping items altogether), further testing, or no change (Willis, 2005). Consistent with Chapter 3, quotes are presented both verbatim and excerpts integrated within the text, and participants were assigned an anonymous identifier (e.g., P1).

⁶ This step was not necessary for the second interview due to the different method of data collection.

4.3. Results: Interview 1

All 10 participants took part in the first interviews. There was no significant difference in self-reported mood using the visual analogue scale before versus after the first interviews ($t(9) = -1.305$, $p = .112$). Table 10 summarises key issues and revisions for version 1 of the self-harm assessment tool. See C3 in Appendix C for version 2 with annotated revisions.

Table 10.

Key issues and revisions for the self-harm assessment tool version 1.

	Key issues	Revisions
General		
<i>Layout</i>	Guidance	Add in “this is a continuation of Q...” for any question that continues onto the next page. Space out or break up sections in italics.
<i>Relevance</i>	Q6	Add that Q6 is optional depending on what the tool is being used for and whether the information is relevant.
<i>Language</i>	Comprehension	Replace “deliberately hurt yourself” in all questions with “self-harmed”.
Item		
Q1	Comprehension	Add to the instructions that the NICE (2022) definition of self-harm is only a guide and extend this definition to include and validate diverse experiences of self-harm.
Q2	Guidance	Remove “If you have ever deliberately hurt yourself in this way AND in the past 3 months, please select both” from the instructions.
	Sensitive content	Provide a content warning before the question, asking participants if they are able to continue or want to skip.
	Response (comprehension, consistency, missing options)	Improve response options: <ul style="list-style-type: none"> - Change “abused any kind of medication or drug” to include alcohol and add a separate option for overdose (i.e., above recommended or prescribed dose). - Remove “self-defeating thoughts” as this is a cognition, not a behaviour. - Make it known that response options are not an exhaustive list and provide hyperlinks for definitions of terms in the online version.

		<ul style="list-style-type: none"> - Remove thresholds and “intentionally” from response options to maintain consistency. - Make the person as the object of the clause consistent (e.g., tried to break your own bone(s) vs carved words or symbols into the skin). - Include missing options suggested by participants: engaging in risky behaviour, getting a body piercing or tattoo, hair-pulling.
<i>i.</i>	Layout	Place this at the top of the page and make it more obvious to capture attention.
	Guidance	Include self-harmed “in ANY way” but acknowledge that not all behaviours relate to the following questions.
Q3	Judgement	<p>Include frequency-related words with numbers to aid estimations.</p> <p>Make the numbering consistent across response options.</p>
Q4	Retrieval	<p>Rephrase the question to indicate that it is okay to provide an estimate.</p> <p>Change the answer format to also include age brackets.</p>
Q5	Comprehension	<p>Provide examples for “more severely than expected”.</p> <p>Replacing “deliberately hurt yourself” with “self-harmed” in all questions will resolve the contradictory wording.</p>
Q6	Guidance	Specify that Q6 is optional based on the tool’s purpose and the relevance of the information.
	Judgement	<p>Add guidance to leave options blank if they do not remember.</p> <p>Order body areas logically (head to toes) and remove the no column.</p>
Q7	Guidance	Clarify whether the question asks how much vs how often of a reason.
	Visual aid	Use a different visual aid for the scale, such as faces.
	Response (comprehension, missing options)	<p>Improve response options:</p> <ul style="list-style-type: none"> - Simplify or add definitions for jargonistic terms. - Include missing options suggested by participants: sensory overwhelm, voices and hallucinations, feeling like you are OR you are trapped (physically or mentally), because you had the opportunity to, something to focus on so everything else slows down, feeling helpless, not being bothered if you live or die, a general sense of frustration.
<i>ii.</i>	Guidance	Underline important information.

		Place this at the top of the page and make it more obvious to capture attention.
Q8	Judgement	Differentiate between specific incidents and underlying causes by changing response options to include “24 hours before” and “more than 24 hours before”.
	Response (comprehension, missing options)	Improve response options: <ul style="list-style-type: none"> - Change relevant options to include both factual and perceived experiences. - Include missing options suggested by participants: flashbacks or nightmares, dissociation, routine was disrupted, experiences of discrimination, not having support needs met.
Q9	Guidance	Move guidance on strategies from 9b to 9a. Also, additional clarification and more concrete examples are needed.
	Sensitive content	Clearly outline the potential consequences of answering Q9c and any follow-up within a research setting.
	Response (missing options)	Reword questions to remove the burden of support from the individual. Improve response options: <ul style="list-style-type: none"> - Include missing options suggested by participants: Yes, but I am not ready/ comfortable to do that right now, I don't know.

4.3.1. General Feedback

Most participants thought the layout of the assessment tool was clear, logical and easy to follow. Initially, some found the tool too long but revised this view after going through it. They found the item formatting (e.g., questions in bold, guidance in italics) “really helpful in that, like, it's a mix of like normal, sideways [italics], bold” (P4). One participant suggested breaking up the guidance, where it would “make sense to have short lines as opposed to one paragraph” (P7). A few participants with dyslexia highlighted that making the assessment tool easy to read was important. Several found it clear when the question continued on the next page, whereas others wanted an acknowledgement when there was a continuation, as they were “trying to

work out what was the difference between [question] two and two, when actually they were the same thing” (P3).

“All the questions are in bold, which helps as well because your eyes are automatically drawn there, but it's clear where the questions are, where to answer, and then when the next question begins as well. So, it flows really well and the formatting's easy to follow.”

(P9)

Likewise, most participants indicated that all items were relevant to assessing self-harm in autistic people. Although a few felt that Q6 (Have you ever deliberately hurt yourself on the following areas of your body?) “doesn't seem like a relevant question” (P8), they also acknowledged that for some individuals, “specific parts of their body have particular importance” (P2), and relevance probes revealed several valid reasons for inclusion (see corresponding section for Q6 below). Others advised that Q4 (How old were you the first time you deliberately hurt yourself?) would only be meaningful to establish self-harm history if additional indicators were collected. Moreover, two suggestions were given for additional items, such as “something in there about like have things changed [self-harm over time]?” (P4) and “if you've engaged in self-harm activities recently, how in control did you feel while engaging in them?” (P9), but these were from separate participants and not reflected by others.

“It feels like there were some autistic people somewhere involved in the genesis of the thing [self-harm tool]. You get that impression without having to be told it, if that makes sense?” (P7)

Nearly all participants were satisfied with the tone and language used around self-harm. It was described as having “no value attached” (P2), that it did not “beat around the bush” (P1) or “dance around the issues and avoid saying the words” (5P),

while also avoiding being “condescending” or “too clinical” (P9). Nonetheless, it was emphasised that variations in language preferences and definitions should be acknowledged from the outset because “finding a label that fits everyone is gonna be really difficult” (P3).

“That validation and explanation of actually, deliberately hurt yourself means self-harm, or might mean self-injury, or might mean this or that to different people. Maybe that would be a way for people to connect it more.” (P3).

4.3.2. Item Feedback

1. Have you ever deliberately hurt yourself?

This question aimed to determine whether the participant has ever self-harmed (i.e., deliberately hurt themselves), as defined in the introduction of the tool according to current guidelines (NICE, 2022)⁷. The definition of “deliberately” (i.e., on purpose, planned) received mixed reactions, where “deliberately and on purpose kind of makes sense, meaning the same thing, but then planned means something different.” (P4). Likewise, many participants did not like the use of “deliberately hurt yourself” to refer to self-harm, particularly in terms of behaviour that is involuntary. Self-harm was described as a loss of control where “any small change can cause someone's reaction, and they weren't expecting themselves to be overwhelmed in that way” (P10); as harmful but “not conscious” (P5); and difficult to define “in terms of dissociative experiences” (P3). It was suggested to replace this with “self-harm” as “you've defined it... it's easier if you then use the words.” (P4).

⁷ “This assessment tool will ask about your experiences of self-harm. Self-harm is defined as deliberately poisoning or hurting yourself regardless of the purpose of the behaviour.”

"I think in a lot of cases, there's behaviours you do just out of stress or whatnot that you wouldn't exactly pick up on as deliberately hurting yourself, and so you wouldn't classify that as self-harm, so that question would go unanswered." (P9)

2. Have you ever deliberately hurt yourself in any of the following ways?

This question sought to identify which of 20 self-harm behaviours (including "other" options) participants had engaged in during their lifetime (ever), recently (past 3 months), or never. Participants understood the timeframes as intended, whereas some felt they had to determine whether they were engaging in a behaviour "deliberately or not" (P6) before responding. Others found it confusing to select both "ever" and "past 3 months", questioning "how can you have done it [behaviour] in the past three months and not ever?" (P2). The content of this question was also highlighted as particularly challenging, where "there was nothing on the cover sheet or anything that warned me it [self-harm behaviours] was gonna be there and I wasn't prepared" (P3). This was reflected in concerns that behaviours could be seen as "a list of goals of things to try" (P3) or "squirrelling away" (P7) information. Overall, the list of response options was perceived as lengthy and intimidating, but necessary for capturing diverse experiences.

"I did find having a big list of different things, some of which may have been features for me and some of which may not have, and some of which I hadn't thought of, might be a bit counterproductive" (P7)

Several issues also arose regarding the interpretation of response options. Participants requested additional clarification and clearer definitions, such as "give overdose as an example somewhere" (P4) for abusing any kind of medication or drug, and where engaging in self-defeating thoughts could be "something like

negative talking to yourself rather than positive, or thoughts that are not going anywhere?" (P6). Moreover, one participant expressed confusion over the inconsistent use of the object within the clause, where "in some of them [behaviours], the person feels quite like it's been purposefully removed, and in other things, it seemed like there's a deliberate reference to like grounding it in things you've done to yourself" (P4). Participants also highlighted certain response options had a threshold (e.g., bitten yourself to the point that bleeding occurs, or marks remain on the skin) which implies self-harm is "not bad enough to count unless it left a mark" (P2), or included the word "intentionally" when others do not (e.g., intentionally prevented wounds from healing). Other response options were considered insensitive (e.g., engaged in abusive relationships), where "we have to be careful that it can't be interpreted as blaming the victim" (P3), or ambiguous (e.g., neglecting basic needs) as "like most autistic people, I don't know that I'm hungry until I have a tummy ache or feel really weird physically" (P6). Several missing response options were suggested, with the most common being engaging in risky behaviours, such as "not looking both ways from walking into a road (P9), followed by getting a piercing or tattoo "because they like it being painful" (P7), and "hair pulling" (P6).

i. We understand there are many forms of self-harm. The next set of questions refers to ANY way that you have deliberately hurt yourself.

Participants generally interpreted this guidance as intended. While a few noted it was easy to miss, they did not feel this impacted their ability to continue with the tool, as one participant explained "by virtue of Q2 being quite broad, I'm already thinking wide" (P7). It was also highlighted that some behaviours did not fit with the guidance for all the following questions, such as neglecting basic needs where "you couldn't say what area of your body that was" (P4).

3. How often on average have you deliberately hurt yourself during the past 3 months?

This question aimed to assess the average number of occasions a respondent has self-harmed during the past 3 months, measured on a 7-item scale of “never” to “1 or more times a day”. Most participants highlighted concerns about the accuracy of estimating self-harm frequency, noting fluctuations over time, such as having “a month where I was self-harming every day, and a month where I wasn't self-harming at all” (P2), or uncertainty about what to count - “is that once because it was like one episode, or is that five because I've got 5 wounds?” (P4). A common answer strategy involved recalling self-harm frequency over a shorter period (e.g., a week) and then averaging this across the 3 months.

“Try and think of a typical week, but that's a bit hard because it varies, right? Try and do some sort of, adding it all up and dividing by three business” (P2)

Participants also expressed uncertainty about interpreting the time points, noting that “the same number [3 months] could mean so many different patterns” (P4) or that they might select “the middle because that seems like a safe place to be” (P3). Others struggled with the inconsistent use of numbers in the scale labels, stating “one minute it's one, one minute it's two” (P10), and suggested adding frequency-related terms to the scale (e.g., very often = 2 to 6 times a week).

4. How old were you the first time you deliberately hurt yourself?

This question aimed to identify the age at which participants first self-harmed, using an open-ended response. The majority indicated this question was straightforward and would use recall strategies “based on what year I was in school,

and kind of work out my age from that” (P5). Participants also suggested that factors such as “age and awareness of the person” (P6) could influence whether they recognised a behaviour as self-harm. Additionally, some highlighted memory difficulties, which could impact their ability to accurately remember their age (e.g., “sometimes I forget my own age. I forget the age of people I meet” P8), which also extended to the intentionality of behaviours.

"I could probably tell you roughly the age that I engaged in purposeful, like objective, like conscious self-harm. But I was probably engaging in behaviours, you know, in childhood that would be classed as self-harm, but they weren't me objectively thinking that I'm going to harm myself" (P5).

Several participants suggested that including age brackets would be helpful, such as “young years, an example in the middle, and then your older years” (12P). While the question was generally viewed as a relevant indicator of self-harm history, participants highlighted the importance of distinguishing whether “this is the first episode [of self-harm], because that is very different to a long pattern” (P3).

5. Have you ever deliberately hurt yourself more severely than you expected?

This question aimed to determine whether a participant has ever self-harmed and it has ended up being more severe (e.g., going beyond their usual threshold, needing medical attention), using a yes or no response. Participants generally indicated it would be “quite easy to think of, because times where that has happened, it sort of sticks in your mind” (P1). “More severely than expected” was mainly interpreted as intended, such as “you went beyond your own boundary” (P6), “causing more damage than what I had intended” (P5), or “ended up more medically

severe than you thought” (P4). On the other hand, some participants needed “more guidance about what was more severe” (P7).

“So, like, I have been in A&E, but I also know friends that have self-harmed and needed plastic surgery. I get that that's what the question is getting at, but there's no example of what that actually means in real life, whereas in the other questions, you do have examples.” (P3)

Others highlighted that “deliberately” and “more severely than expected” contradict each other, where “it kind of sounds like you intended to hurt yourself more severely” (P5). Overall, participants considered this question relevant and important for understanding intention and potential risks. However, one participant suggested that allowing them to “write a mini paragraph in there, rather than just circle a yes” (P2) would provide more valuable insights.

6. Have you ever deliberately hurt yourself on the following areas of your body?

The goal of this question was to identify where a participant has self-harmed from 20 locations on the body. Participants generally found this an easy question to answer via a “mental scan” (P9) or to systematically “go through them all [body areas] and try and treat it quite straightforwardly” (P6). Despite participants suggesting that this was the least relevant question to include in the self-harm assessment tool, they also highlighted why it could be important.

“I suppose it would be helpful, because like, if they did it across a number of different areas, I think it might be helpful in capturing how often or like, how severe it would be in a kind of like, how widespread the issue was” (P5)

Likewise, certain self-harm behaviours might carry additional connotations (e.g., genital vs arm), with one participant expressing that “some areas of the body I wouldn't necessarily want to admit to having self-harmed, because I feel like there is stigma and confusion” (P3). A few participants found the question about body areas to be uncomfortable, noting it “feels pretty weird and unpleasant” (P2) or “makes you imagine self-harm, like going through all the different body parts” (P7). Participants also suggested that recalling relevant body areas could be challenging for older individuals who might “be guessing some of them” (P6), or for those who have “self-harmed for so long in different areas” (P3). Others found it confusing that the body parts were not listed “systematically from toes up or head down” (P2), and that “some like [self-harm] methods don't really apply at all” (P8) to body parts (e.g., engaging in risk-taking behaviour). Additionally, it was suggested that the question be simplified “by taking out the no column” (P8), as this was redundant given the “select all that apply” format.

7. When I deliberately hurt myself, it is/was...

This question sought to measure the extent to which respondents agreed with 36 different functions (including “other” options) of self-harm at any point in their lifetime. A four-point Likert scale of definitely disagree to definitely agree was utilised, similar to that of the AQ (Baron-Cohen et al., 2001). Most participants confirmed that the scale for this question made sense and that they could use it as intended to “try and look back on my reasons for why I would do anything [self-harm]” (P9). However, a few stated they would have more difficulty interpreting the scale in terms of “how much of a reason or how often a reason” (P2), remembering “what the feelings were” (P6), or knowing how to answer because the function of their self-

harm has “varied so much” (P3). Feedback on the measuring jugs as a visual aid was mixed. While several participants found them helpful, others overinterpreted their meaning, as “cups full or empty already have other connotations” (P4).

"If you maybe have self-harmed for this reason before, like once, does that mean you put definitely agree because it was a reason at some point, or should you put slightly agree because it's not usually a reason?" (P5)

Participants highlighted that the language in certain response options needed to be simplified or defined (e.g., intrusive thoughts or rumination, dysregulation). Concerns were also raised about the stigma associated with interpersonal functions (e.g., to get back at, hurt, or shock someone), with participants expressing fear they might be perceived as “manipulative” or “doing it for attention” (P3), indicating they would select “strongly disagree, because otherwise you'd be judged on it” (P7). In addition, various missing response options were suggested, though these were specific to participants rather than reflecting a pattern across the group. This included creating “a physical pain that I can control” (P2), to “slow everything down again” (P5), because they “have access to something” to hurt themselves with (P4) or “couldn't care less one way or another” if they live or die (P7), as well as to deal with feeling “trapped” (P4) or “helpless” (P6), “sensory overwhelm” (P2), “voices and hallucinations” (P2), and “general frustration” (P8).

ii. Please only answer question 8 if you have deliberately hurt yourself during the past 3 months. If you have not, move on to question 9.

Similarly to the previous guidance, this was either understood as intended or overlooked. One participant suggested reiterating that the instructions apply to any

self-harm behaviour (P7), while another recommended specifically including this with Q8 (P9).

8. Did any of the following events or experiences happen to you in the 24 hours before the most recent occasion when you deliberately hurt yourself?

This question sought to identify which of 39 events or experiences (including “other” options) had occurred in the 24 hours leading up to the participant's most recent episode of self-harm, using a yes or no response. Participants indicated that this question required “a bit more thinking” (P1). For example, if they engaged in self-harm less frequently, it might be “difficult to pinpoint exactly which one [antecedent] was the most recent” (P5), or if they have self-harmed more than once in 24 hours as “a lot can change in a day” (P4). The 24-hour time period was also considered “quite restrictive” (P3) in that it could “hinder pinpointing exactly what's contributing” (P9). In line with this, participants said they would choose response options “even if it was a bit more than 24 hours” (P8), as they would not want to “leave out a major thing” (P2). A clear distinction was also made between specific incidents versus underlying causes, where the former was described as “the tip of the iceberg” (P10) or the “straw that broke the camel's back” (P6).

“So, there is, I think, perhaps a risk that twenty-four hours gives you an answer that isn't representative of what the actual problem is, as opposed to what the trigger is, and the trigger and the cause aren't necessarily the same thing” (P7)

Several concerns were highlighted with the response options. Participants described a “scale issue” (P2), where “minor things” (e.g., you had physical health problems or discomfort) might not seem “bad enough” to select when grouped with

“enormous” ones (e.g., you lost custody of your children). Additionally, options that were “more long term” (P3) or ongoing (e.g., you were signed off from work for at least 2 months due to physical or mental health reasons) did not align with the 24-hour timeframe. It was suggested that perceived experiences should also be included alongside objective ones (e.g., someone was OR you felt like someone was disappointed with you) because “you might logically know that they're not angry with you, but you feel like they are” (P5). One participant further recommended that this question be phrased in the first person to encourage “taking ownership and seeing it from your perspective” (P3). Several missing response options were also proposed. This included having “nightmares and flashbacks” for when “a trauma has been triggered, rather than just the trigger” (A4), “some sort of disruption of routine” (A7), and systemic barriers such as “having to go through some horrendous battle, just to try and engage in the same way as anyone else” (P7) or “fighting for what you are entitled to is exhausting because you're often turned down” (P3).

- 9. a. Do you have any strategies to support yourself when you feel like you want to deliberately hurt yourself?**
- b. Please use the space below to provide further information on these strategies if you want to.**
- c. Do you want to find a way to support yourself that does not involve deliberately hurting yourself?**

This question aimed to establish whether participants have strategies to manage self-harm (e.g., prevention, safe engagement), to explore what these are, and to identify those who currently lack but desire such strategies. Using a mixture of yes/no and open-ended responses, it concluded the tool by encouraging participants

to consider support options or initiate conversations about safety planning where appropriate.

"It's a nice open question to end on, and it's quite an easy one to answer, to be honest. I think in terms of sort of mental taxation like it's nowhere near as difficult to answer as the other ones, and to finish on that one, I think is definitely a more positive way of ending the questionnaire as well." (P9)

Participants mostly interpreted "strategies to support yourself" as intended, describing things they would do "before or after [self-harm] to try and support myself, make myself feel better about it, or maybe even try and stop myself" (P1), as well as using techniques from dialectical behaviour therapy (P3) or positive behaviour support (P10). However, some sought additional clarification on whether strategies were "explicitly to prevent self-harm, or could broader harm reduction stuff be included?" (P2). Several participants wanted the example strategies to be presented in Q9a to guide their thinking immediately, and that these should be "quite different from each other" (P4) to ensure that if "their specific experience isn't on that list, they will know roughly what you're getting at" (P10). Participants also acknowledged the benefits of writing out strategies in that "it might help you think about them" (P8), particularly for those who "want to find more" (P2) or already have some "they're just unaware of" (P3). However, it was preferred to keep 9b open-ended rather than providing a list of response options "because strategies can be different for every single person" (P9).

On the other hand, several participants raised concerns about the purpose of 9c and the consequences of answering truthfully. For instance, some noted their "first inclination would be to say no"(P8) but feared "someone might want to section

me or take my choice away from me” (P3), or that they would “be taken to some other [web] page that maybe I’m not ready to see” (P5). Additionally, the question was perceived as “asking for help, and asking for help is never easy” (P9), where it could be considered “a cliff edge in a research setting” if no follow-up is offered. It was also recommended to include response options for individuals who may wish to stop self-harming but do not feel ready or comfortable to do so at the moment.

"I ought to say yes because obviously, that would be a sensible thing to want, but maybe I just don't want to go down there, so I'll just say no to shut off the conversation" (P2)

Overall, most participants viewed this question as relevant and important, providing valuable insight into the strategies and support that are helpful for autistic individuals. For example, one participant noted that if “society doesn’t label them as coping strategies, others might not necessarily recognise them as such” (P3). Despite this, another participant expressed concerns that the question “feels less supportive”, “leans more toward being “self-helpy” and “could do with quite a bit of expanding” (P7).

4.4. Results: Interview 2

Attrition for interview 2 was 20% ($n = 2$), with one participant not responding to emails and the other choosing to withdraw (see Table 9 for demographics). There was no significant difference in self-reported mood using the visual analogue scale before versus after the second interview ($t(7) = -1.239, p = .128$). Key issues and revisions for version 2 of the self-harm assessment tool are summarised in Table 11. See C4 in Appendix C for version 3 with annotated revisions.

Table 11.

Key issues and revisions for the self-harm assessment tool version 2.

	Key issues	Revisions
General		
<i>Layout</i>	Layout	In the online survey, split response options over multiple pages so the list is less daunting (similar to the paper version).
Items		
Q1	Comprehension	Repeat self-harm definition.
	Sensitive content	Include signposting information in the footer/ banner and add a reminder that this information will also be in the debrief.
Q2	Comprehension	Repeat self-harm definition.
	Sensitivity of content	Change the wording of the content warning.
	Response (comprehension)	Improve response options: <ul style="list-style-type: none"> - Add a description for trichotillomania rather than a hyperlink. - Remove 'dangerous' from description of the item 'took an overdose of any kind of medication, drug or alcohol'
Q3	Guidance	Add a reminder in the guidance that questions can be skipped.
Q4	Response (missing item)	Include a question about recent self-harm to provide additional indicators of self-harm history.
Q5	Response	Include an open-text option so participants can expand on what happened. This will also provide an opportunity to check for interpretation issues.
Q6	Guidance	Shorten the optional statement and instead expand on this in the tool's instructions.
	Response (interpretation)	Clarify body areas (e.g., lips, face, head).
Q7	Visual aid	Provide the option to complete with or without a visual aid and a selection to choose from (e.g., measuring jugs, faces, colour grading).
	Layout	In the online survey, split response options over multiple pages so the list is less daunting (similar to the paper version).
Q8	Guidance	Make guidance text more clear/ obvious.

	Layout	In the online survey, split response options over multiple pages so the list is less daunting (similar to the paper version)
Q9	Guidance	Add further clarification on why Q9 is helpful within a research context.

4.4.1. General Feedback

Overall, participants found the second version of the tool to be clear, relevant (see Table 12 for ratings of each item), and easy to follow, with helpful additional clarifications. The online version was highlighted as less overwhelming, simpler to navigate, and mobile-friendly. However, some participants still found the lengthy response option lists intimidating and suggested breaking these down or allowing the tool to be revisited in stages. Participants also appreciated the acknowledgement in the introduction that definitions and language for self-harm are not universally agreed upon, as well as the option to skip questions.

Table 12.

Participant ratings of relevance and clarity.

Item	Relevance (0-10) <i>M (SD)</i>	Clear (Yes) <i>n (%)</i>
<i>Introduction</i>	8.75 (0.89)	8 (100)
Q1	9.63 (0.74)	8 (100)
Q2	9.00 (0.93)	8 (100)
Q3	8.88 (0.99)	8 (100)
Q4	7.00 (1.31)	8 (100)
Q5	8.25 (1.58)	7 (87.5)
Q6	5.63 (2.67)	8 (100)
Q7	9.0 (0.93)	7 (87.5)
Q8	8.88 (1.64)	8 (100)
Q9	8.13 (1.13)	8 (100)

4.4.2. *Item Feedback*

Regarding specific items, Q1 was considered clear and relevant. The only suggestions involved improving signposting (e.g., providing information in the banner/ footer) and re-including the self-harm definition. One participant found the visual presentation of Q2 easier to follow in the online survey, while another requested further clarification on the timeframes (ever, past 3 months, never). The reference to trichotillomania in Q2 was welcomed (distinguished from hair pulling as a self-harm behaviour), though a definition on the page was preferred to a hyperlink. Moreover, there were concerns about the interpretation of 'dangerous' in the description for one of the response options (e.g., overdose vs stated dose of medication), with suggestions to remove the word. Participants also proposed improving the wording of the content warning. For Q3, the frequency-related words were found to be helpful, though one participant worried about being judged if they self-harmed frequently versus not being deserving of help if it was rarely. Another requested a repeat of the self-harm definition and more information in the guidance about what to expect regarding the upcoming questions. Moreover, Q4 was generally well-received, where participants found the age brackets alongside the open text option helpful. However, others questioned whether it was still okay to give an estimate of their age if they did not remember exactly, suggested smaller age brackets, or raised concerns about the question's relevance as the sole indicator of self-harm history. The additional clarification for Q5 was viewed as helpful, though one participant still struggled with what "severely" meant to them. Feedback on Q6 indicated that participants appreciated the logical ordering of body areas (head to toe) and the "select all that apply" format. Suggestions included simplifying the

guidance about the question being optional, making the "not applicable" option more obvious, and further clarifying body areas (e.g., head vs face). This question was also rated as the least relevant in the tool (see Table 12). One participant found Q7 unclear and questioned whether an agreement scale could truly capture the complex nature of self-harm. The use of faces as a visual aid received mixed opinions, with some participants finding them helpful, while others deemed them inappropriate for the topic or distracting. While the range of response options was generally appreciated, concerns about the length of the list remained. Participants typically found Q8 important and easy to understand, with a good range of response options. However, similar to Q2 and Q7, some found the list length daunting. Lastly, feedback on Q9 was positive, where changes to the phrasing and the addition of further examples were well-received. The only suggestion for improvement was to clarify the purpose of the question further. Suggested revisions were made to the self-harm assessment tool in line with this feedback (see C4 in Appendix C for the final version of the tool).

4.5. Discussion

No self-harm assessment tools have been previously developed or validated for use with autistic adults despite the high rates and increased risk of self-harm in this group (Blanchard et al., 2021; Stark et al., 2022; Steinfeldt-Kristensen et al., 2020). To address this gap, the current study employed two rounds of cognitive interviews to develop a new self-harm assessment tool with and for autistic adults with lived experience of self-harm. This process identified and addressed issues of content validity across clarity, relevance, and representativeness of items, particularly during the first round of interviews, with fewer, more minor revisions

suggested in the second. Sources of error consistent with Tourangeau's (1984) four-stage model of survey response included comprehension (e.g., “deliberately hurt yourself” or “more severely than expected”), retrieval (e.g., depending on age and awareness), judgements (e.g., interpreting time points on Likert scales), and response (e.g., missing options). These findings underscore the need to refine wording, formatting, and response options to ensure new tools are accessible and appropriate for autistic individuals. Therefore, this study highlights cognitive interviewing as a valuable and effective method for enhancing content validity and ensuring the meaningful inclusion of the target population in measure development.

Similarly to Chapter 3, the current findings align with previous research highlighting common challenges with assessment tools for autistic individuals, including difficulties with Likert scales, complex language, and vague response options (Cassidy et al., 2020; Nicolaidis et al., 2020). Specifically, a key comprehension issue across items involved the phrase “deliberately hurt yourself,” reflecting findings from Chapter 3 and the broader literature. While this phrase is consistent with the conceptualisation of self-harm as “deliberate” (Nock, 2010), participants struggled to reconcile this with their interpretations of intentionality, particularly given the overlap with harmful stimming behaviours (Marsden et al., 2024). Moreover, participants felt that “deliberately” also conflicted with the wording in other items, such as “planned” (Q1) and “more severely than expected” (Q5), further illustrating the complexities posed by ambiguous language. In response, revisions were made to improve the clarity of items and minimise misinterpretation.

In addition to comprehension, challenges with retrieval and judgement were also noted. For instance, participants found it difficult to recall their first self-harm episode (Q4), which was influenced by their current age and awareness of behaviour

as self-harm at the time. Such difficulties are consistent with episodic memory challenges that autistic individuals may experience (Lind et al., 2014; Lind & Bowler, 2010), whereby age brackets were incorporated to reduce the cognitive load of this question. Moreover, fluctuations in the frequency of self-harm complicated efforts to provide an accurate average across the past three months (Q3), emphasising the dynamic and complex nature of self-harm (Townsend et al., 2016). To improve the interpretation of the associated Likert scale, verbal labels were included alongside numbered time points (Krosnick & Fabrigar, 1997). Issues with response options were also recurrent across multiple items (e.g., Q2, Q7, Q8), including missing options and jargonistic language or confusing sentence structures. Participants made suggestions similar to those in Chapter 3 and in line with existing literature, such as incorporating broader forms of self-harm in Q2 (e.g., non-recreational risk-taking; Hawton et al., 2012), and self-harm as a way to deal with sensory overwhelm (Marsden et al., 2024; Moseley et al., 2019). On the other hand, missing antecedents indicated the possible role of discrimination and unmet support needs (Botha & Frost, 2020; Brede et al., 2022; Camm-Crosbie et al., 2019) in pathways to self-harm in autistic people. Consequently, revisions were implemented to aid in retrieval and judgement processes, while ensuring response options accurately reflected the diverse experiences of autistic individuals.

In terms of the overall tool, participants emphasised the importance of clear guidance, good layout, and effective use of visual aids. Visual aids can aid with the clarity of response options and have been implemented in other tools developed with and for autistic adults, such as faces (Nicolaidis et al., 2020), measuring jugs (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021), or colour grading (Hedley et al., 2023). While there is no

consensus on which visual aid is best, providing the option can enhance accessibility. Moreover, recommendations were made regarding the sensitivity of the content in order to avoid reinforcing negative perceptions about autistic individuals and those who self-harm, both of whom are already stigmatised groups (Burke et al., 2019; Turnock et al., 2022). As such, revisions to the tool focused not only on improving accessibility but also on ensuring that harmful myths or misconceptions were not perpetuated.

4.5.1. Strengths and Limitations

A key strength of the current study was the use of cognitive interviewing as an evidence-based method for establishing content validity (Terwee et al., 2018). This approach ensured that items on the new tool were clear, relevant, and representative of self-harm in autism. Additionally, the involvement of autistic adults in the development process provided valuable insights from those with lived experience, reinforcing the tool's accessibility and meaningfulness (Nicolaidis et al., 2020).

On the other hand, the new tool was developed exclusively with cognitively able autistic adults and may not be accessible for those with co-occurring ID. Although meta-analyses suggest that the prevalence of self-harm is similar between autistic individuals with and without co-occurring ID (Steenfeldt-Kristensen et al., 2020) there is a persistent selection bias excluding autistic people with co-occurring ID across autism research (Russell et al., 2019). Despite efforts to recruit participants from this demographic in the research, the only individual with self-reported mild co-occurring ID withdrew from the current study. This raises concerns about potential barriers in the study design and the tool itself, as well as the need to consider

inclusive methods and further adaptations to ensure accessibility for all cognitive abilities (Nicolaidis et al., 2019).

4.5.2. Next Steps

The cognitive interviewing process allowed for the development of a new self-harm assessment tool in collaboration with autistic adults, addressing key aspects of its content validity (Nicolaidis et al., 2020; Terwee et al., 2018). The next step will involve testing the tool's measurement properties to ensure it is both valid and reliable for use in the population for which it was developed. Chapter 5 will explore this further by piloting the new tool using an online survey of autistic adults with lived experience of self-harm. Guided by COSMIN taxonomy, preliminary evidence for each of the tool's measurement properties will be evaluated in line with established criteria (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018).

4.6. Conclusion

This chapter highlights the value of cognitive interviewing as a method to develop a new self-harm assessment tool designed with and for autistic adults, thus ensuring content validity. Over two rounds of interviews, key issues with clarity, relevance, and representativeness of items were identified and addressed, with specific attention given to comprehension, retrieval, judgement, and response as sources of error. Subsequently, Chapter 5 will explore preliminary evidence for the new tool's measurement properties, which is essential to ensure an accurate assessment of self-harm in autistic adults. The development of this new tool provides a critical step in advancing research and clinical practice aimed at understanding and preventing self-harm in autistic populations.

4.7. Reflexive Statement

4.7.1. Recruitment of Autistic Adults with Mild Co-occurring ID

From the thesis outset, I was keen to make my research as inclusive as possible by including autistic adults both with and without mild co-occurring ID. To achieve this, I implemented several strategies to facilitate participation in the research. This included requiring participants to attend an introductory meeting, which provided the opportunity to build rapport, explain the research process, and discuss accessibility needs (Becker et al., 2004). For those who self-reported mild co-occurring ID, a short 6-item questionnaire was also presented to ensure they understood the research before providing consent (Horner-Johnson & Bailey, 2013). Moreover, I adapted my research materials (e.g., participant information, consent, debrief) to be available in both standard and easy-read versions (Taua et al., 2014). Participants could also use alternative communication methods to participate (e.g., chat function vs speaking) or ask a trusted person to support them.

Despite these efforts, recruiting individuals with mild co-occurring ID for this chapter proved challenging. I reached out to a large number of relevant service providers and organisations (i.e., gatekeepers), hoping to build connections and seek assistance recruiting participants (Williams, 2019). However, I received very few responses or interest, with some citing the sensitive nature of the research as a reason for not engaging. Even when individuals expressed interest, many who self-reported co-occurring ID had confused this with specific learning difficulties (e.g., dyslexia).

In the end, only one participant with mild co-occurring ID completed the first cognitive interview but did not respond to follow-ups for the second. The data from

this participant was still included in the analysis, although I had to change my research to primarily focus on those without co-occurring ID. This experience highlighted the systemic barriers and gatekeeping that autistic individuals with ID may face in accessing research opportunities.

4.7.2. Fraudulent Participants

An unexpected challenge that emerged during this chapter was the issue of fraudulent participants. As recruitment progressed, I noticed patterns of concern consistent with those flagged in previous research, both within and external to our team (French et al., 2024; Pellicano et al., 2024). This included expressions of interest from multiple nearly identical email addresses and generic, similarly formatted messages without subject lines (Pellicano et al., 2024). Consequently, these individuals were asked to confirm their eligibility, and those who displayed further inconsistencies were not invited to an introductory meeting. During online meetings, participants were also required to have their cameras on at least intermittently. While this was primarily for safeguarding purposes, given the sensitive research topic, it may have also acted as a deterrent for fraudulent participants. Although these steps added extra layers to the process, they helped to maintain data integrity.

As a result of this experience, I decided to implement various strategies to mitigate fraudulent responses in the subsequent anonymous online survey (French et al., 2024; Pellicano et al., 2024). For instance, no financial compensation was offered for participating, and separate survey links were utilised for each recruitment method (e.g., social media vs research databases). After data collection, responses were also checked for CAPTCHA scores, survey completion time and inconsistent or

illogical answers. The number and percentage of participants excluded due to concerns about data integrity were also reported to maintain transparency about this issue ($n = 14$, 2.3%).

Chapter 5. Measurement Properties of the Self-Harm Questionnaire – Autism
(SHQ-A) in an International Community Sample of Autistic and Possibly
Autistic Adults.

v. Preface

Chapter 4 detailed the iterative development of a new self-harm assessment tool (henceforth, the Self-harm Questionnaire – Autism; SHQ-A) over two rounds of cognitive interviews with autistic adults who have lived experience of self-harm. Key issues related to item clarity, relevance, and representativeness were identified and addressed to improve content validity. In the final empirical study of the thesis, Chapter 5 will use data collected via an online survey of autistic adults with lived experience of self-harm to explore the measurement properties of the new tool. This will ensure that the SHQ-A is reliable and valid for the target population for which it was developed.

5.1. Introduction

Autistic individuals and those with high autistic traits have a high prevalence and increased risk of self-harm (Blanchard et al., 2021; Figueiredo et al., 2023; Stark et al., 2022; Steinfeldt-Kristensen et al., 2020), along with being more vulnerable to contributing factors and adverse consequences (e.g., Kim et al., 2024; Lai et al., 2019; Moseley et al., 2022; Newell et al., 2023). Thus, it is crucial to be able to accurately identify self-harm in autistic individuals. However, a lack of validated and appropriate tools poses a major barrier to research and clinical practice (see Chapters 2-3). To address this gap, Chapter 4 detailed the iterative development of the first self-harm assessment tool with and for autistic adults, henceforth, the Self-harm Questionnaire – Autism (SHQ-A). The use of cognitive interviews, combined with direct involvement from autistic individuals, provided a strong foundation for content validity – regarded as the most important measurement property on which all others rely, according to the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN; Mokkink et al., 2018). Building on this, it is now necessary to explore the SHQ-A's other measurement properties to ensure it accurately assesses self-harm in autistic populations.

Following content validity, COSMIN recommends evaluating a tool's internal structure on the quality of and relationship between items, starting with structural validity, then internal consistency, and cross-cultural validity/ measurement invariance (Mokkink et al., 2018). These properties indicate how well the items within the tool relate to one another and whether they capture the construct they intend to measure (Mokkink et al., 2018). However, internal structure is only relevant for tools measuring latent constructs (i.e., variables that cannot be directly observed) when based on a reflective model, where items are seen as manifestations of the

underlying construct (Mokkink et al., 2018). As the SHQ-A assesses multiple facets of self-harm, encompassing both observable variables (e.g., self-harm behaviours, body areas self-harmed) and latent constructs (e.g., self-harm functions), only the functions of self-harm subscale would meet the assumption of unidimensionality, as its items measure a single construct. Consequently, an analysis of the SHQ-A as a whole is neither theoretically nor empirically meaningful (Machleit, 2019). Consistent with this, research validating self-harm assessment tools in general populations has focused solely on the internal structure of function subscales (e.g., Klonsky & Glenn, 2009; Turner et al., 2012; Whitlock et al., 2014), extracting between two and five factors, though the evidence supporting these structures remains mixed (see Chapter 1; Newell et al., 2024). Given these inconsistencies, and the possibility that self-harm functions may differ qualitatively for autistic individuals (e.g., to deal with sensory overwhelm – see Chapters 3-4; Marsden et al., 2024; Moseley et al., 2019), the underlying factor structure of the new tool may also differ.

Once content validity and internal structure have been established, the remaining measurement properties of reliability, measurement error, criterion validity, construct validity, and responsiveness can be considered (Mokkink et al., 2018). According to COSMIN, these measurement properties focus more on the overall quality of a tool or its subscales rather than at the item level, and none are considered more important than the other (Mokkink et al., 2018). However, not all of these properties will be examined in the current study, where the primary focus is to provide preliminary psychometric evidence for the SHQ-A. For example, measurement error and responsiveness are more relevant to determining a tool's clinical utility after its validity and reliability have been established (McKechnie & Fisher, 2022). Moreover, there is no agreed-upon gold standard for criterion validity

(Faura-Garcia et al., 2021; Newell et al., 2024), and the administration of multiple self-harm assessment tools would likely be repetitive and emotionally taxing for participants. Therefore, the present study will prioritise reliability and construct validity, which will offer the most valuable preliminary insights.

The SHQ-A was developed in partnership with autistic adults to more accurately capture their experiences of self-harm (see Chapters 3-4). As a result, the tool is anticipated to demonstrate promising preliminary measurement properties reflecting the rigorous groundwork to establish content validity. Accordingly, the current study will pilot the SHQ-A via an online survey to provide preliminary evidence for its content validity, structural validity, internal consistency, test-retest reliability, and construct validity (convergent and divergent).

5.2. Methods

5.2.1. Participants

The main sample consisted of 364 adults with lived experience of self-harm and/ or self-injury who self-reported either a formal diagnosis of autism or suspected they were autistic but had not yet been diagnosed (i.e., self-identifying)⁸. There was no significant difference in the AQ-10 scores ($t(360) = -1.330, p = .184$) of those with a formal diagnosis ($M = 7.97, SD = 1.73$) compared to those who self-identified as autistic ($M = 7.69, SD = 1.63$). Of the total participants, a test-retest subsample completed the SHQ-A at a second time point ($n = 82$). Demographic characteristics of both the main sample and test-retest subsample can be found in Table 13. Participants from the UK were recruited through various channels, including

⁸ Previous research has typically demonstrated similarities in autistic traits and characteristics across both diagnosed and self-identified groups (Overton et al., 2023).

established research databases (e.g., the Autistica Network, MQ Mental Health Research charity), reputable organisations (e.g., the National Autistic Society), social media platforms, and the University of Nottingham's Autism Social Network. Participants were also recruited from Australia through the Olga Tennison Autism Research Centre's mailing list, blog, and social media accounts⁹. There was no significant difference in age ($t(362) = .748, p = .455$), age of autism diagnosis ($t(277) = 1.207, p = .228$), AQ-10 total score ($t(360) = .788, p = .431$), or formally diagnosed vs self-identified as autistic ($\chi^2(1) = .655, p = .418$) between the UK and Australian samples, supporting these subsamples being combined.

Table 13.

Participant demographics for the main and test-retest sample.

Demographics	Main sample (n = 364) <i>n (%) / M (SD)</i>	Test-retest subsample (n = 82)
<i>Autism</i>		
Formally diagnosed	279 (76.6)	63 (75.9)
Self-identified	85 (23.4)	20 (24.1)
Age of diagnosis (if applicable)	27.11 (11.93) 3 – 67	26.67 (12.25) 3 – 64
<i>Age</i>	31.54 (10.99) 18 – 70	31.73 (11.90) 18 – 70
<i>Location</i>		
UK	235 (64.6)	53 (63.9)
Australia	129 (35.4)	30 (36.1)
<i>Gender identity*</i>		
Male	40 (11.0)	8 (9.8)
Female	229 (62.9)	52 (63.4)
Non-binary/ non-conforming	91 (25.0)	22 (26.8)
Transgender	38 (10.4)	11 (13.4)
Questioning	9 (2.5)	2 (2.4)
Prefer to self-identify	16 (4.4)	4 (4.9)
<i>Ethnicity*</i>		
Asian or Asian British	15 (4.1)	4 (4.9)
Black, Black British, Caribbean or African	1 (0.3)	-
Hispanic or Latinx	1 (0.3)	-

⁹ This Australian sample was included due to concerns about hitting the recruitment target within the UK. Australian colleagues experienced in autism and suicide research (e.g., Hedley et al., 2023) assisted with recruitment and provided guidance on region-specific safeguarding.

Mixed or multiple ethnic groups	21 (5.8)	6 (7.3)
Middle Eastern or Arab	1 (0.3)	-
White or Caucasian	321 (88.2)	71 (86.6)
Other	8 (2.2)	1 (1.2)
Prefer not to say	3 (0.8)	-
<i>Employment status*</i>		
Employed full-time	94 (25.8)	15 (18.3)
Employed part-time	91 (25.0)	22 (26.8)
Volunteering full-time	1 (0.3)	-
Volunteering part-time	35 (9.6)	13 (15.9)
Student full-time	76 (20.9)	17 (20.7)
Student part-time	39 (10.7)	10 (12.2)
Self-employed	22 (6.0)	5 (6.1)
Unemployed looking for work	28 (7.7)	5 (6.1)
Unemployed not looking for work	6 (1.6)	3 (3.7)
Unable to work due to illness or disability	86 (23.6)	21 (25.6)
Carer or homemaker	16 (4.4)	5 (6.1)
Retired	6 (1.6)	3 (3.7)
Other	5 (1.4)	1 (1.2)
Prefer not to say	2 (0.5)	1 (1.2)
<i>Highest education level</i>		
No formal qualifications	8 (2.2)	2 (2.4)
Secondary/ high school	102 (28.0)	21 (25.6)
Vocational training	30 (8.2)	5 (6.1)
Undergraduate Degree (or equivalent)	114 (31.3)	26 (31.7)
Postgraduate Degree (or equivalent)	100 (27.5)	24 (29.3)
Other	5 (1.4)	1 (1.2)
Prefer not to say	5 (1.4)	3 (3.7)
<i>Lifetime co-occurring developmental conditions</i>		
<i>Formally diagnosed/ suspected</i>		
> = 1 neurodevelopmental condition	168 (46.2)/ 212 (58.2)	37 (45.1)/ 43 (52.4)
ADHD	125 (34.3)/ 124 (34.1)	28 (34.1)/ 29 (35.4)
Dyspraxia	23 (6.3)/ 91 (25.0)	5 (6.1)/ 17 (20.7)
Epilepsy	5 (1.4)/ 4 (1.1)	1(1.2)/ -
Intellectual/ Learning Disability	8 (2.2)/ 9 (2.5)	- / 1 (1.2)
Specific Learning Difficulty	32 (8.8)/ 52 (14.3)	9 (11.0)/ 7 (8.5)
Social Communication/ Developmental Language Disorder	14 (3.8)/ 19 (5.2)	2 (2.4)/ 5 (6.1)
Tourette's syndrome	4 (0.8)/ 15 (4.1)	1 (1.2)/ -
Other	13 (3.6)/ 8 (2.2)	2 (2.4)/ 2 (2.4)
<i>Lifetime co-occurring psychiatric conditions</i>		
> = 1 psychiatric condition	322 (88.5)/ 259 (71.2)	70 (85.4)/ 59 (72.0)
Anxiety Disorder	250 (68.7)/ 49 (13.5)	56 (68.3)/ 12 (14.6)
Bipolar Disorder	17 (4.7)/ 18 (4.9)	4 (4.9)/ 3 (3.7)
Depression	272 (74.7)/ 47 (12.9)	59 (72.0)/ 13 (15.9)
Eating Disorder	87 (23.9)/ 87 (23.9)	23 (28.0)/ 14 (17.1)
GAD	176 (48.4)/ 68 (18.7)	33 (40.2)/ 21(25.6)
OCD	52 (14.3)/ 70 (19.2)	13 (15.9)/ 15 (18.3)
Panic disorder	46 (12.6)/ 58 (15.9)	7 (8.5)/ 13 (15.9)
BPD/EUPD	42 (11.5)/ 17 (4.7)	9 (11.0)/ 3 (3.7)
Other Personality Disorder	7 (1.9)/ 16 (4.4)	4 (4.9)/ 4 (4.9)
PTSD	122 (33.5)/ 92 (25.3)	30 (36.6)/ 24 (29.3)
CPTSD	6 (1.6)/ 3 (0.8)	1 (1.2)/ 2 (2.4)

Psychosis	22 (6.0)/ 21 (5.8)	4 (4.9)/ 5 (6.1)
Schizophrenia	3 (0.8)/ 7 (1.9)	2 (2.4)/ 1 (1.2)
Schizoaffective Disorder	4 (1.1)/ 6 (1.6)	- / 1 (1.2)
Specific phobia	29 (8.0)/ 23 (6.3)	8 (9.8)/ 5 (6.1)
Other	19 (5.2)/ 14 (3.8)	6 (7.3)/ 1 (1.2)
Measures	<i>M (SD)</i>	
AQ-10	7.91 (1.70)	7.90 (1.86)
QNSSI (functions)	37.00 (14.57)	36.51 (14.66)
SBQ-ASC	13.85 (5.39)	14.13 (5.56)
ADAT-A	67.03 (42.10)	65.50 (45.83)
ASA-A	32.95 (11.71)	32.25 (13.32)

* Participants could select multiple options; total does not add up to n= 364 (100%).

Note. Lifetime suspected/ formally diagnosed conditions do not necessarily reflect current diagnoses.

ADHD = Attentional Deficit Hyperactivity Disorder; AQ-10 = Autism-Quotient – 10; BPD = Borderline Personality Disorder; EUPD = Emotionally Unstable Personality Disorder; GAD = Generalised Anxiety Disorder; OCD = Obsessive Compulsive Disorder; PTSD = Post-traumatic Stress Disorder; CPTSD = Complex Post-traumatic Stress Disorder; QNSSI = Questionnaire for Non-Suicidal Self-Injury; SBQ-ASC = Suicidal Behaviours Questionnaire – Autism Spectrum Conditions; ADAT-A = Autistic Depression Assessment Tool – Adult; ASA-A = Anxiety Scale for Autism – Adults

5.2.2. Measures

5.2.2.1. Autism Quotient – 10 (AQ-10)

The AQ-10 (Allison et al., 2012) was included to quantify autistic traits for comparing those formally diagnosed and self-identifying, as well as to test the divergent validity of the SHQ-A with an unrelated construct (i.e., autistic traits). The AQ-10 is a 10-item subset of the full 50-item Autism Spectrum Quotient (Baron-Cohen et al., 2001), which is widely used in research and recommended by the National Institute for Health and Care Excellence to screen for autism in adults (NICE, 2021). It measures self-reported autistic traits, where scores of 6 or higher indicate possible autism. Each item is rated on a 4-point response scale of definitely agree, slightly agree, slightly disagree and definitely disagree. Scores of 1 are applied to 4 items for slightly or definitely agree responses and 6 items for slightly or definitely disagree responses, resulting in a binary scoring format (0 = trait not

endorsed, 1 = trait endorsed) out of 10. In the current study, Cronbach's alpha for the overall scale was poor ($\alpha = .534$).

5.2.2.2. *Suicidal Behaviours Questionnaire – Autism Spectrum Conditions (SBQ-ASC)*

The SBQ-ASC (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021) was included to test the convergent validity of the SHQ-A with a related but dissimilar construct (i.e., suicidality). The SBQ-ASC is a self-report measure of suicidal thoughts and behaviours, which was adapted with and for autistic adults from the Suicide Behaviours Questionnaire-Revised (Osman et al., 2001). It contains 5 scored items assessing: lifetime experience of suicidal thoughts and behaviours (0 = "Never" to 4 = "I have attempted to end my life"); frequency of intense suicidal thoughts in the last 12 months (0 = "Never" to 6 = "1 or more times a day"); duration of perseverative suicidal thoughts (0 = "Not Applicable", 1 = "Less than 5 minutes" to 5 = "More than 8 hours"); likelihood of a suicide attempt (0 = "Not Applicable", 1 = "No chance at all" to 5 = "Very likely"); and communication of future suicide intent and past suicide attempts (0 = "Not applicable/ No" to 1 = suicidal thoughts, 2 = future suicide attempts, and 3 = past suicide attempts if "Yes, once/ Yes, more than once"). Total scores range from 0 to 26, with higher scores indicating greater levels of suicidal thoughts and behaviours. The SBQ-ASC has strong evidence for content validity, factor structure, internal consistency, test-retest reliability, and both convergent and divergent validity in autistic adults (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021). In the current study, Cronbach's alpha for the overall scale was acceptable ($\alpha = .713$).

5.2.2.3. *Autistic Depression Assessment Tool – Adult (ADAT-A)*

The ADAT-A (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021) was included to test the convergent validity of the SHQ-A with a related but dissimilar construct (i.e., depression). The ADAT-A is a 21-item self-report measure capturing depression symptoms in the past 14 days, also developed with and for autistic adults (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021). It measures three dimensions of depression: Cognitive/ Affective (e.g., “Lack of interest in doing the things you usually enjoy”), Somatic (e.g., “More difficulties with sleep than usual”), and Autistic (e.g., “If attending social events, you need more time than usual to recover afterwards”). Each item follows a staged response format. Respondents first indicate the presence of a symptom in the past 14 days (yes/no). If yes, they rate the duration of the symptom on a scale from 1 (“1–3 days”) to 4 (“12–14 days”) and its impact on everyday functioning from 1 (“Not at all”) to 4 (“Extremely”). If no, the item is scored 0. A visual aid is available to help respondents quantify their responses regarding symptom impact on daily functioning. Scores for individual items range from 0 to 8, and total scores from 0 to 168, with higher scores reflecting a greater severity and impact of depressive symptoms over the past 14 days. The ADAT-A has strong evidence for structural validity, internal consistency, and convergent and divergent validity in autistic adults (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021). In the current study, Cronbach’s alpha for the overall scale was excellent ($\alpha = .966$).

5.2.2.4. *Anxiety Scale for Autism – Adults (ASA-A)*

The ASA-A (Rodgers et al., 2020) was included to test the convergent validity of the SHQ-A with a related but dissimilar construct (i.e., anxiety). The ASA-A is a 20-

item self-report measure of anxiety designed with and for autistic adults, adapted from the Anxiety Scale for Autism Spectrum Disorder (Rodgers et al., 2016). It measures three dimensions of anxiety: Social phobia (e.g., “I worry what other people think of me”), Anxious Arousal (e.g., “All of a sudden I feel really scared”), and Uncertainty (e.g., “I am anxious about unfamiliar things, people, or places”). Each item is rated on a scale from 0 (“Never”) to 3 (“Always”). Total scores range between 0 to 60, where a score of 28 or higher suggests clinically significant anxiety levels. The ASA-A has strong evidence for structural validity, internal consistency, test-retest reliability, and both convergent and divergent validity in autistic adults (Rodgers et al., 2020). In the current study, Cronbach’s alpha for the overall scale was excellent ($\alpha = .927$).

5.2.2.5. *Existing Self-Harm Assessment Tools*

The three self-harm assessment tools used to inform the development of the SHQ-A included the Non-Suicidal Self-Injury – Assessment Tool (NSSI-AT; Whitlock et al., 2014), Inventory of Statements About Self-injury (ISAS; Klonsky & Glenn, 2009), and the Questionnaire for Non-Suicidal Self-Injury (QNSSI; Turner et al., 2012). However, incorporating all three tools into the online survey would have been overly repetitive and increased the emotional burden on participants. Therefore, only items that most closely resembled those in the SHQ-A were utilised (see D1 in Appendix D for a complete list of these items). This allowed for a more direct comparison of clarity and relevance with the new tool, as well as testing the convergent validity of the SHQ-A with a similar construct (i.e., self-harm functions). Nine items were included assessing: 1) presence of self-harm (yes/no); 2) behaviours (15 response options); 3) recency (“less than 1 week ago” to “more than 2 years ago”); 4) age first self-harmed (open-response); 5) severity (yes/no); 6) body

areas (16 response options); 7) functions (40 response options scored from 0 = “Never” to 4 = “Always”); 8) antecedents (20 response options); and 9) desire to stop (yes/no). In the current study, Cronbach’s alpha for the overall functions scale was good ($\alpha = .896$).

5.2.2.6. *Self-harm Questionnaire – Autism (SHQ-A)*

The SHQ-A was developed in three stages throughout this thesis: 1) a COSMIN systematic review of tools used to assess self-harm in autistic and general-population adults (see Chapter 2; Newell et al., 2024); 2) focus groups with autistic adults with lived experience of self-harm and professionals who support them (see Chapter 3); and 3) cognitive interviews with autistic adults with lived experience of self-harm (see Chapter 4). The SHQ-A comprised 10 self-report items designed to assess a range of epidemiological and contextual characteristics of self-harm in autistic adults using the NICE (2022) definition for guidance¹⁰ (see C4 in Appendix C for the final version of the tool). Items included the presence of self-harm (yes/no), behaviours (21 response options) across three timeframes (ever, past 3 months, never), recency (“more than 2 years ago/ not at all recently” to “less than 1 week ago/ very recently”), frequency (“never” to “once or more a day/ very frequently”), age first self-harmed (10 year age brackets, and optional open-response), severity (yes/no, and optional open-response), body areas (20 response options), functions (43 response options determined in Chapter 4, refined to 26 in results, scored from 0= “strongly disagree” to 3= “strongly agree) with optional visual aids (faces, measuring jugs, colour grading), antecedents (45 response options) across two timeframes (more than 24 hours before, 24 hours before, no), and support strategies

¹⁰ For the purpose of this study, those who indicated they had not self-harmed and/ or self-injured at eligibility screening were excluded.

(yes/no, optional open-response, and 5 response options). Although initially developed as a paper format, the online version was utilised for web-based data collection.

5.2.2.7. Demographics

Data was collected on participants' age, gender identity, ethnicity, employment status, highest education level, lifetime suspected or formally diagnosed developmental and psychiatric conditions, autism diagnosis (formally diagnosed or self-identifying), and age of formal autism diagnosis if relevant.

5.2.3. Procedure

Participants were invited to complete an online survey using Qualtrics to develop a new self-harm assessment tool with and for autistic adults. To participate, individuals were informed they needed to be aged 18 years old or above, have a formal diagnosis of autism or self-identify as autistic, have lived experience of self-harm and/ or self-injury, and currently reside in the UK or Australia. The age and location criteria were required due to the sensitive nature of the research topic and to ensure that region-specific support and organisation were available. To address recent concerns about data integrity in online autism research (French et al., 2024; Pellicano et al., 2024), separate survey links were used for different recruitment methods (e.g., social media vs. research databases). This allowed data from each recruitment route to be checked for duplicate responses, CAPTCHA scores below 0.6 (indicating a higher likelihood of bot activity), improbable survey completion times, and inconsistent or illogical responses. However, attention checks were not included, as feedback from previous PPI groups has highlighted that these can create difficulties for autistic participants when completing surveys.

First, participants were briefed about the nature of the research and informed that location-specific web links and phone numbers for support services would be available on each survey page. After providing consent and confirming their eligibility, participants were asked to create a unique seven-digit identification code. This code was used to anonymously link data between time points one and two, or to locate data if a participant wished to withdraw from the study. All participants were then presented with each survey section in the following order: demographic questions, AQ-10, SHQ-A, existing self-harm assessment tools, SBQ-ASC, ADAT-A, and ASA-A. The most relevant measures (i.e., SHQ-A, existing self-harm tools) were presented earlier to account for potential dropout and placed between sections less likely to cause distress, aligning with recommendations for surveying sensitive topics (Lensvelt-Mulders, 2008). Participants were also aware of which self-harm tool had been developed for autistic individuals to build trust and encourage engagement (Dillman et al., 2014). After completing the SHQ-A and existing self-harm assessment tools, participants were also given the option to rate the overall relevance (scale of 0-10) and clarity (yes/no) of these, as well as provide additional feedback (open-response).

After each section, participants were reminded that they could leave questions unanswered, skip sections, close the survey and return later, or withdraw from the study at any time if they felt uncomfortable. At the end of the survey, they were invited to provide consent to be contacted to complete the SHQ-A again after two weeks. Those who agreed were redirected to a separate Qualtrics survey to securely provide their email address. A two-week interval was chosen as it is considered appropriate for assessing test-retest measurement properties (Mokkink et al., 2024). Participants were then provided with full debrief information and signposting

(including a link to download an autism-adapted safety plan; Rodgers et al., 2024), and a positive mood induction procedure (e.g. videos of cute animals; Lockwood et al., 2018). The survey took approximately 45 – 60 minutes to complete. Accessible versions of the participant and debrief information were also available. Ethical approval was received for this study from the University of Nottingham's School of Psychology (ref: S1508).

5.2.4. *Data Management and Analysis*

Analyses were conducted in SPSS version 29. A total of 616 participants initially accessed the survey, where 77 only opened the participant information, 83 did not start the main survey¹¹, and 19 did not complete any sections after demographic information. Fourteen (2.3%) were excluded due to concerns about data integrity, including duplicate responses across recruitment strategies ($n = 7$) and possible nongenuine participants or bots ($n = 7$). This resulted in 423 (68.7%) participants who met the eligibility criteria and chose to proceed with the online survey. Among them, 364 (86.1%) completed all SHQ-A items with no missing data, and 363 participants also filled out at least one additional measure with no missing data. Additionally, 279 (76.6%) participants agreed to be contacted again after two weeks (the test-retest subsample), of which 82 (29.4%) completed the SHQ-A at both time points with no missing data. There was no significant difference in age ($t(444) = -.144, p = .886$), age of autism diagnosis ($t(339) = .259, p = .796$), AQ-10 total score ($t(442) = .030, p = .976$), or formally diagnosed vs self-identified as autistic ($\chi^2(1) = .040, p = .841$) between the main sample and test-retest subsample.

¹¹ Did not: consent ($n = 11$), meet eligibility criteria ($n = 19$), complete eligibility ($n = 7$); complete demographic information ($n = 46$).

Due to the early stage of measure development, participants with missing data were excluded listwise before analysis, leaving only those who had completed all SHQ-A items ($n = 364$). This was to avoid biasing item correlations and the emerging factor structure before relationships are fully understood. All measures were screened for valid responses by checking consistency across questions (e.g., between equivalent items on the SHQ-A and existing self-harm assessment tools) and participants' understanding (e.g., through open-text boxes). Following this, the AQ-10, QNSSI (functions), SBQ-ASC, ADAT-A and ASA-A were checked for missing data using Little's Missing Completely At Random (MCAR) test, and the percentage of missing cases and values was calculated. Pairwise deletion was utilised if more than 10% of the data was missing or the MCAR assumption was violated. If missing data was less than 10% and MCAR, data were imputed by mean item substitution, following a similar approach used in previous research (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021; Cassidy, Bradley, et al., 2020). Each measure had less than 10% missing data for cases and values, however Little's MCAR test was significant for the ADAT-A ($\chi^2 (116) = 145.44, p = .033$). Therefore, data were imputed for the QNSSI (functions), SBQ-ASC, ASA-A and AQ-10, while pairwise deletion was utilised for the ADAT-A.

5.2.4.1. Exploratory Factor Analysis

An exploratory factor analysis was used to identify the underlying factor structure from 43 functions of self-harm in the SHQ-A. The sample size ($n = 364$) was considered very good according to the COSMIN risk of bias checklist, with over 7 participants per item and over 100 participants in total (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). Principal axis factoring for extraction was

used as the most appropriate and robust method against violations of normality, where an oblique rotation method of Oblimin with Kaiser normalisation was applied. This allowed for factors to correlate, which is generally expected in the social sciences, where latent variables are rarely independent of one another (Costello & Osborne, 2005).

The suitability of the data for factor analysis was confirmed by the following assumptions: determinant of the correlation matrix (> 0.00001) to confirm the absence of multicollinearity; the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy; and Bartlett's test of sphericity ($p < .05$). Items with low communalities (< 0.3) were removed, as this suggested they were not adequately represented by the factors (Costello & Osborne, 2005). Items were also removed if they had factor loadings less than 0.40 or where cross-loading was ≥ 0.40 on two or more factors (Costello & Osborne, 2005). Criteria for good structural validity, knowledge of relevant theory, the Kaiser criterion (Eigenvalues ≥ 1), cumulative variance ($\geq 50\%$), and examination of the scree plot informed the number of factors to extract (Mokkink et al., 2024; Osborne, 2014).

5.2.4.2. *Reliability*

Internal consistency of the SHQ-A functions subscale, and its factors were calculated using Cronbach's alpha (α) to explore the degree of interrelatedness among items. Test-retest reliability was also assessed in a subsample of participants who completed the SHQ-A again after 2 weeks ($n = 82$). However, this analysis was limited to items less likely to exhibit real change over time (i.e., total lifetime behaviours, total body areas, total function scores, age of first self-harm, and self-harming more severely than expected), similar to those used to assess the reliability

of the NSSI-AT (Whitlock et al., 2014). Intraclass correlation coefficient (ICC) was used for continuous variables, and Cohen's Kappa (k) for nominal variables. For the ICC, a two-way mixed-effects model with absolute agreement was selected as the most appropriate method (Koo & Li, 2016). According to COSMIN criteria, both internal consistency and test-retest reliability are considered good where values are ≥ 0.70 (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018).

5.2.4.3. *Validity*

Spearman's rank correlations were used to evaluate the convergent and divergent validity of total scores on the SHQ-A functions subscale. Convergent validity was assessed against existing self-harm tools (QNSSI functions), suicidality (SBQ-ASC), depression (ADAT-A), and anxiety (ASA-A), as well as divergent validity in relation to autistic traits (AQ-10). Using the recommendations for evaluation outlined in COSMIN, specific hypotheses were formulated (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). For convergent validity, strong correlations (≥ 0.50) were expected with instruments measuring similar constructs, whereby the SHQ-A and QNSSI functions subscales both aim to capture the underlying motivations for self-harm. Furthermore, correlations with instruments measuring related but dissimilar constructs, such as measures of psychological distress (i.e., SHQ-A with SBQ-ASC, ADAT-A and ASA-A), would be moderate but lower ($0.20^{12} - 0.50$). Given the known associations between self-harm and mental health difficulties in general and autistic populations (e.g., Kim et al., 2024; Liu, 2023), individuals experiencing higher levels of psychological distress may be more likely to endorse a greater number or wider range of self-harm functions. Whereas for divergent validity,

¹² Changed from 0.30 to 0.20 based on relationships in a prior COSMIN review reflecting this (Newell et al., 2024)

weak correlations (< 0.20) were anticipated with instruments measuring unrelated constructs. Namely, the AQ-10 assesses the presence of autistic traits, and not why a person self-harms, which are theoretically distinct constructs. An a priori power analysis was conducted using G*Power (Faul et al., 2007) to determine the necessary sample size to test each hypothesis. The alpha level was adjusted using a Bonferroni correction to account for multiple correlations. For a desired power of $1-\beta = 0.80$, the required sample sizes were 42 for detecting a large effect ($r = .50$, $p = .01$), 137 for a medium effect ($r = .30$, $p = .006$), and 287 for a small effect ($r = .20$, $p = .01$).

To further explore content validity, overall relevance (scale of 0-10) and clarity (yes/no) of the SHQ-A and existing self-harm assessment tools were compared using a Wilcoxon signed-rank test and McNemar's test, respectively. A threshold of 80% consensus (i.e., 80% of participants rate the SHQ-A as either equally or more clear/ relevant than existing tools) was considered acceptable in line with Delphi survey techniques used in previous research (Hasson et al., 2000; McConachie et al., 2018).

5.3. Results

5.3.1. Descriptives

All participants reported having self-harmed. The most common lifetime self-harm behaviour was “engaged in risky, impulsive, or self-destructive behaviour(s)” (62.1%), while “scratched or pinched self with fingernails or other objects” was most frequent in the past 3 months (48.1%). For the most recent occasion of self-harm, 29.9% reported this was “less than 1 week ago”, whereas 25% reported “never” self-harming on average in the past 3 months. The majority of participants first self-

harmed between ages 11–20 (68.4%), with a mean age of 13.54 ($SD = 5.82$) for those who gave an exact estimate. Over half of the participants indicated they had self-harmed more severely than expected (61%). Arms were the most common body area for self-harm (84.3%). Three-quarters of participants chose to use a visual aid for the functions item (74.7%), with faces as the most popular (47%). The mean total functions score was 41.67 ($SD = 13.14$) out of a maximum of 78 across 26 items (scored 0-3). Among participants who reported self-harm in the past 3 months ($n = 259$), the event or experience that most frequently contributed to their most recent episode of self-harm was “your mental health was worse than usual” more than 24 hours before (23.6%), and “you experienced sensory overwhelm” 24 hours before (67.2%). While most participants reported having strategies to cope with self-harm (77.2%), over a third expressed a desire to find alternatives to self-harm (39.8%). Complete descriptives for SHQ-A items are presented in Table 14.

Table 14.

Descriptives for each item on the SHQ-A ($n = 364$).

Item	Answers % (n)/ M (SD), range	
1. Have you ever self-harmed?		
Yes	364 (100)	
2. Have you self-harmed in any of the following ways, either:	i) Ever?	ii) Past 3 months?
Scratched or pinched self with fingernails or other objects	158 (43.4)	175 (48.1)
Cut wrists, arms, legs, torso, or other areas of the body	212 (58.2)	89 (24.5)
Carved words or symbols into the skin	147 (40.4)	13 (3.6)
Ripped or torn skin	153 (42.0)	83 (22.8)
Rubbed glass into skin or stuck sharp objects such as needles, pins, and staples into or underneath the skin	145 (39.8)	30 (8.2)
Prevented wounds from healing	141 (38.7)	148 (40.7)
Dripped acid onto skin or areas of the body	9 (2.5)	3 (0.8)
Burned skin or areas of the body	145 (39.8)	16 (4.4)
Bitten self	191 (52.5)	73 (20.1)
Banged or punched objects	202 (55.5)	91 (25.0)
Punched or banged self	175 (48.1)	112 (30.8)
Tried to break, or broke bone(s)	51 (14.0)	6 (1.6)

Pulled or pulled-out hair	131 (36.0)	62 (17.0)
Ingested a dangerous substance or sharp object(s)	41 (11.3)	5 (1.4)
Abused any kind of medication, drug or alcohol	151 (41.5)	53 (14.6)
Took an overdose of any kind of medication, drug or alcohol	177 (48.6)	31 (8.5)
Engaged in risky, impulsive, or self-destructive behaviour(s)	226 (62.1)	62 (17.0)
Engaged in fighting or other aggressive activities with the intention of getting hurt	51 (14.0)	6 (1.6)
Got a tattoo or body piercing	105 (28.8)	17 (4.7)
Neglecting basic needs	185 (50.8)	143 (39.3)
Ingested or exposed self to something that causes an allergic or adverse reaction	38 (10.4)	33 (9.1)
Other	41 (11.3)	28 (7.7)
<i>Total behaviours</i>	7.79 (3.50), 0 – 18	3.44 (2.99), 0 – 17
3. When was the most recent occasion you self-harmed?		
More than 2 years ago (Not at all recently)	49 (13.5)	
Between 1 and 2 years ago	37 (10.2)	
Between 6 months and 1 year ago	18 (4.9)	
Between 3 and 6 months ago	13 (3.6)	
Between 1 and 3 months ago	49 (13.5)	
Between 1 week and 1 month ago	89 (24.5)	
Less than 1 week ago (Very recently)	109 (29.9)	
4. How often on average have you self-harmed during the past 3 months?		
Never	91 (25.0)	
Less than once a month (Very Rarely)	52 (14.3)	
Once a month (Rarely)	38 (10.4)	
2-3 times a month (Occasionally)	64 (17.6)	
Once a week (Sometimes)	49 (13.5)	
2-6 times a week (Frequently)	51 (14.0)	
Once or more a day (Very Frequently)	19 (5.2)	
5a. How old were you the first time you self-harmed?		
0 – 10 years old	90 (24.7)	
11 – 20 years old	249 (68.4)	
21 – 30 years old	16 (4.4)	
31 – 40 years old	7 (1.9)	
41 – 50 years old	0	
50 + years old	7 (0.5)	
5b. Exact age (n = 256)	13.54 (5.82)	
	3 – 65	
6a. Have you ever self-harmed more severely than you expected?		
Yes	222 (61.0)	
No	142 (39.0)	
7. Have you ever self-harmed on the following areas of your body?		
Head	205 (56.3)	
Face	123 (33.8)	
Lips	70 (19.2)	
Tongue	25 (6.9)	
Neck	54 (14.8)	

Shoulders	83 (22.8)
Arms	307 (84.3)
Wrists	260 (71.4)
Hands	209 (57.4)
Fingers	144 (39.6)
Chest	94 (25.8)
Breasts	69 (19.0)
Stomach	150 (41.2)
Back	25 (6.9)
Buttocks	20 (5.5)
Genitals	24 (6.6)
Rectum	3 (0.8)
Thighs	253 (69.5)
Calves	107 (29.4)
Ankles	82 (15.9)
Feet	58 (15.9)
Not applicable	6 (1.6)
<i>Total body areas</i>	6.51 (3.38)
	1 - 19
<i>Visual aid</i>	272 (74.3)
Measuring jugs	54 (14.8)
Faces	171 (47.0)
Colours	47 (12.9)
None	92 (25.3)

8. When I self-harm, it is...

<i>Sensation generation ($\alpha = .843$)</i>	5.46 (3.72)
	0 – 12
to stop feeling numb or dead	1.45 (1.17)
to feel something, even if it is pain	1.55 (1.17)
to feel my body again	1.43 (1.13)
to regain a sense of reality	1.02 (1.03)
<i>Self-regulation ($\alpha = .753$)</i>	8.56 (3.06)
	0 – 12
to ground myself	2.05 (1.07)
to give me something to focus on so that everything else slows down	1.90 (1.10)
to cope with sensory or social overwhelm	2.09 (1.03)
to cope with dysregulation	2.53 (0.81)
<i>Interpersonal communication ($\alpha = .845$)</i>	2.69 (3.15)
	0 – 12
to seek care or help from others	0.79 (1.03)
to get other people to act differently or change so that others will notice/ understand how desperate I am or how badly I am doing	0.42 (0.84)
to get back at, hurt, or shock someone	1.13 (1.13)
	0.34 (0.76)
<i>Emotion relief ($\alpha = .728$)</i>	9.70 (2.50)
	0 – 12
because the mental pain is unbearable	2.41 (0.88)
to stop/ block out/ decrease/ cope with uncomfortable feelings	2.62 (0.68)

to release the emotional pressure that has built up inside of me	2.65 (0.67)
to change my mental pain into something physical	2.01 (1.07)
<i>Inducing positive states ($\alpha = .726$)</i>	2.97 (2.57)
	0 – 9
because it feels good	1.27 (1.10)
to experience a rush or surge of energy	1.01 (1.10)
because I like the way it looks	0.69 (1.01)
<i>Ambivalent self-preservation ($\alpha = .697$)</i>	4.52 (2.77)
	0 – 9
to avoid attempting suicide	1.52 (1.20)
so that I do not hurt myself in other ways	1.58 (1.19)
because I do not care if I live or die	1.42 (1.14)
<i>Self-punishment ($\alpha = .854$)</i>	7.78 (3.60)
	0 – 12
to stop/ block out/ decrease/ cope with feelings of self-hatred or disgust	2.04 (1.03)
to stop/ block out/ decrease/ cope with feeling worthless	1.96 (1.07)
to stop/ block out/ decrease/ cope with feeling like a burden	1.77 (1.12)
to punish myself	2.01 (1.10)
<i>Total functions ($\alpha = .872$)</i>	41.67 (13.14)
	6 - 78

9. Did any of the following events or experiences contribute to the most recent occasion you self-harmed, either: (<i>n</i> = 259)	i) 24 hours before	ii) More than 24 hours before
You had an argument or conflict with someone	109 (4.1)	27 (10.4)
You tried to spend time with someone but couldn't	48 (18.5)	17 (6.6)
Someone was OR you felt like someone was disappointed with you	112 (43.2)	37 (14.3)
Someone was OR you felt like someone was angry with you, criticised you, or put you down	120 (46.3)	46 (17.8)
Someone rejected you OR you felt like someone rejected you	98 (37.8)	34 (13.1)
Someone let you down or broke a promise	44 (17.0)	27 (10.4)
Someone tricked, pressured, or took advantage of you	16 (6.2)	15 (5.8)
You were bullied by someone you considered to be a friend, in your family, or at work	27 (10.4)	27 (10.4)
You felt like a burden on others	143 (55.2)	38 (14.7)
You were unable to tell anyone how you were feeling	165 (63.7)	40 (15.2)
You were isolated or alone more than you wanted to be	113 (43.6)	38 (14.7)
You lost a person or pet that is important to you	13 (5.0)	25 (9.7)
Your therapist was unavailable	17 (6.6)	15 (5.8)
You had a therapy session before you self-harmed	23 (8.9)	23 (8.9)
You had a therapy session scheduled for later in the day (after you self-harmed)	15 (5.8)	7 (2.7)
You tried to seek help, and this was unsuccessful	50 (19.3)	27 (10.4)
You tried to seek support, and your needs were not met	72 (27.8)	42 (16.2)
You experienced discrimination when trying to seek help or support	29 (11.2)	32 (12.4)
You had financial problems	30 (11.6)	33 (12.7)
You were fired from or left a job	3 (1.2)	14 (5.4)
Disciplinary action was taken against you at work	5 (1.9)	13 (5.0)

You were signed off from work due to physical or mental health reasons	13 (5.0)	22 (8.5)
You were temporarily or permanently excluded from school/ college/ university	2 (0.8)	8 (3.1)
You lost custody of your child(ren) through court proceedings	-	2 (0.8)
Your child(ren) were referred to social services or subject to a child protection investigation due to concerns about your ability to care for them	1 (0.4)	4 (1.5)
You were arrested or cautioned by the police	3 (1.2)	4 (1.5)
You were charged with a criminal offence	-	2 (0.8)
You knew of someone else attempting suicide or harming themselves	9 (3.5)	18 (6.9)
You saw things that you could use to harm yourself or attempt suicide with	53 (20.5)	25 (9.7)
You talked to someone about sexual/ physical/ emotional abuse	28 (10.8)	32 (12.4)
You were sexually/ physically/ emotionally abused	18 (6.9)	40 (15.4)
You experienced a traumatic event or a trigger for previous trauma	93 (35.9)	55 (21.2)
You had flashbacks or nightmares	76 (29.3)	36 (13.9)
You had a dissociative episode	62 (23.9)	29 (11.2)
You had physical health problems or discomfort	82 (31.7)	31 (12.0)
Your mental health was worse than usual	148 (57.1)	61 (23.6)
You did not sleep well, or you did not sleep at all	123 (47.5)	48 (18.5)
You had not eaten/ drank enough, or you did not eat/ drink at all	116 (44.8)	24 (9.3)
You experienced sensory overwhelm	174 (67.2)	25 (9.7)
You experienced social overwhelm	137 (52.9)	43 (16.6)
You had a meltdown or shutdown	162 (62.5)	25 (9.7)
You had a new demand that you were unable to meet	86 (33.2)	38 (14.7)
You could not solve a problem you faced	125 (48.3)	38 (14.7)
Your routine was disrupted	111 (42.9)	38 (14.7)
You tried to get (or continue) something you wanted but couldn't	50 (19.3)	25 (9.7)
Other	25 (6.9)	4 (1.1)
<i>Total antecedents</i>	11.29 (6.73)	4.83 (5.73)
	0 – 32	0 – 32

10a. Do you have any strategies to help you cope when you want to self-harm?

Yes	281 (77.2)
No	83 (22.8)

10c. Would you like to find a way to cope that does not involve self-harm?

Yes	145 (39.8)
Yes – but I am not ready/ comfortable to do that right now	75 (20.6)
I don't know	7 (1.9)
No – I already have strategies that help me cope	25 (6.9)
No	112 (30.8)

5.3.2. *Exploratory Factor Analysis*

Exploratory factor analysis using principal axis factoring with oblimin rotation was performed on the 43 items assessing self-harm functions, as skewness and kurtosis at the item level indicated non-normal distributions. The determinant of the correlation matrix was 8.401, KMO was .831, and Bartlett's test of sphericity was significant ($\chi^2(325) = 4131.398$, $p = .001$), suggesting the data was suitable for factor analysis. Five items with low communalities and 12 that did not load onto any factor were removed over several iterations. Seven factors were extracted based on eigenvalues (1.169) and visual inspection of the scree plot, accounting for 55.53% of the total variance and yielding a final solution with 26 items retained (see Table 15 for final factor loadings). Items were reviewed in line with the literature to define each factor as follows: sensation generation (n items = 4), self-regulation ($n = 4$), interpersonal communication ($n = 4$), emotion relief ($n = 4$), inducing positive states ($n = 3$), ambivalent self-preservation ($n = 3$), and self-punishment ($n = 4$).

5.3.3. *Reliability*

Internal consistency of the overall scale was good ($\alpha = .872$). Each subscale varied from having questionable (ambivalent self-preservation, $\alpha = .697$), acceptable (inducing positive states, $\alpha = .726$; emotion relief, $\alpha = .728$; self-regulation, $\alpha = .753$), to good internal consistency (sensation generation, $\alpha = .843$; self-punishment, $\alpha = .854$; interpersonal communication, $\alpha = .845$), with only ambivalent self-preservation falling marginally below the COSMIN recommended threshold of ≥ 0.70 .

Table 15.*Factor loadings for the final seven-factor solution of self-harm functions.*

Items	Factors						
	Sensation generation	Self-regulation	Interpersonal communication	Emotion relief	Inducing positive states	Ambivalent self-preservation	Self-punishment
to stop feeling numb or dead	.835	.075	-.005	.055	-.003	.018	.097
to feel something, even if it is pain	.776	.071	.019	.118	-.011	.087	.061
to feel my body again	.658	-.221	-.030	-.054	-.109	.015	-.053
to regain a sense of reality	.506	-.237	-.003	-.052	-.060	.028	.025
to ground myself	.196	-.674	.030	-.051	-.074	.039	-.047
to give me something to focus on so that everything else slows down	.196	-.638	.039	.017	-.107	.008	.031
to cope with sensory or social overwhelm	-.008	-.588	.016	.031	.059	.029	.025
to cope with dysregulation	-.117	-.487	-.014	.302	-.040	.026	-.001
to seek care or help from others	.023	-.029	.847	.023	.016	.004	-.062
to get other people to act differently or change	-.042	.043	.767	-.008	.028	-.008	.006
so that others will notice/ understand how desperate I am or how badly I am doing	.077	-.011	.760	.011	.007	.014	-.005
to get back at, hurt, or shock someone	-.101	-.059	.690	-.001	-.097	-.003	.074
because the mental pain is unbearable	.002	.140	.018	.770	-.070	.208	.019
to stop/ block out/ decrease/ cope with uncomfortable feelings	-.092	-.112	.010	.568	.017	-.075	.090
to release the emotional pressure that has built up inside of me	.126	-.088	-.001	.516	-.050	-.032	.054

to change my mental pain into something physical	.285	-.048	.087	.466	.006	.073	.044
because it feels good	-.043	.028	-.111	.077	-.945	.032	-.055
to experience a rush or surge of energy	.075	-.060	.027	.040	-.625	-.058	.016
because I like the way it looks	-.004	.055	.154	-.078	-.487	.019	.055
to avoid attempting suicide	-.015	.000	.041	.023	.011	.894	-.066
so that I do not hurt myself in other ways	-.009	-.198	-.047	-.062	-.049	.524	.092
because I do not care if I live or die	.081	.131	.034	.080	.032	.510	.102
to stop/ block out/ decrease/ cope with feelings of self-hatred or disgust	-.084	-.076	-.020	-.016	.021	-.014	.899
to stop/ block out/ decrease/ cope with feeling worthless	-.021	.037	-.022	.076	.020	-.018	.899
to stop/ block out/ decrease/ cope with feeling like a burden	.111	.047	.003	.003	-.001	.005	.738
to punish myself	.049	.012	.058	-.008	-.054	.092	.508

In the subsample of participants who completed the SHQ-A at both time points ($n = 82$), items assessed for test-retest reliability also demonstrated high agreement in line with COSMIN (≥ 0.70). The mean number of weeks between completing SHQ-A at time points one and two was 2.57 ($SD = 1.14$). For continuous measures, the ICC was 0.875 (95% CI [0.806 - 0.919]) for total lifetime behaviours ($F(81,81) = 8.028$, $p = .001$), 0.925 [0.884 - 0.952] for total body areas ($F(81,81) = 13.271$, $p = .001$), and 0.922 [0.871 - 0.951] for the functions total ($F(81,81) = 13.903$, $p = .001$). For nominal variables, Cohen's Kappa was .710 ($p = .001$) for age of first self-harm episode and .756 ($p = .001$) for having ever self-harmed more severely than expected.

5.3.4. *Validity*

As hypothesised, Spearman's Rank correlations indicated that the total score for the SHQ-A functions was significantly positively associated with the QNSSI functions (≥ 0.50) and the SBQ-ASC, ADAT-A and ASA-A (0.20 – 0.50), supporting convergent validity. There was no significant association with the AQ-10, and the strength of the relationship was consistent with hypothesis 3 (< 0.20), supporting divergent validity. See Table 16 for associations between the SHQ-A and each measure.

Table 16.*Correlations (r^s) between all measure (sub)totals in the main sample.*

	SHQ-A*	QNSSI*	SBQ-ASC	ADAT-A	ASA-A	AQ-10
SHQ-A*	<i>n</i> = 364					
QNSSI*	.838**	<i>n</i> = 328				
SBQ-ASC	.335**	.324**	<i>n</i> = 310			
ADAT-A	.281**	.341**	.358**	<i>n</i> = 321		
ASA-A	.303**	.358**	.337**	.515**	<i>n</i> = 304	
AQ-10	.074	.020	.147**	.085	.281**	<i>n</i> = 362

*Functions subscale

** $p < .001$

QNSSI = Questionnaire for Non-suicidal Self-Injury; SBQ-ASC = Suicidal Behaviours Questionnaire – Autism Spectrum Conditions; ADAT-A = Autistic Depression Assessment Tool – Adult ; ASA-A = Anxiety Scale for Autism – Adults ; AQ-10 = Autism Quotient – 10

Shapiro-Wilk ($p < .001$) and visual inspection of the Q-Q plot revealed significant deviations from normality in the difference scores for relevance of the SHQ-A vs existing self-harm assessment tools. A Wilcoxon signed-rank test showed a statistically significant median difference between the SHQ-A ($Mdn = 8$, $IQR = 3$) and existing self-harm assessment tools ($Mdn = 7$, $IQR = 3$) in terms of overall relevance ($z = -7.86$, $p < .001$, $n = 310$). Specifically, 85.5% of participants either rated the SHQ-A as more relevant ($n = 144$) or just as relevant as the existing tools ($n = 121$), compared to 13.5% that rated the existing tools as more relevant ($n = 42$). McNemar's test also indicated a significant difference in the proportion of participants who rated the SHQ-A vs existing self-harm assessment tools as clear ($\chi^2(1) = 8.80$, $p = .003$, $n = 311$). While most participants rated both tools as clear (78.0%, $n = 242$), a significantly higher proportion rated only the existing tools as clear (12.6%, $n = 39$) compared to those who rated only the SHQ-A as clear (5.2%, $n = 16$). However, the SHQ-A met the recommended consensus threshold for both clarity (85.5%) and relevance (83.2%).

5.4. Discussion

The current study tested the measurement properties of the SHQ-A, a new self-harm assessment tool developed with and for autistic adults. Using a well-powered international community sample of autistic and possibly autistic adults with lived experience of self-harm, preliminary evidence was found to support a range of measurement properties. Structural validity and internal consistency were demonstrated for the functions of self-harm subscale, which was supported as a unidimensional construct through an exploratory factor analysis indicating a seven-factor structure. The subscale also exhibited convergent validity with existing self-harm assessment tools and measures of psychological distress (i.e., QNSSI, SBQ-ASC, ADAT-A, ASA-A), as well as divergent validity with autistic traits (i.e., AQ-10). Test-retest reliability was established for items less likely to exhibit real change over time (i.e., total lifetime behaviours, total body areas, total function scores, age of first self-harm, and self-harming more severely than expected). Moreover, the SHQ-A was rated as significantly more relevant or just as relevant as existing self-harm assessment tools, and although this was less straightforward concerning clarity, both relevance and clarity met the recommended threshold for consensus (> 80%). Overall, the SHQ-A demonstrates promising measurement properties, reflecting the efforts made to establish content validity, and providing initial support for its utility in research.

Encouragingly, the SHQ-A's initial factor structure aligns with established theoretical models of self-harm and shares similarities with existing self-harm assessment tools. Consistent with the Four-Function Model of self-harm (FFM; Nock & Prinstein, 2004), the function of automatic-negative reinforcement (e.g., to escape, reduce, or distract from unwanted affective states) is represented by the SHQ-A's

factors of emotion relief and self-regulation, and automatic-positive reinforcement (e.g., to induce a desired affective state) by sensation generation and inducing positive states. In contrast, the SHQ-A's interpersonal communication factor appears to only align with the function of social-positive reinforcement (e.g., gaining something from others, such as care or attention), but not negative. Although, other self-harm assessment tools have similarly only identified a single social factor (e.g., Klonsky & Glenn, 2009; Turner et al., 2012; Whitlock et al., 2014). Likewise, the SHQ-A's factors of self-punishment and ambivalent self-preservation reflect those found in other tools, such as self-punishment in the QNSSI (Turner et al., 2012) and self-retribution and deterrence in the NSSI-AT (Whitlock et al., 2014). Moreover, self-punishment is also recognised as an NSSI-specific vulnerability in the integrated theoretical model of self-harm (Nock, 2009). Notably, the factor of self-regulation may be more distinct for autistic individuals. While there are functional similarities in self-harm across autistic and non-autistic populations (Goldfarb et al., 2021; Maddox et al., 2017; Moseley et al., 2019), for autistic individuals, self-harm may extend beyond regulating affective states to include managing things like sensory overwhelm (Marsden et al., 2024; Moseley et al., 2019). Nonetheless, it is important to note that these findings are preliminary, and a confirmatory factor analysis is required to confirm the factor structure before any group comparisons or conclusions can be made.

Despite overall evidence for internal consistency within the SHQ-A function subscale, one factor (ambivalent self-preservation) fell slightly below the COSMIN recommended threshold of $\alpha \geq 0.70$ (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). Since the items in this factor reflect self-harm as an alternative to suicide and a general apathy towards life, these subtle differences may arise from

its conceptual overlap with suicidality, despite both being part of a shared construct. Additionally, although test-retest reliability was supported across relevant items, others (e.g., self-harm frequency, recency) were not analysed due to the dynamic and complex nature of self-harm (Townsend et al., 2016), where real change could occur even within a two-week interval between survey administration. It is also important to note that the sample included participants with both lifetime and recent self-harm. This could influence stability across time points, as behaviours and motivations may be more likely to fluctuate among individuals actively engaging in self-harm (Coppersmith et al., 2021; Witt et al., 2019). Moreover, evidence for construct validity (both convergent and divergent) supported the hypothesised relationships for the SHQ-A functions subscale. Specifically, the subscale demonstrated stronger correlations with constructs capturing psychological distress (suicidality, depression, anxiety) than autistic traits. These findings also align with existing literature indicating that self-harm is associated with increased suicide risk in autistic individuals (Cassidy et al., 2018; Moseley et al., 2020b) and the possible contribution of co-occurring psychiatric conditions (Jokiranta-Olkonien et al., 2021; Kim et al., 2024; Lopez-Arvizu et al., 2025).

5.4.1. Strengths and Limitations

As in Chapters 3-4, a key strength of this study was the involvement of autistic individuals in the development of the SHQ-A. Additionally, most measures included in the online survey had also been developed and validated with and for autistic adults (e.g., SBQ-ASC, ADAT-A, ASA-A). This is particularly important given the lack of understanding surrounding autistic people's mental health and the need to ensure their experiences are accurately represented (Brede et al., 2022; Camm-Crosbie et al., 2019). Another notable strength was the well-powered international sample from

the UK and Australia, enhancing the generalisability of findings across different cultural contexts. However, as in Chapters 3–4, similar limitations with sample representativeness were observed. Participants were predominantly female-identifying, cognitively able (58.8% educated to degree level), and White Caucasian. While the strong representation of autistic females who are often excluded from research (D’Mello et al., 2022) is encouraging, greater efforts are needed to include other underserved groups, such as ethnic minorities and those with co-occurring ID (Bennett & Goodall, 2022).

Furthermore, the decision not to counterbalance measures in the online survey and to inform participants which self-harm tool had been developed for autistic individuals may have introduced limitations. Order effects were evident in the lower completion rates of the SBQ-ASC ($n = 310$), ADAT-A ($n = 321$) and ASA- A ($n = 304$), which were administered consecutively following the SHQ-A ($n = 364$) and the existing tools ($n = 328$). This pattern suggests that fatigue or disengagement may have contributed to higher dropout rates for later measures. Moreover, knowledge about the tool's development may have inadvertently introduced bias (Dillman et al., 2014; Krosnick & Alwin, 1987). For example, participants were more likely to rate existing tools as clear compared to the SHQ-A, which may reflect the perceived credibility of established self-harm assessment tools or the influence of order effects rather than actual clarity. Moreover, the AQ-10 demonstrated poor internal consistency in this study, indicating weak inter-item correlations and a lack of unidimensionality. However, this appears to be a common finding across research (e.g., Bertrams & Shah, 2021; Hudson et al., 2024), where even the original AQ-50 only had acceptable internal consistency (i.e., ≥ 0.70) for one domain (Baron-Cohen et al., 2001). While widely used, the AQ-10 may be less suitable than longer or more

nuanced measures of autistic traits (e.g., Comprehensive Autism Trait Inventory, English et al., 2021; Ritvo Autism Asperger Diagnostic Scale-Revised, Ritvo et al., 2011), potentially contributing to measurement error or affecting associations with other variables. Therefore, findings concerning tool clarity and autistic traits should be interpreted with caution, considering the potential impact of order effects, bias, and the limitations of the AQ-10.

Lastly, it is important to acknowledge how missing data were handled for the measures used to test construct validity of the SHQ-A. In the present study, if missingness was less than 10% and determined to be MCAR, mean item substitution was used, replacing missing values with the mean score for that specific item across all respondents. While this is a pragmatic approach for low levels of missingness, and similar methods have been used in previous research (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021), it is not the most optimal. Specifically, mean substitution can introduce bias or lead to invalid conclusions if missing values are not strictly random (Kang, 2013). Future research should consider more sophisticated imputation methods, such as multiple imputation or Full Information Maximum Likelihood (FIML; Kang, 2013), especially as the SHQ-A progresses beyond early development.

5.4.2. Next Steps

Having established initial structural validity, future research should conduct confirmatory factor analysis to verify the SHQ-A's factor structure and provide empirical support for its use (Brown, 2015). This could involve collecting data from an independent sample of autistic adults with lived experience of self-harm, following COSMIN recommendations for sample size (Mokkink et al., 2018; Prinsen et al.,

2018). To mitigate order effects and bias, the administration of self-harm assessment tools should be counterbalanced and participants blinded to which measures have been developed with and for autistic people. Additionally, incorporating alternative measures of autistic traits may improve reliability and confidence in subsequent associations, while employing more sophisticated methods to handle missing data (e.g., multiple imputation or FIML) will enhance the robustness of statistical analyses (Kang, 2013). Measurement invariance analysis could then be conducted to determine whether the SHQ-A's factor structure remains consistent across subgroups (e.g., gender; Putnick & Bornstein, 2016). Given the limitations of sample representativeness, establishing cross-cultural validity in more diverse or underrepresented groups is also necessary. These steps will help confirm the SHQ-A's internal structure and establish its utility in research for understanding self-harm in autistic adults.

5.5. Conclusion

This chapter presents the first self-harm assessment tool developed and validated with and for autistic adults. The SHQ-A demonstrated evidence to support a range of measurement properties, including content validity, structural validity (exploratory factor structure), internal consistency, test-retest reliability, and construct validity (convergent and divergent). While these findings are promising, further work is needed to confirm the internal structure of the SHQ-A and to extend this to more diverse and representative samples. Nonetheless, the SHQ-A provides a broad and holistic method for understanding self-harm in autism, which, in turn, could facilitate better identification, understanding, and tailored therapeutic approaches for this population.

5.6. Reflexive statement

5.6.1. Sample Size

The main methodological challenge I faced for this chapter was recruiting a large enough sample to test the measurement properties of the SHQ-A. Initially, I aimed to conduct both exploratory and confirmatory factor analysis as consecutive steps. However, best practice guidelines recommend independent samples for each analysis (Knekta et al., 2019). Moreover, to meet the “very good” criteria for structural validity on COSMIN’s risk of bias checklist, seven participants per item are required, amounting to 100 or more in total (Mokkink et al., 2018; Prinsen et al., 2018). Given that the SHQ-A’s original functions subscale contained 43 items, this meant I would need a sample size of at least $n = 301$ for each analysis.

Despite sustained recruitment efforts and multiple strategies, I was only able to secure a sufficient sample for the exploratory factor analysis within the remaining timeframe of my PhD. I now fully appreciate the reality of conducting large-scale quantitative research and how difficult it can be to reach the required numbers. Therefore, while the current findings in the thesis are valuable, I also recognise that these remain preliminary until verified with a confirmatory factor analysis. Therefore, this research provides a strong foundation for further validation studies, and I hope to continue building on this work.

Chapter 6. General Discussion.

vi. Preface

This thesis has detailed the development of a new self-harm assessment tool across four empirical chapters, employing a mixed methods approach. First, Chapter 1 established the background and context, highlighting the urgent need for better tools to assess self-harm in autism and outlining the overall research aims. Chapter 2 demonstrated that no assessment tools had been developed or validated to assess self-harm in autistic adults. In Chapter 3, focus groups with autistic adults with lived experience of self-harm and the professionals who support them revealed that existing tools were neither appropriate nor acceptable for autistic people who self-harm. Chapter 4 detailed the cognitive interview process used to refine and co-develop the first self-harm assessment tool for autistic adults – the SHQ-A. Chapter 5 then presented the final empirical study, providing promising preliminary evidence to support the SHQ-A's measurement properties in a community sample of autistic adults with lived experience of self-harm. Chapter 6 will now synthesise and critically reflect on the key findings and novel contributions from each empirical study in relation to the research aims outlined in Chapter 1. This discussion will also evaluate the strengths and limitations of the methodological approaches used throughout the thesis, explore implications for research, clinical practice and policy, and outline directions for future research.

6.1. General Summary

The purpose of this thesis was to develop a new self-harm assessment tool with and for autistic adults, using a combination of methodologies to address the research aims. First, a systematic review using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN; Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018b) was conducted to 1) identify self-harm assessment tools frequently used with some evidence of validity in autistic and general population adults; and 2) evaluate the measurement properties of these tools to determine whether an existing one could be adapted for autistic adults, or a new tool was required. While no self-harm assessment tools had been developed or validated for autistic adults, the review identified three potential self-harm assessment tools with evidence supporting their measurement properties in the general population, warranting further investigation. These included the Non-Suicidal Self-Injury – Assessment Tool (NSSI-AT; Whitlock et al., 2014), Inventory of Statements About Self-injury (ISAS; Klonsky & Glenn, 2009), and the Questionnaire for Non-Suicidal Self-Injury (QNSSI; Turner et al., 2012).

Following the COSMIN review, focus groups were used to explore the perspectives of autistic individuals with lived experience of self-harm and professionals who support them regarding the previously identified self-harm assessment tools (ISAS, NSSI-AT, QNSSI). However, none of the three were considered appropriate or acceptable for use with autistic adults who self-harm, prompting the development of a new autism-specific self-harm assessment tool. Guided by insights from the focus groups, existing self-harm assessment tools, relevant literature and theoretical models of self-harm, an initial version of the tool was created. The tool was then refined through two rounds of cognitive interviews

with autistic adults with lived experience of self-harm. This iterative process ensured the tool's content validity concerning clarity, relevance, and representativeness of items by involving the target population in its development.

Finally, the new tool, the Self-harm Questionnaire – Autism (SHQ-A), was piloted via an online survey. The findings provided preliminary evidence of the tool's measurement properties, including content validity, structural validity (exploratory factor structure), internal consistency, test-retest reliability, and construct validity (convergent and divergent). Table 17 summarises the key findings and novel contributions from each empirical chapter.

Table 17.

Summary of novel contributions and key findings associated with each chapter and study design.

Chapter	Study design	Novel findings and contributions
2	COSMIN – <i>Systematic review</i>	<p>First COSMIN systematic review to identify and evaluate self-harm assessment tools used in autistic and general-population adults.</p> <ul style="list-style-type: none"> - Nine tools were used frequently and had some evidence of validity in general population adults, compared to only one (NSSI-AT) in autistic adults. - Eight tools demonstrated mixed evidence for measurement properties in general population adults, but none had evidence in autistic adults. - The ISAS had the most evidence overall, which was generally favourable, with only the ISAS and QNSSI meeting one of the two COSMIN criteria for recommendation. - While evidence for NSSI-AT was questionable, it also had potential as the only tool used with autistic adults.
3	Focus groups – <i>Qualitative</i>	<p>Explored perspectives of key stakeholders (autistic individuals with lived experience of self-harm and professionals who support them) on existing self-harm assessment tools (ISAS, NSSI-AT, QNSSI).</p> <ul style="list-style-type: none"> - The overarching main theme, “picking the best of a bad bunch”, reflected that none of the three tools were appropriate or acceptable for autistic adults who self-harm.

		<ul style="list-style-type: none"> - Subthemes highlighted some strengths of the tools, but these were outweighed by concerns about cognitive considerations, missing elements, challenges conceptualising self-harm, addressing stigma, the role of co-occurring conditions and duty of care.
4	Cognitive interviews – <i>Qualitative</i>	<p>Developed the first autism-specific self-harm assessment tool (SHQ-A) with and for autistic adults with lived experience of self-harm.</p> <ul style="list-style-type: none"> - Most revisions occurred in the first round of interviews, with fewer and more minor suggestions in the second. - Key issues related to item clarity, relevance, and representativeness were identified and addressed to improve the tool's content validity. - Sources of error included comprehension, retrieval, judgement, and response.
5	Online survey – <i>Quantitative</i>	<p>Validated the SHQ-A in a large international sample of autistic and possibly autistic adults with lived experience of self-harm.</p> <ul style="list-style-type: none"> - The self-harm functions subscale demonstrated evidence for: <ul style="list-style-type: none"> o Structural validity and internal consistency, with a seven-factor structure identified via exploratory factor analysis. o Convergent validity with existing self-harm tools and measures of psychological distress, as well as divergent validity with autistic traits. - Test-retest reliability was established for items less likely to exhibit real change over time. - The SHQ-A met the threshold of consensus for clarity and relevance. However, it was only rated significantly more or equally relevant (but not clearer) compared to existing self-harm tools.

This thesis contributes to the existing literature and emphasises the importance of accessibility and content validity in tool development. The findings presented in Chapter 2 align with previous research that highlights a lack of evidence supporting the measurement properties of various assessment tools in autistic populations (Cassidy et al., 2018b, 2018a; Thoen et al., 2023). Despite COSMIN's emphasis on content validity as the most important and foundational measurement property (Mokkink et al., 2018; Terwee et al., 2018), its thorough consideration or analysis has been neglected in tool development (Cassidy et al., 2018b, 2018a; Newell et al., 2024). This oversight may contribute to weak evidence for

measurement properties in existing self-harm assessment tools, including inconsistencies in their factor structures (see Chapter 2; Newell et al., 2024). In contrast, research has shown that adapting various assessment tools with and for autistic people can improve their measurement properties compared to the original versions (Cassidy, Bradley, et al., 2021; Cassidy, Cogger-Ward, et al., 2021). Therefore, by prioritising content validity and community involvement through Chapters 3-4, this thesis addresses the limitations of existing tools identified in Chapter 2, and demonstrates that new tools (i.e., the SHQ-A) can be effectively developed with and for autistic adults, leading to more accurate representation and measurement of relevant constructs. In doing so, the thesis also highlights the utility of COSMIN, not only as a rigorous method for identifying and evaluating existing assessment tools but also as a valuable framework for developing new tools tailored to the needs of a specific population (Mokkink et al., 2018, 2018; Prinsen et al., 2018).

During the SHQ-A's development, findings from Chapters 3-4 highlighted similar limitations to those noted in previous research regarding the accessibility of measurement instruments for autistic people. These limitations included difficulties with Likert scales, complex language, vague response options, identifying and describing emotions, and absence of autism-specific items (Cassidy, Bradley, et al., 2021; Cassidy, Cogger-Ward, et al., 2021; Nicolaidis et al., 2020). Likewise, Chapters 3-5 provided further support for unique experiences of self-harm in autistic people, such as the conceptual overlap with harmful stimming behaviours and functions of regulating sensory and social overwhelm (Marsden et al., 2024; Moseley et al., 2019). Chapter 5 also established that, much like other tools co-developed with autistic adults (Cassidy, Bradley, et al., 2021; Cassidy, Cogger-Ward, et al.,

2021), addressing these issues and incorporating autism-specific experiences into the SHQ-A contributed positively to its measurement properties. Consequently, the development of the SHQ-A, the first self-harm assessment tool developed with and for autistic adults, fulfilled the main aims of the thesis.

6.2. Strengths and Limitations

While each study's strengths and limitations are discussed in their respective empirical chapters (2-5), it is also important to provide a broader evaluation of the methodological approaches used in this thesis.

6.2.1. *Mixed Methods Approach*

The studies in this thesis followed a rigorous development process to ensure the accessibility of the SHQ-A and to establish support for its measurement properties. Specifically, a mixed methods approach provided a comprehensive understanding of self-harm by combining the strengths of qualitative and quantitative research. This integration captured both lived experiences and statistically validated constructs (Creswell, 2014), which is particularly important in self-harm and suicide research to enhance understanding of these complex and clinically significant topics (Kral et al., 2012). As such, an exploratory sequential procedure was utilised, beginning with qualitative methods followed by quantitative, where each phase expanded or elaborated on the previous one (Creswell, 2014). In line with this approach, the thesis began with a systematic review to identify gaps in the assessment of self-harm for autistic adults (Chapter 2), where qualitative studies then informed the next steps in the research process and development of the SHQ-A (Chapters 3-4), and a quantitative study provided supporting evidence for its measurement properties (Chapter 5). This mixed methods approach ensured that

each research aim in the thesis was addressed using the most appropriate methodology, strengthening the overall robustness of the findings.

6.2.2. Community Involvement

Furthermore, a key strength of the thesis was the co-development of the SHQ-A, ensuring that it was valid, reliable, and appropriate for autistic adults (Nicolaidis et al., 2020). The use of COSMIN complemented this approach because of its emphasis on content validity, which is best achieved through engagement with the target population (Nicolaidis et al., 2020; Terwee et al., 2018). The active involvement of autistic people in the development process strengthened the overall quality of the research and ensured that the SHQ-A was both meaningful and psychometrically sound. However, the participatory element of the thesis could have been improved further by working with a dedicated research advisory group (Taylor-Bower et al., 2024), and including more diverse perspectives at all stages of the research, especially from underserved autistic populations (e.g., ethnic minorities; Bennett & Goodall, 2022). Unfortunately, constraints on time and funding made this impractical within the scope of the current PhD (Pickard et al., 2022). Future research could incorporate an involvement fund to facilitate more meaningful coproduction, ensuring individuals are fairly compensated for their expertise (National Institute for Health and Care Research, 2022) and providing sufficient resources to support those from diverse backgrounds or with varying capacities for engagement (Reynolds et al., 2021).

6.2.3. Online Recruitment and Methods

In addition, the thesis capitalised on online recruitment and research methods, such as social media, video call platforms, and online surveys. Online research has

many benefits, allowing for faster recruitment of large samples from a greater geographical reach with relative ease (Moseson et al., 2020). This was evident in the well-powered international sample recruited for Chapter 5, especially given that no previous studies have evaluated the measurement properties of existing self-harm assessment tools in an autistic sample of any size (see Chapter 2; Newell et al., 2024). Online research may also be particularly beneficial for autistic individuals. Allowing participants to engage in their own environment can help reduce or eliminate issues related to sensory sensitivities and anxiety, while offering greater flexibility for different communication needs and preferences (Nicolaidis et al., 2019; Rubenstein & Furnier, 2021). Additionally, online methods can improve access to research for individuals who may be autistic or self-identify as such but remain undiagnosed due to diagnostic barriers, allowing them to participate in opportunities that might otherwise be unavailable to them (Lewis, 2017; Rutherford et al., 2016).

On the other hand, online methods can include limitations such as the risk of sampling and selection bias (Rødgaard et al., 2022; Rubenstein & Furnier, 2021). As reflected in the samples throughout this thesis, autism research recruiting in part or entirely via social media often results in a higher proportion of females, which is not representative of diagnostic ratios (Loomes et al., 2017). Additionally, these samples tend to include individuals with higher employment rates and education levels, fewer individuals with co-occurring intellectual disability (ID), and later age of diagnosis (Rødgaard et al., 2022). Digital inequality can also further impact autistic individuals from disadvantaged socioeconomic backgrounds, who may be less likely to have access to technologies (Hassrick et al., 2021), as well as those with co-occurring ID, who face greater barriers to its use (Sheehan & Hassiotis, 2017). Consequently, the use of technology can inadvertently perpetuate inequalities experienced by

underserved groups (Bennett & Goodall, 2022). Thus, while online methods offer many benefits, biases related to accessibility can limit the generalisability of findings to the broader autistic population.

Moreover, online autism research has increasingly been targeted by fraudulent participants posing as autistic people, which can compromise the integrity of collected data (French et al., 2024; Pellicano et al., 2024). After encountering such issues within the thesis (see reflexive statement, Chapter 4), recommended measures were taken to deter such participants (French et al., 2024; Pellicano et al., 2024). However, this possibility cannot be entirely ruled out, particularly in the online survey, where anonymity made it more challenging to detect problematic responses.

6.2.4. Sample Representativeness

A broader consideration of sample representativeness and its implications for the generalisability of findings are also needed. The high proportion of autistic females, similar to those in other online-recruited samples, could be considered a strength of this thesis, as it contrasts with their historical underrepresentation in autism research (D'Mello et al., 2022; Rødgaard et al., 2022). This pattern may also reflect trends in the general population, where females are more likely to self-harm (Bresin & Schoenleber, 2015) and report on associated thoughts and behaviours (Fox et al., 2018). However, it also raises important questions. While a greater representation of autistic females is valuable, it remains unclear whether their experiences of self-harm differ qualitatively from those of the general population due to factors such as camouflaging, social pressures, and unmet support needs (Loomes et al., 2017; Mandy & Lai, 2017). Furthermore, despite emerging evidence for sex differences in autistic people who self-harm, current findings are inconclusive

(e.g., Nyrenius et al., 2023; Schwartzman et al., 2024). This issue is further complicated by the high prevalence of gender diversity in the autistic population (Kallitsounaki & Williams, 2023; Mitchell et al., 2022), underscoring the need for further investigation. Consequently, it will be important to confirm whether the SHQ-A measures self-harm consistently across sex and gender while ensuring that future samples are representative of the diversity in the autistic population.

Additionally, the selection bias against autistic adults with co-occurring ID in autism research (Russell et al., 2019) was a limitation of the thesis (see reflexive statement, Chapter 4). One potential challenge to recruitment is gatekeeping, where service providers act as intermediaries with the power to grant or withhold access to this group (Williams, 2019). Overcoming this issue may require more proactive efforts to establish trust and collaboration with gatekeepers, such as working closely with organisations, identifying community partners to assist with recruitment, and building relationships to address questions or concerns about the research (Lennox et al., 2005; Williams, 2019). Alternatively, the research process itself may not have been sufficiently accessible, potentially limiting participation. Further alternative modes of participation could have been provided, such as allowing for proxy reports (e.g., a parent or caregiver reporting on an individual's behalf) or presenting interview questions in an easy-read format (Nicolaidis et al., 2019). Consulting autistic individuals, particularly those with co-occurring ID, could help refine the research design, address recruitment challenges, and improve the generalisability of findings.

6.3. Implications

The development of the SHQ-A in this thesis offers many practical implications for improving the accurate identification, understanding, and treatment of self-harm in autistic individuals, particularly in the contexts of research, clinical practice and policy.

6.3.1. Research

First and foremost, this thesis highlights the importance of collaborating with autistic people across all stages of research. Coproduction should begin with a priority-setting exercise so that autistic voices guide what research is being funded and conducted (Cassidy, Cogger-Ward, Robertson, et al., 2021). For example, exploring what autistic people consider central to understanding and supporting those who self-harm, where existing research has highlighted potential key areas, such as recognising the reason and function, responding appropriately, and challenging problematic assumptions (Moseley et al., 2019). Where resources allow, it is also recommended to work with a representative research advisory group of autistic individuals throughout the lifespan of a project (Taylor-Bower et al., 2024). This approach will ensure that research is meaningful and respectful, along with identifying and addressing barriers to participation.

Moreover, once fully validated, the SHQ-A will provide a valid and reliable tool for identifying and understanding self-harm in autistic people. It could then facilitate comparisons between autistic and non-autistic samples by examining both similarities (e.g., age of onset, methods used, regulation of affective states; Maddox et al., 2017; Moseley et al., 2019) and differences in self-harm (e.g., stimming, meltdowns, sensory and social overwhelm; Marsden et al., 2024). From a theoretical

perspective, these insights could help determine whether existing models of self-harm, such as the Four-Functions Model (Nock & Prinstein, 2004) or Integrated Model (Nock, 2009), apply to autistic populations or require adaptation to account for autism-specific experiences. Likewise, the SHQ-A could contribute to identifying risk markers and factors for self-harm in autism, an area currently lacking in the literature. A valuable starting point would be to extend what is presently known about co-occurring conditions (Kim et al., 2024; Lopez-Arvizu et al., 2025) and sex and gender differences (e.g., Nyrenius et al., 2023; Schwartzman et al., 2024), as well as to explore known risk factors in the general population, such as younger age, sexual or gender minority status, and disadvantaged socioeconomic backgrounds (Kiekens et al., 2023; Liu, 2023; Mitchell et al., 2022). The SHQ-A could also be combined with methods such as the Card sort Task for Self-harm (CaTS; Pelton et al., 2025; Townsend et al., 2016) to explore proximal and distal contributing factors or identify potential targets for intervention. Furthermore, the SHQ-A has the potential to strengthen suicide prevention efforts for autistic individuals by complementing the Suicidal Behaviours Questionnaire – Autism Spectrum Conditions (SBQ-ASC; Cassidy, Bradley, et al., 2021) to improve understanding of the relationship between self-harm and suicidality. Additionally, it could further build on existing research into the Interpersonal Theory of Suicide in autism, which suggests that NSSI may serve as a precursor to suicidal behaviour (Moseley et al., 2020a). Therefore, the SHQ-A has numerous implications for future research through the improved assessment of self-harm in autism.

6.3.2. Clinical Practice

While the SHQ-A requires further validation for use in clinical practice, including testing its predictive value for future adverse events (e.g., progression to

suicidal behaviours), existing self-harm assessment tools have limited utility. Specifically, these tools are neither validated for autistic samples (see Chapter 2; Newell et al., 2024) nor considered suitable for use by professionals (see Chapter 3). In contrast, the SHQ-A has a variety of potential clinical implications, such as improving professionals' understanding of self-harm in autism, supporting psychological formulation to determine the function of behaviours, and contributing to comprehensive risk assessments and treatment planning (Quinlivan et al., 2016). For example, the SHQ-A could help professionals differentiate between self-harm behaviours that serve a regulatory function (e.g., stimming) and those that indicate significant distress or increased suicide risk (Marsden et al., 2024; Moseley et al., 2019). However, many professionals currently lack autism-specific training (Brede et al., 2022), and without this, autistic people may continue to be disbelieved or told that their self-harm and mental health difficulties are inherent to autism (Camm-Crosbie et al., 2019; Marsden et al., 2024). Consequently, successful application of the SHQ-A within clinical settings would require proper training to ensure accurate interpretation of tool responses within the context of autism.

Moreover, the SHQ-A has the potential to serve as an outcome measure for clinical trials and intervention efforts, reducing reliance on multiple, often burdensome, outcome measures that lack theoretical grounding (Owens et al., 2020). It may also help identify key risk factors or markers and highlight areas where tailored support is needed. Currently, few evidence-based interventions for suicidal thoughts and behaviours have been specifically adapted for autistic people, with notable exceptions such as autism-adapted safety plans (Rodgers et al., 2024) and dialectical behaviour therapy (Huntjens, van den Bosch, et al., 2024). The latter has shown efficacy in the general population for self-harm, both with and without suicidal

intent (Calvo et al., 2022; Witt et al., 2021), suggesting a promising avenue of further investigation for NSSI in autistic individuals. Beyond this, the SHQ-A could help identify autism-specific intervention targets. For example, autistic individuals may require additional support in recognising and understanding the emotions associated with their self-harm, particularly if they also have alexithymia (Kinnaird et al., 2019). Similarly, pinpointing causes of sensory and social overwhelm that contribute to self-harm (Marsden et al., 2024; Moseley et al., 2019) could inform strategies to mitigate these challenges and improve coping mechanisms. The same applies to identifying other factors that precede self-harm (Pelton et al., 2025). Consequently, the SHQ-A represents a valuable resource for clinicians and service providers working to reduce self-harm in autistic individuals.

6.3.3. Policy Recommendations

Policy changes would also be necessary for the SHQ-A to have a meaningful impact, such as those introduced by the UK government to address the mental health of autistic individuals. This includes The National Strategy for Autistic Children, Young People, and Adults (2021–2026), which aims to reduce health and care inequalities that autistic people face (Department of Health and Social Care [DHSC], 2021), and the Suicide Prevention Strategy for England (2023–2028) that recognises autistic people as a priority group (DHSC, 2023). However, such policies must also be expanded to explicitly address self-harm. Moreover, current clinical guidelines for self-harm assessment and intervention do not include autism-specific recommendations (National Institute for Health and Care Excellence [NICE], 2022), leaving a critical gap in care. To ensure effective and accessible self-harm support for autistic individuals, policymakers should invest in targeted funding to:

- Develop evidence-based clinical guidelines that recognise autistic people as an at-risk priority group for self-harm and incorporate autism-specific experiences.
- Standardise the use of validated psychosocial assessment tools adapted for autistic people within clinical practice.
- Support research into the understanding and prevention of self-harm in autism, including longitudinal studies on progression over time and randomised controlled trials of interventions.
- Provide mandatory autism training for professionals working in self-harm, crisis or mental health services.
- Improve pathways between autism and mental health services to ensure timely and coordinated care.

By implementing these recommendations, policymakers can improve self-harm assessment and intervention for autistic individuals, reduce systemic barriers, and ensure that services are tailored to the needs of this population.

6.4. Future Research Directions

6.4.1. Further Validation

As outlined in this discussion and Chapter 5 (also see reflexive statement), research following this thesis should aim to validate the SHQ-A further. First, a confirmatory factor analysis is needed to verify the factor structure from the exploratory factor analysis (Brown, 2015). This will require collecting data from an independent sample in line with best practice and COSMIN guidelines (Knehta et al., 2019; Mokkink et al., 2018; Prinsen et al., 2018). It would also be beneficial to assess measurement invariance to determine whether the factor structure is consistent across subgroups, such as those examined in the validation of the SBQ-

ASC (e.g., formally diagnosed vs self-identifying as autistic, binary vs diverse gender identities; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021), as well as cross-cultural validity across geographic contexts (e.g., the UK and Australia) and in more ethnically diverse or underserved samples (Putnick & Bornstein, 2016). Consequently, these analyses will provide empirical support for the internal structure of the SHQ-A and its utility in future research.

6.4.2. Adaptations for Subgroups

Moreover, the sample involved in the development and preliminary validation of the SHQ-A were autistic adults without co-occurring ID. Further testing is needed to assess its suitability for autistic young people and those with co-occurring ID, particularly given the overlap with self-injurious behaviour in these groups (Minshawi et al., 2014). As autistic people demonstrate a similar age of self-harm onset as the general population (Maddox et al., 2017; Moseley et al., 2019), adolescence may represent a critical period for assessment and intervention (Gandhi et al., 2018; Plener et al., 2015). To be relevant in younger populations, the SHQ-A would require age-appropriate adaptations (Kwan & Rickwood, 2015), possibly accounting for different interpersonal functions or risks of self-harm experienced at this stage of life (e.g., bullying; Myklestad & Straiton, 2021; Park et al., 2020). In addition to the underrepresentation of autistic individuals with co-occurring ID in research (Russell et al., 2019), very few outcome measures are validated for people with ID in general (Kumar et al., 2024). Moreover, discrepancies have been found between proxy (often relied upon in this population) and self-reported health and wellbeing, which raises concerns about accuracy (Scott & Havercamp, 2018). Therefore, to encourage self-reporting among autistic people with co-occurring ID, the SHQ-A may need further

refinement to reduce cognitive demands in item content and layout, as well as provide additional support for completion (Nicolaidis et al., 2019; Schwartz et al., 2018). To address group-specific needs, qualitative research and cognitive interviews with each target population are needed to establish what adaptations are needed and how to implement them.

6.5. Conclusion

This thesis provided a rigorous development process by which the research aims outlined in Chapter 1 were achieved. Beginning with a COSMIN review, Chapter 2 established that no existing self-harm assessment tools had been developed or validated for use with autistic adults but identified several potential candidates for further investigation. Chapter 3 built on this by conducting focus groups with autistic adults who have lived experience of self-harm and professionals who support them, which revealed that existing self-harm assessment tools were not appropriate or acceptable for autistic people who self-harm. As a result, the decision was made to develop a new tool, where Chapter 4 detailed the cognitive interview process to refine and co-develop the SHQ-A with autistic adults with lived experience of self-harm. This was followed by Chapter 5, which provided preliminary evidence in support of the SHQ-A's measurement properties using an online survey with autistic adults with lived experience of self-harm.

Finally, Chapter 6 provided a synthesised discussion of the overall thesis, summarising the research findings and novel contributions to the literature. This chapter also evaluated the strengths and limitations of the overall methodological approaches, focusing on mixed methods, community involvement, online research, and sample representativeness. Implications included ways the SHQ-A could be

used to improve understanding and support for autistic people who self-harm across research and clinical practice, along with policy recommendations to improve impact. Future research directions were also considered in terms of further validation of the SHQ-A, as well as adaptations for autistic youth and those with co-occurring ID.

Ultimately, this thesis demonstrated the importance of evaluating whether existing assessment tools are appropriate and accessible for autistic populations. It also demonstrates how the active involvement of autistic people in tool development and validation can enhance the measurement properties of new instruments. Thus, adopting a similar approach in future research will ensure that assessment tools are aligned with the needs of the communities they aim to serve.

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Appendix A

A1. *Generic hypotheses to evaluate construct validity and responsiveness.*

Generic Hypotheses

- 1 Correlations with (changes in) instruments measuring similar constructs should be ≥ 0.50
 - 2 Correlations with (changes in) instruments measuring related, but dissimilar constructs should be lower, i.e., $0.20-0.50$ ¹
 - 3 Correlations with (changes in) instruments measuring unrelated constructs should be < 0.20
 - 4 Correlations defined under 1, 2, and 3 should differ by a minimum of 0.10
 - 5 Meaningful changes between relevant (sub)groups (e.g., patients with expected high vs low levels of the construct of interest)
 - 6 For responsiveness, AUC should be ≥ 0.70
-

AUC = Area Under the Curve with an external measure of change used as the 'gold standard'.

¹ Changed from 0.30 to 0.20 based on most relationships in the review reflecting this.

A2. Updated criteria for good measurement properties.

Measurement Property	Rating ¹	Criteria
Structural Validity	+	CTT²: EFA: factor loadings table for all items, at least 3 items have factor loadings ≥ 0.4 , and no items that cross load > 0.4 on more than one factor CFA: CFI or TLI or comparable measure > 0.95 OR RMSEA < 0.06 OR SRMR < 0.08 ³ IRT/Rasch: No violation of unidimensionality ⁴ : CFI or TLI or comparable measure > 0.95 OR RMSEA < 0.06 OR SRMR < 0.08 AND no violation of local independence: residual correlations among the items after controlling for the dominant factor < 0.20 OR Q3's < 0.37 AND no violation of monotonicity: adequate looking graphs OR item scalability > 0.30 AND adequate model fit: IRT: $\chi^2 > 0.01$ Rasch: infit and outfit mean squares ≥ 0.5 and ≤ 1.5 OR Z standardized values > -2 and < 2
	?	CTT: Not all information for '+' reported IRT/Rasch: Model fit not reported
	-	Criteria for '+' not met
Internal Consistency	+	At least low evidence ⁵ for sufficient structural validity ⁶ AND Cronbach's alpha(s) ≥ 0.70 for each unidimensional scale or subscale ⁷
	?	Criteria for "At least low evidence ⁵ for sufficient structural validity ⁶ " not met
	-	At least low evidence ⁵ for sufficient structural validity ⁶ AND Cronbach's alpha(s) < 0.70 for each unidimensional scale or subscale ⁷
Reliability	+	ICC or weighted Kappa ≥ 0.70
	?	ICC or weighted Kappa not reported
	-	ICC or weighted Kappa < 0.70
Measurement error	+	SDC or LoA $< \text{MIC}^6$
	?	MIC not defined
	-	SDC or LoA $> \text{MIC}^6$
Hypotheses testing for construct validity	+	The result is in accordance with the hypothesis ⁸
	?	No hypothesis defined (by the review team)

	-	The result is not in accordance with the hypothesis ⁸
Cross-cultural validity\measurement invariance	+	No important differences found between group factors (such as age, gender, language) in multiple group factor analysis OR no important DIF for group factors (McFadden's $R^2 < 0.02$)
	?	No multiple group factor analysis OR DIF analysis performed
	-	Important differences between group factors OR DIF was found
Criterion validity	+	Correlation with gold standard ⁹ ≥ 0.70 OR AUC ≥ 0.70
	?	Not all information for '+' reported
	-	Correlation with gold standard ⁹ < 0.70 OR AUC < 0.70
Responsiveness	+	The result is in accordance with the hypothesis ⁸ OR AUC ≥ 0.70
	?	No hypothesis defined (by the review team)
	-	The result is not in accordance with the hypothesis ⁸ OR AUC < 0.70

The criteria are based on Prinsen et al., (2016) and Terwee et al., (2007).

AUC = area under the curve, CFA = confirmatory factor analysis, CFI = comparative fit index, CTT = classical test theory, DIF = differential item functioning, ICC = intraclass correlation coefficient, IRT = item response theory, LoA = limits of agreement, MIC = minimal important change, RMSEA: Root Mean Square Error of Approximation, SEM = Standard Error of Measurement, SDC = smallest detectable change, SRMR: Standardized Root Mean Residuals, TLI = Tucker-Lewis Index

¹ "+" = sufficient, "-" = insufficient, "?" = indeterminate

² If EFA and CFA/IRT, rating of CFA/IRT was prioritised

³ To rate the quality of the summary score, the factor structures should be equal across studies

⁴ Unidimensionality refers to a factor analysis per subscale, while structural validity refers to a factor analysis of a (multidimensional) patient-reported outcome measure

⁵ As defined by grading the evidence according to the GRADE approach

⁶ This evidence may come from different studies

⁷ The criteria 'Cronbach alpha < 0.95 ' was deleted, as this is relevant in the development phase of a PROM and not when evaluating an existing PROM.

⁸ The results of all studies should be taken together, and it should then be decided if 75% of the results are in accordance with the hypotheses

⁹ Standard gold is not agreed. We estimate standards gold as SITBI, FASM, FAST, SASII or DSHI (based on Faura-Garcia et al., (2021) or DSM/ ICD diagnoses.

Appendix B

B1. Interview Schedule.

Autistic adults:

1. Are the questions for the following self-harm assessment tools **relevant**?
2. Are there any questions **missing** from the following self-harm assessment tools?
3. Are the instructions, questions, and response options **clear and understandable** for the following self-harm assessment tools?
4. Which assessment tool would you be **most** likely to recommend for assessing self-harm in autistic people with or without mild co-occurring intellectual disability?
 - [probe] Why?
5. Which assessment tool would you be **least** likely to recommend for assessing self-harm in autistic people with or without mild co-occurring intellectual disability?
 - [probe] Why?

Professionals:

1. Which assessment tool includes items most **relevant** for assessing self-harm in autistic adults with or without mild-co-occurring intellectual disability?
 - [probe] Which assessment tool includes items most relevant for use in research or clinical contexts?
2. Are there any autism-specific items **missing** from these assessment tools?

3. Would the instructions, items and response options of these assessment tools be **clear and understandable** for autistic adults with or without mild-co-occurring intellectual disability?
4. Which assessment tool would you be **most** likely to recommend for assessing self-harm in autistic adults with or without mild co-occurring intellectual disability?
 - [probe] Why?
5. Which assessment tool would you be **least** likely to recommend for assessing self-harm in autistic adults with or without mild co-occurring intellectual disability?
 - [probe] Why?



Participant Wellbeing Plan



This plan was developed by Dr Sarah Cassidy and Dr Emma Nielsen at the University of Nottingham and Professor Jacqui Rodgers, Dr Jane Goodwin and Lucy Isard at Newcastle University.

The purpose of the plan is to help autistic people and those who support them when taking part in research discussing difficult topics, such as mental health problems and self-harm. This plan has been adapted by Victoria Newell, Dr Sarah Cassidy, Dr Caroline Richards, and Prof Ellen Townsend to support participants in adapting an assessment tool for self-harm.

The current research will require you to think about questions that relate to self-harm. Your wellbeing is our priority. We remind participants to prioritise their own wellbeing and only contribute to the research in ways that feel safe. We will store a copy of this plan on a password protected computer for two weeks after participation.

Your details:

- Name:
- Email address:
- Address where you plan to be when you undertake the task
(**ONLINE ONLY**):

The language that we use to talk about autism:

Do you prefer identity first (e.g., autistic adult) or person-first (e.g., person with autism) language?

Are there any adjustments that we can make to make so that participating in the study is easier for you? For example, do you prefer to speak or type? Would you like to see a copy of the questions in advance? Is there anything else you would like us to know?

What support do you have? For example, do you have friends, relatives, or professional support? Would you like details of professional support organisations?

Please share the details of a trusted person with us. We will only use this information in the case of an emergency.

- Name:
- Relationship to you:
- Phone number:
- Email address:

Would you like to share a copy of this plan with them? Would you like us to let them know the date and time of your research meeting?

Yes / No (delete as appropriate)

How would we know if you are becoming distressed or finding it difficult to participate in the study? For example, some people might become mute or might become fidgety. How is this for you?

How can we best support you if you become distressed or find it difficult to participate in the research? For example, would you like me to talk or stay quiet?

What sort of calming activities do you enjoy? For example, some people like to listen to music or watch a favourite video. What do you like to do to relax?

What do you plan to do after taking part in our study? What do you enjoy doing? We suggest that you plan something positive, relaxing or distracting after the research.

Appendix C

C1. *Self-harm Assessment Tool Version 1.*

This assessment tool will ask about your experiences of self-harm. Self-harm is defined as deliberately poisoning or hurting yourself regardless of the purpose of the behaviour¹³.

We understand the topic of self-harm may be difficult to think or answer questions about. Please note that you can take a break or stop at any point during the survey if you start to feel triggered or at all uncomfortable, and you can skip any questions that you do not want to answer. Web links will also be available on every page and at the end of the survey with contact information for support groups and organisations if you would like to talk to someone.

We appreciate your contribution to this topic, the information you provide will be used to help others who self-harm.

¹³ National Institute for Health and Care Excellence. Self-harm: assessment, management and preventing recurrence. NG225. September 2022. Available from: <https://www.nice.org.uk/guidance/ng225>. Clinical Guideline CG133.

1. Have you ever deliberately hurt yourself?

Deliberately: on purpose, planned.

YES / NO

2. Have you ever deliberately hurt yourself in any of the following ways?

You may not have deliberately hurt yourself in some of these ways. If this is the case, answer “Never” and move onto the next option. If you have ever deliberately hurt yourself in this way AND in the past 3 months, please select both.

	Ever	Past 3 months	Never
Severely scratched or pinched with fingernails or other objects to the point that bleeding occurs, or marks remain on the skin			
Cut wrists, arms, legs, torso, or other areas of the body <i>For example, with razor blades</i>			
Dripped acid onto skin			
Carved words or symbols into the skin			
Ingested a caustic substance(s) or sharp object(s) <i>For example, bleach, cleaning substances, pins</i>			
Bitten yourself to the point that bleeding occurs, or marks remain on the skin			
Tried to break your own bone(s)			
Broke your own bone(s)			
Ripped or torn skin			
Intentionally prevented wounds from healing <i>For example, picking scabs</i>			
Abused any kind of medication or drug <i>This includes over-counter, prescription, illegal etc.</i>			
Burned wrists, hands, arms, legs, torso, or other areas of the body <i>For example, with cigarettes, boiling water</i>			
Engaged in fighting or other aggressive activities with the intention of getting hurt			
Engaged in self-defeating thoughts			
Neglecting basic needs <i>For example, not eating, drinking, or sleeping</i>			

Question 2 continues on the next page.

2. Have you ever deliberately hurt yourself in any of the following ways?

You may not have deliberately hurt yourself in some of these ways. If this is the case, answer “Never” and move onto the next option. If you have ever deliberately hurt yourself in this way AND in the past 3 months, please select both.

	Ever	Past 3 months	Never
Engaged in abusive relationships <i>This includes emotional, sexual, or physical abuse</i>			
Banged or punched <i>objects</i> to the point of bruising or bleeding <i>For example, banging head against a wall</i>			
Punched or banged <i>oneself</i> to the point of bruising or bleeding <i>For example, punching self in the head</i>			
Intentionally ingesting or exposing yourself to something that you are allergic to or that causes an adverse reaction <i>For example, eating gluten if you are intolerant</i>			
Rubbed glass into skin or stuck sharp objects such as needles, pins, and staples into or underneath the skin <i>This does NOT include tattooing, body piercing, or needles used for medication use</i>			
Other <i>Please use the space below to list these if you want to, then select the appropriate box.</i>			

We understand there are many forms of self-harm. The next set of questions refer to ANY way that you have deliberately hurt yourself.

3. How often on average have you deliberately hurt yourself during the past 3 months?

Please tick one box only.

Never	Less than once a month	Once a month	2-3 times a month	Once a week	2-6 times a week	1 or more times a day

4. How old were you the first time you deliberately hurt yourself?

Please give age in years.

Age: _____

5. Have you ever deliberately hurt yourself more severely than you expected?

YES / NO




6. Have you ever deliberately hurt yourself on the following areas of your body?

Please select all that apply.

	YES	NO
Wrists		
Hands		
Arms		
Fingers		
Calves		
Ankles		
Thighs		
Stomach		
Chest		
Back		
Buttocks		
Head		
Feet		
Face		
Lips		
Tongue		
Shoulders		
Neck		
Breast		
Genitals		
Rectum		

7. When I deliberately hurt myself, it is/was...





You may not have experienced some of the following reasons for deliberately hurting yourself. If this is the case, answer "Definitely Disagree" and move onto the next option.

	 Definitely Disagree	 Slightly Disagree	 Slightly Agree	 Definitely Agree
to stop/ block out/ decrease/ cope with uncomfortable feelings. <i>For example, guilt, anger, sadness, anxiety, overwhelm.</i>	1	2	3	4
because the mental pain was unbearable	1	2	3	4
to bring my mood to a comfortable level	1	2	3	4
to release the emotional pressure that has built up inside of me	1	2	3	4
to relieve stress, pressure, or tension	1	2	3	4
to relieve feelings of loneliness or isolation	1	2	3	4
to stop/ block out/ decrease/ cope with feelings of self-hatred/ disgust	1	2	3	4
to stop/ block out/ decrease/ cope with feeling worthless	1	2	3	4
to stop/ block out/ decrease/ cope with feeling like a burden	1	2	3	4
to punish myself	1	2	3	4
because I get the urge and cannot stop it	1	2	3	4
on impulse without planning	1	2	3	4
to regain control over myself or my life	1	2	3	4
to feel my body again	1	2	3	4
to stop feeling numb or dead	1	2	3	4
to feel something, even if it is pain	1	2	3	4
to regain a sense of reality	1	2	3	4
because it feels good	1	2	3	4
because I like the way it looks	1	2	3	4
to experience a rush or surge of energy	1	2	3	4
to get back at, hurt, or shock someone	1	2	3	4

Question 7 continues on the next page.

7. When I deliberately hurt myself, it is/was...

You may not have experienced some of the following reasons for deliberately hurting yourself. If this is the case, answer "Definitely Disagree" and move onto the next option.

	 Definitely Disagree	 Slightly Disagree	 Slightly Agree	 Definitely Agree
to escape from thoughts, memories, feelings, situations, other people, or myself	1	2	3	4
to change my mental pain into something physical	1	2	3	4
to stop/ block out/ decrease/ cope with repetitive/ intrusive thoughts or rumination	1	2	3	4
to stop/ block out/ decrease/ cope with feeling trapped	1	2	3	4
because I could not tell anyone how I'm feeling	1	2	3	4
because I could not think of anything else to do	1	2	3	4
so that I do not hurt myself in other ways	1	2	3	4
to avoid attempting suicide	1	2	3	4
to cope with other harms that I am experiencing which are worse	1	2	3	4
to deal with dysregulation or to ground myself	1	2	3	4
so that others will notice/ understand how desperate I am or how badly I am doing	1	2	3	4
to seek care or help from others	1	2	3	4
to gain admission into a hospital or treatment program	1	2	3	4
to get other people to act differently or change	1	2	3	4
because my friends hurt themselves	1	2	3	4
Other <i>Please use the space below to list these if you want to, then select the appropriate box.</i>	1	2	3	4

Please only answer question 8 if you have deliberately hurt yourself during the past 3 months. If you have not, move on to question 9.

8. Did any of the following events or experiences happen to you in the 24 hours before the most recent occasion when you deliberately hurt yourself?

You may not have experienced some of the following events or experiences in the 24 hours before the most recent occasion you deliberately hurt yourself. If this is the case, answer “No” and move onto the next option.

	YES	NO
You had an argument or conflict with another person		
You tried to spend time with someone but couldn't		
Someone was disappointed with you		
Someone was angry with you, criticized you, or put you down		
Someone let you down or broke a promise		
Someone tricked, pressured, or took advantage of you <i>For example, into breaking the law, giving them money or possessions</i>		
Someone rejected you		
You were bullied by someone you considered to be a friend, in your family, or at work		
You felt like a burden on others		
You were unable to tell anyone how you were feeling		
You lost a person or pet that is important to you (even if temporary loss)		
Your therapist went out of town or took a break from having sessions		
You were isolated or alone more than you wanted to be		
You had financial problems		
You were fired from or left a job		
Disciplinary action was taken against you at work		
You were signed off from work for at least 2 months due physical or mental health reasons		
You lost custody of your child(ren) through court proceedings		
Your child(ren) were referred to social services or subject to a child protection investigation due to concerns about your ability to care for them		
You had physical health problems or discomfort		
Your mental health was worse than usual		

Question 8 continues on the next page.

8. Did any of the following events or experiences happen to you in the 24 hours before the most recent occasion when you deliberately hurt yourself?

You may not have experienced some of the following events or experiences in the 24 hours before the most recent occasion you deliberately hurt yourself. If this is the case, answer “No” and move onto the next option.

	YES	NO
You were temporarily or permanently excluded from school/ college/ university		
You tried to seek help, and this was unsuccessful, or your support needs were not met		
You were arrested or cautioned by the police (not including cautions for minor traffic offences)		
You were charged with a criminal offense (not including speeding or parking fines)		
You had a new demand that you were unable to meet		
You could not solve a problem you faced		
You tried to get (or continue) something you wanted but couldn't		
You knew of someone else attempting suicide or harming themselves		
You saw things that you could use to harm yourself or attempt suicide with		
You talked to someone about sexual/ physical/ emotional abuse		
You were sexually/ physically/ emotionally abused		
You experienced a traumatic event or a trigger for previous trauma		
You had a therapy session before you deliberately hurt yourself		
You had a therapy session scheduled for later in the day (after you deliberately hurt yourself)		
You did not sleep well, or you did not sleep at all		
You had not eaten/ drank enough, or you did not eat/ drink at all		
You experienced sensory or social overwhelm		
You had a meltdown or shutdown		
Other <i>Please use the space below to list these if you want to, then select the appropriate box.</i>		

9a. Do you have any strategies to support yourself when you feel like you want to deliberately hurt yourself?

YES / NO

If your answer to question 9a is YES, move on to question 9b.

If your answer to question 9a is NO, move on to question 9c.

9b. Please use the space below to provide further information on these strategies if you want to.

For example, you might distract yourself with something you enjoy, you might reach out to somebody you trust, or you might have a comfort object (e.g., a fidget cube).

9c. Do you want to find a way to support yourself that does not involve deliberately hurting yourself?

YES / NO

C2. Interview schedule for cognitive interview 1.

Asterisk () and italics highlight optional / follow-up questions depending on observation /answers.*

General questions

Layout

- What was going through your mind / what were you thinking about when you first saw the questionnaire?
 - *Tell me more about what you were thinking about.*
- What do you think about the layout of the questionnaire?
 - **I noticed you were looking here (and here) / were looking confused when you answered this question / paused here / took a long time to answer here. What were you thinking? / What led to that?*
- How difficult / easy was it to make sense the layout when you first looked at the questionnaire?
 - *Why was that?*

Relevance

- How relevant were the questions to you?
 - *Were there any questions you thought were irrelevant?*
 - *Why was that? / Tell me more about that ...*
- Were there any important topics or areas missing?

Language

- What do you think about the language in this questionnaire?
 - *With the questionnaire addressing a tricky topic...*

Specific question probes

1. Have you ever deliberately hurt yourself?

- What does “deliberately hurt yourself” mean to you?
 - *What would you say this question is asking of you? / Can you repeat the question in your own words?*
- Was this question easy or difficult to answer?
 - *Why was that?*

2. Have you ever deliberately hurt yourself in any of the following ways?

- What does “ever” mean to you?
 - *How did you work that out?*
- What does “the past 3 months” mean to you?
 - *How did you work that out?*
- What do you think about the response options for this question?
 - *Were they clear? Relevant? What do you think about the language?*
 - *Are there any in particular that were better or worse (e.g., in terms of clarity, relevance, language)?*
 - *Tell me more about that ...*
 - *What do you think of the “other” option?*
- Are there any response options missing for this question?
- Was this question easy or difficult to answer?
 - *Why was that?*

We understand there are many forms of self-harm. The next set of questions refer to ANY way that you have deliberately hurt yourself.

- What does “ANY way that you have deliberately hurt yourself” mean to you?

- *What would you say this statement is asking of you?*

3. How often on average have you deliberately hurt yourself during the past 3 months?

- What does: less than once a month/ once a month/ 2-3 times a month/ once a week/ 2-6 times a week/ 1 or more times a day, mean to you? (Ask this separately for each item of the scale).
 - *How did you work that out?*
 - *Did you try to count each time you used the scale, or did you make an estimate?*
- How difficult / easy was it to use the scale when answering the questions?
 - *Why was that?*

4. How old were you the first time you deliberately hurt yourself?

- How relevant was this question?
 - *Tell me more about that ...*
- Was this question easy or difficult to answer?
 - *Why was that?*

5. Have you ever intentionally hurt yourself more severely than you expected?

- What does “more severely than expected” mean to you?
 - *What would you say this question is asking of you? / Can you repeat the question in your own words?*
- How relevant was this question?
 - *Tell me more about that ...*
- Was this question easy or difficult to answer?
 - *Why was that?*

6. Have you ever deliberately hurt yourself on the following areas of your body?

- How relevant was this question?
 - *Tell me more about that ...*
- Was this question easy or difficult to answer?
 - *Why was that?*

7. When I deliberately hurt myself, it is/was...

- What do you think about the response options for this question?
 - *Were they clear? Relevant? What do you think about the language?*
 - *Are there any in particular that were better or worse (e.g., in terms of clarity, relevance, language)?*
 - *Tell me more about that ...*
- Are there any response options missing for this question?
- What did you think of the scale?
 - *How difficult / easy was it to use the scale when answering the questions?*
 - *Why was that?*
- Was this question easy or difficult to answer?
 - *Why was that?*
 - *Were the instructions clear? What do the instructions mean to you?*

8. Did any of the following events or experiences happen to you in the 24 hours before the most recent occasion when you deliberately hurt yourself?

- What does “the 24 hours before” mean to you here?

- *What would you say this question is asking of you? / Can you repeat the question in your own words?*
- What does “the most recent occasion” mean to you here?
 - *How did you work that out?*
- What do you think about the response options for this question?
 - *Were they clear? Relevant? What do you think about the language?*
 - *Are there any in particular that were better or worse (e.g., in terms of clarity, relevance, language)?*
 - *Tell me more about that ...*
- Are there any response options missing for this question?
- Was this question easy or difficult to answer?
 - *Why was that?*
 - *Were the instructions clear? What do the instructions mean to you?*

9a. Do you have any strategies to support yourself when you feel like you want to deliberately hurt yourself?

9b. Please use the space below to provide further information on these strategies if you want to.

9c. Do you want to find a way to support yourself that does not involve deliberately hurting yourself?

- What does “strategies to support yourself” mean to you here?
 - *How did you decide if something was a strategy?*
 - *Would you prefer a list of strategies to choose from?*
- How relevant was this question?
 - *Tell me more about that ...*
- Was this question easy or difficult to answer?

General follow-up questions

- Is there anything you would like to add, which wasn't covered in the previous questions?
- Which question do you think is the most important in the questionnaire?
 - *Why was that?*
- Which question was the most difficult to answer in the questionnaire?
 - *Why was that?*

Additional spontaneous prompts if needed

- *What was going through your mind when you answered this question?*
- *I noticed that you were spending some time with this question – can you tell me what you were thinking about?*
- *I noticed that you hesitated here – what were you thinking about?*
- *Why did you say that? / Can you tell me a bit more about that?*

C3. Self-harm Assessment Tool Version 2.

This assessment tool will ask about your experiences of self-harm. We appreciate that definitions and language used for self-harm are not universally agreed upon, and self-harm can mean very different things to different people. As a guide, NICE (2022) defines self-harm as deliberately poisoning or hurting yourself regardless of the purpose of the behaviour. We ask that you complete this assessment tool in line with your experiences of self-harm.

We also understand the topic of self-harm may be difficult to think or answer questions about. In particular, this tool includes examples of possible self-harm behaviours. If you feel triggered or at all uncomfortable, you can take a break or stop at any point and skip any questions that you do not want to answer. If you would like to talk to someone, web links and contact information will also be available on every page, along with further information on support groups and organisations at the end of the tool.

We appreciate your contribution to this topic, the information you provide will be used to help others who self-harm.

Please note:

Questions will be in bold.

Guidance on how to answer the questions will be in italics.

Important information will be underlined.

Commented [VN1]: We have included extra information to be inclusive and validate diverse experiences of self-harm.

Commented [VN2]: We have included a key to highlight what the different text formatting means.

1. Have you ever self-harmed?

Yes ☐

No ☐

The next question includes examples of possible self-harm behaviours. These may be upsetting to remember or think about.

Are you prepared to continue?

Yes ☐

I would like to skip this question ☐

[If "I would like to skip this question" is selected, go to question 3]

Commented [VN3]: We replaced "deliberately hurt yourself" in questions with "self-harmed" as many did not feel like "deliberately" captured their experiences.

Commented [VN4]: We have included another content warning and the option to skip this question as Q2 was noted to be particularly tricky to think about.

2. Have you **self-harmed** in any of the following ways, either:

- Ever?
- In the past 3 months?

You may not have self-harmed in some of these ways, and not all of these ways will be self-harm for you. If either is the case, answer "Never" and move on to the next option.

	Ever	Past 3 months	Never
Scatched or pinched self with fingernails or other objects			
Cut wrists, arms, legs, torso, or other areas of the body <i>For example, with razor blades</i>			
Carved words or symbols into the skin			
Ripped or torn skin			
Rubbed glass into skin or stuck sharp objects such as needles, pins, and staples into or underneath the skin <i>This does NOT include tattooing, body piercing, or needles used for medication use</i>			
Prevented wounds from healing <i>For example, picking scabs, pulling stitches, opening sores/ulcers</i>			
Dripped acid onto skin or areas of the body			
Burned skin or areas of the body <i>For example, with cigarettes, boiling water</i>			
Bitten self			
Banged or punched objects <i>For example, banging head against a wall</i>			
Punched or banged self <i>For example, punching self in the head</i>			
Tried to break, or broke bone(s)			
Pulled or pulled-out hair <i>This does NOT include trichotillomania</i>			
Ingested a dangerous substance or sharp object(s) <i>For example, bleach, cleaning products, pins</i>			
Abused any kind of medication, drug or alcohol <i>For example, above average use, an over-reliance to function</i>			
Took an overdose of any kind of medication, drug or alcohol <i>For example, a dangerous amount above that of a recommended or prescribed dose</i>			

Question 2a continues on the next page.

Commented [VN5]: We have provided clarification as not all options are in line with NICE guidelines, but can be forms of self-harm for some people.

Commented [VN6]: We removed "If you have ever deliberately hurt yourself in this way AND in the past 3 months, please select both" as this was considered unnecessary.

Commented [VN7]: We removed the threshold on this option to make all options consistent and of equal weighting.

Commented [VN8]: We removed intentionally on this option and expanded on example.

Commented [VN9]: We removed the threshold on this option to make all options consistent and of equal weighting.

Commented [VN10]: We removed the threshold on this option to make all options consistent and of equal weighting.

Commented [VN11]: We removed the threshold on this option to make all options consistent and of equal weighting.

Commented [VN12]: We removed the inconsistent pronouns "your(self)" and combined options.

Commented [VN13]: We added in a suggested missing option and distinguished this as different from trichotillomania.

Commented [VN14]: We changed "caustic" to a more accessible term.

Commented [VN15]: We changed this option to distinguish it from an overdose, and included alcohol.

Commented [VN16]: We added in separate response option for overdose. **Does it need the definition?**

This is a continuation of Question 2.

2. Have you self-harmed in any of the following ways, either:

i. Ever

ii. In the past 3 months?

You may not have self-harmed in some of these ways, and not all of these ways will be self-harm for you. If either is the case, answer "Never" and move on to the next option.

	Ever	Past 3 months	Never
Engaged in risky, impulsive, or self-destructive behaviour(s) For example, driving recklessly, not looking when crossing the road, seeking out or staying in unhealthy relationships			
Engaged in fighting or other aggressive activities with the intention of getting hurt			
Got a tattoo or body piercing For example, because you want to feel something, or you do not care what happens to your body			
Neglecting basic needs For example, knowingly not eating, drinking, or sleeping			
Ingested or exposed self to something that causes an allergic or adverse reaction For example, intentionally eating gluten if you are intolerant			
Other Please use the space below to list these if you want to, then select the appropriate box.			

Commented [VN17]: We have included a sentence to acknowledge question continuations.

Commented [VN18]: We removed the "Engaging in self-defeating thoughts" option as this is not a behaviour.

Commented [VN19]: We added in a suggested missing option.

Commented [VN20]: We removed the option "Engaged in emotionally/ sexually/ physically abusive relationships". We instead provided this example under risky, impulsive or self-destructive behaviour and reconsidered the language used.

Commented [VN21]: We added in a suggested missing option and included an example to distinguish from aesthetic purposes.

Commented [VN22]: We added "intentionally" to example.

We understand there are many forms of self-harm. The next questions refer to ANY way that you have self-harmed.

3. How often on average have you **self-harmed** during the past 3 months?

Please select one box only.

Never	Less than once a month (Very Rarely)	Once a month (Rarely)	2-3 times a month (Occasionally)	Once a week (Sometimes)	2-6 times a week (Frequently)	Once or more a day (Very Frequently)

Commented [VN23]: We moved this sentence to the top of the page so it is less likely to be missed.

Commented [VN25]: We tried to make wording/ numbers more consistent across options, but this was the only one we could change for it to still make sense.

Commented [VN24]: We included verbal alongside numerical options to help with estimations.

4a. How old were you the first time you **self-harmed**?

Chose the most accurate age bracket. Please select one box only.

0 – 10 years old	
11 – 20 years old	
21 – 30 years old	
31 – 40 years old	
41 – 50 years old	
50 + years old	

Commented [VN26]: We have changed the main part of the question to include age brackets so that those who may not remember can still give an estimate.

4b. If you remember how old you were exactly, please give this in years below.

Age: _____

5. Have you ever **self-harmed more severely** than you expected?

For example, if the injury needed medical attention (where it wouldn't normally) or went beyond your usual boundary (i.e., in terms of severity), either accidentally or without meaning to.

Yes ☐

No ☐

Commented [VN27]: We have resolved the contradictory wording by replacing “deliberately hurt yourself” in the question with “self-harmed”.

Commented [VN28]: We have included an example of what “more severely than expected” might mean in the context of this question for additional guidance.

This next question is optional. Our research indicates users find it to be the least relevant question in the tool. Inclusion should be considered on whether it will be useful to the research or clinical context.

Commented [VN29]: We added in a statement that this question is optional.

6. Have you ever self-harmed on the following areas of your body?

Please select all boxes that apply. If you do not remember, leave the box blank.

If your self-harm does not apply to this question, answer "Not applicable" and move on to the next question.

Commented [VN30]: We have provided additional clarification on what to do if someone cannot remember or a behaviour doesn't apply to body areas.





Head	
Face	
Lips	
Tongue	
Neck	
Shoulders	
Arms	
Wrists	
Hands	
Fingers	
Chest	
Breast	
Stomach	
Back	
Buttocks	
Genitals	
Rectum	
Thighs	
Calves	
Ankles	
Feet	
Not applicable	

Commented [VN31]: We have ordered the body parts more logically and we have removed the yes/ no option as it was redundant.

7. When I self-harm, it is...

Please select how much you generally agree with the following statements.

You may not have experienced some of the following reasons for self-harm. If this is the case, answer "Definitely Disagree" and move on to the next option.

	 Definitely Disagree	 Slightly Disagree	 Slightly Agree	 Definitely Agree
to stop/ block out/ decrease/ cope with uncomfortable feelings. For example, guilt, anger, sadness, anxiety, overwhelm.	1	2	3	4
because the mental pain is unbearable	1	2	3	4
to bring my mood to a comfortable level	1	2	3	4
to release the emotional pressure that has built up inside of me	1	2	3	4
to relieve stress, pressure, or tension	1	2	3	4
to relieve frustration	1	2	3	4
to relieve feelings of loneliness or isolation	1	2	3	4
to stop/ block out/ decrease/ cope with feelings of self-hatred or disgust	1	2	3	4
to stop/ block out/ decrease/ cope with feeling worthless	1	2	3	4
to stop/ block out/ decrease/ cope with feeling like a burden	1	2	3	4
to punish myself	1	2	3	4
to stop/ block out/ decrease/ cope with constant, repetitive or uncontrollable thoughts	1	2	3	4
to escape from thoughts, memories, feelings, situations, other people, or myself	1	2	3	4
to stop/ block out/ decrease/ cope with voices or hallucinations	1	2	3	4
to stop/ block out/ decrease/ cope with feeling trapped (either physically or mentally)	1	2	3	4
to regain control over myself or my life	1	2	3	4

Question 7 continues on the next page.

Commented [VN32]: We clarified that this requires agreement on "how much" of a reason for each response option.

Commented [VN33]: We changed the visual scale from jugs to faces as a better representation for levels of agreement.

Commented [VN34]: We added in a suggested missing option.

Commented [VN35]: We made the language used in this option more accessible.

Commented [VN36]: We added in a suggested missing option.





Commented [VN37]: We added additional clarification to cover physical entrapment.

This is a continuation of Question 7.

7. When I self-harm, it is...

Please select how much you generally agree with the following statements.

You may not have experienced some of the following reasons for self-harm. If this is the case, answer "Definitely Disagree" and move on to the next option.

	 Definitely Disagree	 Slightly Disagree	 Slightly Agree	 Definitely Agree
to cope with dysregulation For example, feeling overwhelmed and unable to manage or control reactions	1	2	3	4
to ground myself For example, by focusing on the physical world rather than emotions or feelings	1	2	3	4
to cope with sensory or social overwhelm	1	2	3	4
to give me something to focus on so that everything else slows down	1	2	3	4
to feel my body again	1	2	3	4
to stop feeling numb or dead	1	2	3	4
to feel something, even if it is pain	1	2	3	4
to change my mental pain into something physical	1	2	3	4
to regain a sense of reality	1	2	3	4
on impulse without planning	1	2	3	4
because I had access to the means or an opportunity to	1	2	3	4
to experience a rush or surge of energy	1	2	3	4
because it feels good	1	2	3	4
because I like the way it looks	1	2	3	4
because I cannot tell anyone how I'm feeling	1	2	3	4
because I cannot think of anything else to do	1	2	3	4
because I feel helpless	1	2	3	4
so that I do not hurt myself in other ways	1	2	3	4

Question 7 continues on the next page.

Commented [VN38]: We have included a sentence to acknowledge question continuations.

Commented [VN39]: We separated options into two and added an example to aid understanding.

Commented [VN40]: We separated options into two and added an example to aid understanding.

Commented [VN41]: We added in a suggested missing option.

Commented [VN42]: We added in a suggested missing option.

Commented [VN43]: We added in a suggested missing option.





Commented [VN44]: We added in a suggested missing option.

This is a continuation of Question 7.

7. When I self-harm, it is...

Please select how much you generally agree with the following statements.

You may not have experienced some of the following reasons for self-harm. If this is the case, answer "Definitely Disagree" and move on to the next option.

	 Definitely Disagree	 Slightly Disagree	 Slightly Agree	 Definitely Agree
because I do not care if I live or die	1	2	3	4
to avoid attempting suicide	1	2	3	4
to cope with other harms I am experiencing that are worse For example, abuse	1	2	3	4
so that others will notice/ understand how desperate I am or how badly I am doing	1	2	3	4
to get back at, hurt, or shock someone	1	2	3	4
to seek care or help from others	1	2	3	4
to gain admission into a hospital or treatment program	1	2	3	4
to get other people to act differently or change	1	2	3	4
because my friends hurt themselves	1	2	3	4
Other Please use the space below to list these if you want to, then select the appropriate box.	1	2	3	4

Commented [VN45]: We added in a suggested missing option.

Commented [VN46]: We added example to aid understanding of this option.

Please only answer question 8 if you have self-harmed in ANY way during the past 3 months. If you have not, move on to question 9.

8. Did any of the following events or experiences contribute to the most recent occasion you self-harmed, either:

i. in the 24 hours before the self-harm?

ii. more than 24 hours before the self-harm?

You may not have experienced some of the following events or experiences. If this is the case, answer "No" and move on to the next option.

	More than 24 hours before	24 hours before	No
You had an argument or conflict with someone <i>This also includes if it was resolved</i>			
You tried to spend time with someone but couldn't			
Someone was OR you felt like someone was disappointed with you			
Someone was OR you felt like someone was angry with you, criticized you, or put you down			
Someone rejected you OR you felt like someone rejected you			
Someone let you down or broke a promise			
Someone tricked, pressured, or took advantage of you <i>For example, into breaking the law, giving them money or possessions</i>			
You were bullied by someone you considered to be a friend, in your family, or at work			
You felt like a burden on others			
You were unable to tell anyone how you were feeling			
You were isolated or alone more than you wanted to be			
You lost a person or pet that is important to you <i>This also includes temporary loss</i>			
Your therapist was unavailable <i>For example, they were on annual leave or unwell</i>			
You had a therapy session before you self-harmed			
You had a therapy session scheduled for later in the day (after you self-harmed)			
You tried to seek help, and this was unsuccessful			

Question 8 continues on the next page.

Commented [VN47]: We have reworded and structured the question to capture events/ experiences which contribute both 24 hours before AND more than 24 hours before. The original timeframe was considered to be too restrictive and would not accurately reflect experiences.

Commented [VN48]: We changed answer format to reflect the question.

Commented [VN49]: We added additional clarification for this option.

Commented [VN50]: We changed this option to include both factual and perceived feelings.

Commented [VN51]: We changed this option to include both factual and perceived feelings.

Commented [VN52]: We changed this option to include both factual and perceived feelings.

Commented [VN53]: We changed the wording of this option and added in an example.

Commented [VN54]: We separated support needs from this item to have its own option.

This is a continuation of Question 8.

8. Did any of the following events or experiences contribute to the most recent occasion you self-harmed, either:

- i. in the 24 hours before the self-harm?
- ii. more than 24 hours before the self-harm?

You may not have experienced some of the following events or experiences. If this is the case, answer "No" and move on to the next option.

	More than 24 hours before	24 hours before	No
You tried to seek support, and your needs were not met			
You experienced discrimination when trying to seek help or support			
You had financial problems			
You were fired from or left a job			
Disciplinary action was taken against you at work			
You were signed off from work for at least 2 months due to physical or mental health reasons			
You were temporarily or permanently excluded from school/ college/ university			
You lost custody of your child(ren) through court proceedings			
Your child(ren) were referred to social services or subject to a child protection investigation due to concerns about your ability to care for them			
You were arrested or cautioned by the police			
You were charged with a criminal offense			
You knew of someone else attempting suicide or harming themselves			
You saw things that you could use to harm yourself or attempt suicide with			
You talked to someone about sexual/ physical/ emotional abuse			
You were sexually/ physically/ emotionally abused			
You experienced a traumatic event or a trigger for previous trauma			

Question 8 continues on the next page.

Commented [VN55]: We have included a sentence to acknowledge question continuations.

Commented [VN56]: We added in a suggested missing option.

Commented [VN57]: We added in a suggested missing option.

Commented [VN58]: We removed exclusion criteria of speeding or parking fines, as this could still cause distress.

Commented [VN59]: We removed exclusion criteria of speeding or parking fines, as this could still cause distress.

This is a continuation of Question 8.

8. Did any of the following events or experiences contribute to the most recent occasion you self-harmed, either:

- i. in the 24 hours before the self-harm?
- ii. more than 24 hours before the self-harm?

You may not have experienced some of the following events or experiences. If this is the case, answer “No” and move on to the next option.

	More than 24 hours before	24 hours before	No
You had flashbacks or nightmares			
You had a dissociative episode			
You had physical health problems or discomfort			
Your mental health was worse than usual			
You did not sleep well, or you did not sleep at all			
You had not eaten/ drank enough, or you did not eat/ drink at all			
You experienced sensory overwhelm			
You experienced social overwhelm			
You had a meltdown or shutdown			
You had a new demand that you were unable to meet			
You could not solve a problem you faced			
Your routine was disrupted			
You tried to get (or continue) something you wanted but couldn't			
Other Please use the space below to list these if you want to, then select the appropriate box.			

Commented [VN60]: We added in a suggested missing option.

Commented [VN61]: We added in a suggested missing option.

Commented [VN62]: We separated sensory and social overwhelm into two options.

Commented [VN63]: We added in a suggested missing option.

9a. Do you have any strategies to help you cope when you want to self-harm?

You might use strategies to stop, distract from, or replace urges to self-harm before the behaviour occurs. Different people will find different strategies useful, and the same strategies may not work every time.

Some examples include (but are not limited to): doing something you enjoy (e.g., listening to music, exercising, spending time with your pet), talking to somebody you trust, writing down what you are feeling, self-soothing (e.g., stimming), or using a comfort object (e.g., soft toy, fidget cube, weighted blanket).

Yes ☐

No ☐

9b. Please use the space below to provide further information on these strategies if you would like to.

9c. Would you like to find a way to cope that does not involve self-harm?

Please remember the current survey is completely anonymous and we cannot offer any follow up. You can use the weblinks if you would like to talk to someone. Contact information for support groups and organisations will also be provided once the survey is complete.

Yes ☐

Yes – but I am not ready/ comfortable to do that right now ☐

I don't know ☐

No ☐

Commented [VN64]: We have changed the wording of the question and “support yourself” is no longer included to avoid implying responsibility is on the person. Branching has also been removed.

Commented [VN65]: We have elaborated on what “strategies” involve.

Commented [VN66]: We have moved this from 9b to 9a and have included more examples of strategies.

Commented [VN67]: We have changed the wording of the question and “support yourself” is no longer included, as in Q9a.

Commented [VN68]: We have provided additional information on the limited follow up we can give in research contexts. This can be removed in a clinical setting to open up further conversations for support (e.g., completing a safety plan).

Commented [VN69]: We have included additional response options to acknowledge that this is not always a straightforward answer.

C4. Self-harm Assessment Tool Version 3 (FINAL).

This assessment tool will ask about your experiences of self-harm. We appreciate that definitions and language used for self-harm are not universally agreed upon, and self-harm can mean very different things to different people. As a guide, NICE (2022) defines self-harm as deliberately poisoning or hurting yourself regardless of the purpose of the behaviour. We ask that you complete this assessment tool in line with your experiences of self-harm.

We also understand the topic of self-harm may be difficult to think or answer questions about. In particular, this tool includes examples of possible self-harm behaviours. If you feel at all uncomfortable, you can take a break or stop at any point and skip any questions that you do not want to answer. If you would like to talk to someone, web links and contact information will also be available on every page, along with further information on support groups and organisations at the end of the tool.

We appreciate your contribution to this topic, the information you provide will be used to help others who self-harm.

Please note:

Questions will be in bold.

Guidance on how to answer the questions will be in italics.

Important information will be underlined.

Commented [VN70]: Removed this sentence as it felt repetitive and unnecessary.

Commented [VN71]: The formatting has been changed to be consistent with the key.

Commented [VN72]: Removed the word “triggered” from the sentence.

Commented [VN73]: We will provide signposting in the footer of every page so it is more easily accessible. We have also included a reminder that further information will be provided at the end of the tool (e.g., in the debrief).

* [Include signposting information here].
Further information on support groups and organisations will be provided at the end of the tool.

1. Have you ever self-harmed?

NICE (2022) defines self-harm as deliberately poisoning or hurting yourself regardless of the purpose of the behaviour. Please complete this assessment tool in line with your experiences of self-harm.

Yes ☐

No ☐

The next question includes examples of possible self-harm behaviours. These may be upsetting to remember or think about.

Are you able to continue?

Yes ☐

I would like to skip this question ☐

[If “I would like to skip this question” is selected, go to question 3a]

Commented [VN74]: We have re-included the definition of self-harm for this question.

2. Have you self-harmed in any of the following ways, either:

iii. **Ever?**

iv. **In the past 3 months?**

You may not have self-harmed in some of these ways, and not all of these ways will be self-harm for you. If **neither** is the case, answer “Never” and move on to the next option.

	Ever	Past 3 months	Never
Scratched or pinched self with fingernails or other objects			
Cut wrists, arms, legs, torso, or other areas of the body <i>For example, with razor blades</i>			
Carved words or symbols into the skin			
Ripped or torn skin			
Rubbed glass into skin or stuck sharp objects such as needles, pins, and staples into or underneath the skin <i>This does NOT include tattooing, body piercing, or needles used for medication use</i>			
Prevented wounds from healing <i>For example, picking scabs, pulling stitches, opening sores/ulcers</i>			
Dripped acid onto skin or areas of the body			
Burned skin or areas of the body <i>For example, with cigarettes, boiling water</i>			
Bitten self			
Banged or punched objects <i>For example, banging head against a wall</i>			
Punched or banged self <i>For example, punching self in the head</i>			
Tried to break, or broke bone(s)			
Pulled or pulled-out hair <i>This is different from trichotillomania (when a person has an intense urge to pull out their hair, and they experience growing tension until they do. After pulling their hair out, they feel a sense of relief)</i>			
Ingested a dangerous substance or sharp object(s) <i>For example, bleach, cleaning products, pins</i>			
Abused any kind of medication, drug or alcohol <i>For example, above average use, an over-reliance to function</i>			

Question 2 continues on the next page.

Commented [VN75]: We provided a brief definition (from www.nhs.uk) instead of a link.

This is a continuation of Question 2.

2. Have you self-harmed in any of the following ways, either:

iii. **Ever**

iv. **In the past 3 months?**

You may not have self-harmed in some of these ways, and not all of these ways will be self-harm for you. If **neither** is the case, answer “Never” and move on to the next option.

	Ever	Past 3 months	Never
Took an overdose of any kind of medication, drug or alcohol <i>For example, an amount above that of a recommended or prescribed dose</i>			
Engaged in risky, impulsive, or self-destructive behaviour(s) <i>For example, driving recklessly, not looking when crossing the road, seeking out or staying in unhealthy relationships</i>			
Engaged in fighting or other aggressive activities with the intention of getting hurt			
Got a tattoo or body piercing <i>For example, because you want to feel something, or you do not care what happens to your body</i>			
Neglecting basic needs <i>For example, knowingly not eating, drinking, or sleeping</i>			
Ingested or exposed self to something that causes an allergic or adverse reaction <i>For example, intentionally eating gluten if you are intolerant</i>			
Other <i>Please use the space below to list these if you want to, then select the appropriate response.</i>			

Commented [VN76]: We removed the word “dangerous”.

Commented [VN77]: We changed ‘box’ to ‘response’ to better reflect that this may not actually be a ‘box’ in the online version.

The next questions refer to ANY of the previously mentioned ways that you have self-harmed.

You can still take a break or stop at any point and skip any questions that you do not want to answer.

3. When was the most recent occasion you self-harmed?

Please select one option only.

More than 2 years ago (Not at all recently)	Between 1 and 2 years ago	Between 6 months and 1 year ago	Between 3 and 6 months ago	Between 1 and 3 months ago	Between 1 week and 1 month ago	Less than 1 week ago (Very recently)
0	1	2	3	4	5	6

4. How often on average have you self-harmed during the past 3 months?

Please select one option only.

Never	Less than once a month (Very Rarely)	Once a month (Rarely)	2-3 times a month (Occasionally)	Once a week (Sometimes)	2-6 times a week (Frequently)	Once or more a day (Very Frequently)
0	1	2	3	4	5	6

5a. How old were you the first time you self-harmed?

Choose the most accurate age bracket. Please select one option only.

0 – 10 years old	
11 – 20 years old	
21 – 30 years old	
31 – 40 years old	
41 – 50 years old	
50 + years old	

5b. If you remember exactly how old you were, please give this in years below:

Age: _____

Commented [VN78]: We have changed the wording and formatting to reflect how to answer the question.

Commented [VN81]: Although we are not including a content warning for the rest of the questions, we have included a reminder that these can still be skipped.

Commented [VN79]: We included a question about recency alongside Q3 to provide a more complete history of an individuals self-harm.

Commented [VN80]: We changed 'box' to 'option' to better reflect that this may not actually be a 'box' in the online version.

Commented [VN82]: We changed 'box' to 'option' to better reflect that this may not actually be a 'box' in the online version.

Commented [VN83]: We changed 'box' to 'option' to better reflect that this may not actually be a 'box' in the online version.

6a. Have you ever self-harmed more severely than you expected?

For example, if the injury needed medical attention (where it wouldn't normally) or went beyond your usual boundary (i.e., in terms of severity), accidentally or without meaning to.

Yes ☐

No ☐

6b. If you would like to provide further information on what happened, please use the space below:

Commented [VN84]: We included an open text option so more context could be provided for this question.

The inclusion of the next question should be considered on whether it will be useful to the research or clinical context.

7. Have you ever self-harmed on the following areas of your body?

Please select all that areas apply. If you do not remember, leave the option blank.

If your self-harm does not apply to this question, answer “Not applicable” and move on to the next question.

Head	
Outside of the facial area	
Face	
Including eyes, nose, lips, ears	
Tongue	
Neck	
Shoulders	
Arms	
Wrists	
Hands	
Fingers	
Chest	
Breasts	
Stomach	
Back	
Buttocks	
Genitals	
Rectum	
Thighs	
Calves	
Ankles	
Feet	

Not applicable ☐

Commented [VN85]: We have shortened this optional statement and will instead expand on this in the guidelines for researchers/ clinicians.

Commented [VN86]: We changed ‘box’ to ‘option’ to better reflect that this may not actually be a ‘box’ in the online version.

Commented [VN87]: We removed lips as an option, and added this under face. We also clarified what counts as head vs face.

Commented [VN88]: We moved this from the table to be its own option, so that it was easier to find.

The next question includes a scale of agreement which can be completed with or without a visual aid aids.





Some people involved in our previous research have said that having a visual aid with the questions makes them easier to answer, whereas others have said it can make the questions more confusing.

Everybody will see the same questions.

How would you like to continue?

			
Definitely Disagree	Slightly Disagree	Slightly Agree	Definitely Agree

I would like to continue with this visual aid ☐

			
Definitely Disagree	Slightly Disagree	Slightly Agree	Definitely Agree

I would like to continue with this visual aid ☐

Definitely Disagree	Slightly Disagree	Slightly Agree	Definitely Agree
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I would like to continue with this visual aid ☐

Definitely Disagree	Slightly Disagree	Slightly Agree	Definitely Agree
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I would like to continue without a visual aid ☐

Commented [VN89]: We have included the option to complete Q7 with or without a selection of visual aids. In paper format, there will be different copies. In the online format, we will branch the question according to the response.

8. When I self-harm, it is...

Please select how much you generally agree with the following statements.

You may not have experienced some of the following reasons for self-harm. If this is the case, answer "Definitely Disagree" and move on to the next option.

	Definitely Disagree	Slightly Disagree	Slightly Agree	Definitely Agree
to stop/ block out/ decrease/ cope with uncomfortable feelings <i>For example, guilt, anger, sadness, anxiety, overwhelm</i>	1	2	3	4
because the mental pain is unbearable	1	2	3	4
to bring my mood to a comfortable level	1	2	3	4
to release the emotional pressure that has built up inside of me	1	2	3	4
to relieve stress, pressure, or tension	1	2	3	4
to relieve frustration	1	2	3	4
to relieve feelings of loneliness or isolation	1	2	3	4
to stop/ block out/ decrease/ cope with feelings of self-hatred or disgust	1	2	3	4
to stop/ block out/ decrease/ cope with feeling worthless	1	2	3	4
to stop/ block out/ decrease/ cope with feeling like a burden	1	2	3	4
to punish myself	1	2	3	4
to stop/ block out/ decrease/ cope with constant, repetitive or uncontrollable thoughts	1	2	3	4
to escape from thoughts, memories, feelings, situations, other people, or myself	1	2	3	4
to stop/ block out/ decrease/ cope with voices or hallucinations	1	2	3	4
to stop/ block out/ decrease/ cope with feeling trapped (either physically or mentally)	1	2	3	4
to regain control over myself or my life	1	2	3	4

Commented [VN90]: The scale will be provided with or without visual aids based on what was indicated.

Question 8 continues on the next page.

This is a continuation of Question 8.

8. When I self-harm, it is...

Please select how much you generally agree with the following statements.

You may not have experienced some of the following reasons for self-harm. If this is the case, answer "Definitely Disagree" and move on to the next option.

	Definitely Disagree	Slightly Disagree	Slightly Agree	Definitely Agree
to cope with dysregulation <i>For example, feeling overwhelmed and unable to manage or control reactions</i>	1	2	3	4
to ground myself <i>For example, by focusing on the physical world rather than emotions or feelings</i>	1	2	3	4
to cope with sensory or social overwhelm	1	2	3	4
to give me something to focus on so that everything else slows down	1	2	3	4
to feel my body again	1	2	3	4
to stop feeling numb or dead	1	2	3	4
to feel something, even if it is pain	1	2	3	4
to change my mental pain into something physical	1	2	3	4
to regain a sense of reality	1	2	3	4
on impulse without planning	1	2	3	4
because I had access to the means or an opportunity to	1	2	3	4
to experience a rush or surge of energy	1	2	3	4
because it feels good	1	2	3	4
because I like the way it looks	1	2	3	4
because I cannot tell anyone how I'm feeling	1	2	3	4
because I cannot think of anything else to do	1	2	3	4
because I feel helpless	1	2	3	4
so that I do not hurt myself in other ways	1	2	3	4

Question 8 continues on the next page.

This is a continuation of Question 8.

8. When I self-harm, it is...

Please select how much you generally agree with the following statements.

You may not have experienced some of the following reasons for self-harm. If this is the case, answer "Definitely Disagree" and move on to the next option.

	Definitely Disagree	Slightly Disagree	Slightly Agree	Definitely Agree
because I do not care if I live or die	1	2	3	4
to avoid attempting suicide	1	2	3	4
to cope with other harms I am experiencing that are worse <i>For example, abuse</i>	1	2	3	4
so that others will notice/ understand how desperate I am or how badly I am doing	1	2	3	4
to get back at, hurt, or shock someone	1	2	3	4
to seek care or help from others	1	2	3	4
to gain admission into a hospital or treatment program	1	2	3	4
to get other people to act differently or change	1	2	3	4
because my friends hurt themselves	1	2	3	4
Other Please use the space below to list these if you want to, then select the appropriate response.	1	2	3	4

Commented [VN91]: We changed 'box' to 'response' to better reflect that this may not actually be a 'box' in the online version.

Please only answer question 9 if you have self-harmed in ANY of the previously mentioned ways in the past 3 months. If you have not, move on to question 10.

Does this apply to you?

Yes ☐

No ☐

[If "No" is selected, go to question 10a]

Commented [VN92]: We have changed the wording and formatting to reflect how this relates to question 9.

9. Did any of the following events or experiences contribute to the most recent occasion you self-harmed, either:

iii. in the 24 hours before the self-harm?

iv. more than 24 hours before the self-harm?

You may not have experienced some of the following events or experiences. If this is the case, answer “No” and move on to the next option.

	More than 24 hours before	24 hours before	No
You had an argument or conflict with someone <i>This also includes if it was resolved</i>			
You tried to spend time with someone but couldn't			
Someone was OR you felt like someone was disappointed with you			
Someone was OR you felt like someone was angry with you, criticized you, or put you down			
Someone rejected you OR you felt like someone rejected you			
Someone let you down or broke a promise			
Someone tricked, pressured, or took advantage of you <i>For example, into breaking the law, giving them money or possessions</i>			
You were bullied by someone you considered to be a friend, in your family, or at work			
You felt like a burden on others			
You were unable to tell anyone how you were feeling			
You were isolated or alone more than you wanted to be			
You lost a person or pet that is important to you <i>This also includes temporary loss</i>			
Your therapist was unavailable <i>For example, they were on annual leave or unwell</i>			
You had a therapy session before you self-harmed			
You had a therapy session scheduled for later in the day (after you self-harmed)			
You tried to seek help, and this was unsuccessful			

Question 9 continues on the next page.

This is a continuation of Question 9.

9. Did any of the following events or experiences contribute to the most recent occasion you self-harmed, either:

- iii. **in the 24 hours before the self-harm?**
- iv. **more than 24 hours before the self-harm?**

You may not have experienced some of the following events or experiences. If this is the case, answer "No" and move on to the next option.

	More than 24 hours before	24 hours before	No
You tried to seek support, and your needs were not met			
You experienced discrimination when trying to seek help or support			
You had financial problems			
You were fired from or left a job			
Disciplinary action was taken against you at work			
You were signed off from work due to physical or mental health reasons			
You were temporarily or permanently excluded from school/ college/ university			
You lost custody of your child(ren) through court proceedings			
Your child(ren) were referred to social services or subject to a child protection investigation due to concerns about your ability to care for them			
You were arrested or cautioned by the police			
You were charged with a criminal offense			
You knew of someone else attempting suicide or harming themselves			
You saw things that you could use to harm yourself or attempt suicide with			
You talked to someone about sexual/ physical/ emotional abuse			
You were sexually/ physically/ emotionally abused			
You experienced a traumatic event or a trigger for previous trauma			

Question 9 continues on the next page.

This is a continuation of Question 9.

9. Did any of the following events or experiences contribute to the most recent occasion you self-harmed, either:

- iii. in the 24 hours before the self-harm?
- iv. more than 24 hours before the self-harm?

You may not have experienced some of the following events or experiences. If this is the case, answer "No" and move on to the next option.

	More than 24 hours before	24 hours before	No
You had flashbacks or nightmares			
You had a dissociative episode			
You had physical health problems or discomfort			
Your mental health was worse than usual			
You did not sleep well, or you did not sleep at all			
You had not eaten/ drank enough, or you did not eat/ drink at all			
You experienced sensory overwhelm			
You experienced social overwhelm			
You had a meltdown or shutdown			
You had a new demand that you were unable to meet			
You could not solve a problem you faced			
Your routine was disrupted			
You tried to get (or continue) something you wanted but couldn't			
Other Please use the space below to list these if you want to, then select the appropriate response.			

Commented [VN93]: We changed 'box' to 'response' to better reflect that this may not actually be a 'box' in the online version.

9a. Do you have any strategies to help you cope when you want to self-harm?

You might use strategies to stop, distract from, or replace urges to self-harm before the behaviour occurs. Different people will find different strategies useful, and the same strategies may not work every time. Some examples include (but are not limited to): doing something you enjoy (e.g., listening to music, exercising, spending time with your pet), talking to somebody you trust, writing down what you are feeling, self-soothing (e.g., stimming), or using a comfort object (e.g., soft toy, fidget cube, weighted blanket).

Yes ☐

No ☐

9b. Please use the space below to provide further information on these strategies if you would like to.

9c. Would you like to find a way to cope that does not involve self-harm?

For research purposes, this will help us understand the needs of individuals who may want strategies to help them cope but who do not currently have any.

Please remember the current survey is completely anonymous, and we cannot offer any follow-up. You can use the weblinks if you would like to talk to someone. Contact information for support groups and organisations will also be provided once the survey is complete.

Yes ☐

Yes – but I am not ready/ comfortable to do that right now ☐

I don't know ☐

No – I already have strategies that help me cope ☐

No ☐

Appendix D

D1. *Existing self-harm assessment tools questions used in the online survey.*

QNSSI

1. Do you deliberately hurt yourself, or have you ever deliberately hurt yourself?

- Yes
- No

7. Which expectations do you generally connect with self-injuring behaviour?

- To decrease tension
- To decrease uncomfortable feelings (e.g. guilt, rage)
- To stop feelings of self-hatred or shame
- to be able to concentrate better
- to bring my mood to a comfortable level
- to experience a sort of rush (kick)
- to experience affection
- to feel my body again
- To feel something, even if it was pain
- To stop feeling numb or dead
- that others see how badly I am doing
- to experience feelings of lust
- to regain a sense of reality
- to punish myself
- to regain control
- To stop bad feelings

- To communicate to or let others know how desperate you are
- To get help
- To gain admission into a hospital or treatment program
- To die
- To get a vacation from having to try so hard
- To get out of doing something
- To shock or impress others
- To prove to yourself that things really were bad
- To give you something, anything to do
- To get other people to act differently or change
- To get back at or hurt someone
- To make others better off
- To get away or escape from: Thoughts and memories/ My feelings/ Other people/ Myself
- To prevent being hurt in a worse way
- To stop feeling angry, frustrated, or enraged
- To demonstrate to others how wrong they are/were
- To relieve anxiety or terror
- To distract yourself from other problems
- To relieve feelings of aloneness, emptiness, or isolation
- To express anger or frustration
- To obtain relief from a terrible state of mind
- To make others understand how desperate you are
- To stop feeling sad

- Other (please specify):

- I have no expectations

8. Did any of the events or experiences on this list happen to you in the 24 hours before your self-injury?

- You had an argument or conflict with another person
- You tried to spend time with someone but couldn't
- Someone was disappointed with you
- Someone was angry with you, criticised you, or put you down
- Someone let you down or broke a promise
- Someone rejected you
- You lost someone important (even if temporary loss)
- Therapist went out of town or took a break from having sessions
- You were isolated or alone more than you wanted to be
- You had financial problems
- You lost a job
- You had health problems or physical discomfort
- You had a new demand 13a _____.
- You tried to get (or continue) something you wanted but couldn't
- You heard of someone else attempting suicide or harming themselves
- You saw things that you could use to harm yourself or attempt suicide with
- You talked to someone about sexual abuse or rape
- You talked with your therapist about sexual abuse or rape
- You had a therapy session before your self-injury/suicide attempt (on the same day)

- You had a therapy session scheduled for later in the day (after self-injury/suicide attempt)
- Other important negative events happened which could have triggered your parasuicide

NSSI-AT

2a. Have you ever done any of the following with the purpose of intentionally hurting yourself?

- Severely scratched or pinched with fingernails or other objects to the point that bleeding occurs, or marks remain on the skin
- Cut wrists, arms, legs, torso or other areas of the body
- Dripped acid onto skin
- Carved words or symbols into the skin
- Ingested a caustic substance(s) or sharp object(s) (Drano, other cleaning substances, pins, etc.)
- Bitten yourself to the point that bleeding occurs or marks remain on the skin
- Tried to break your own bone(s)
- Broke your own bone(s)
- Ripped or torn skin
- Burned wrists, hands, arms, legs, torso or other areas of the body
- Rubbed glass into skin or stuck sharp objects such as needles, pins, and staples into or underneath the skin (not including tattooing, body piercing, or needles used for medication use)
- Banged or punched objects to the point of bruising or bleeding
- Punched or banged oneself to the point of bruising or bleeding

- Intentionally prevented wounds from healing
- Engaged in fighting or other aggressive activities with the intention of getting hurt

2b. Are there any other ways that you have physically hurt or mutilated your body with the purpose of intentionally hurting yourself?

- Yes (please specify):

- No

3. When was the last time you intentionally hurt yourself in one of the ways listed in the previous question?

- Less than 1 week ago
- Between 1 week and 1 month ago
- Between 1 and 3 months ago
- Between 3 and 6 months ago
- Between 6 months and 1 year ago
- Between 1 and 2 years ago
- More than 2 years ago

4. How old were you the first time you intentionally hurt yourself?

5. Have you ever intentionally hurt yourself more severely than you expected?

- Yes
- No

6. On what areas of your body have you intentionally hurt yourself?

- Wrists

- Hands
 - Arms
 - Fingers
 - Calves or ankles
 - Thighs
 - Stomach or chest
 - Back
 - Buttocks
 - Head
 - Feet
 - Face
 - Lips or tongue
 - Shoulders or neck
 - Breasts
 - Genitals or rectum
 - Other (please specify):
-

ISAS

9. Do/ did you want to stop self-harming?

- Yes
- No