

**DEVELOPING, DELIVERING AND  
EVALUATING STROKE SPECIFIC  
VOCATIONAL REHABILITATION:  
A FEASIBILITY RANDOMISED  
CONTROLLED TRIAL**

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# **Abstract**

## **Background**

Approximately 152,000 people have a stroke in the UK every year, a quarter are working age and only 40% return to work. Vocational rehabilitation (VR) provision is patchy in the UK and has not been evaluated for the stroke population.

## **Aim**

This study aimed to develop, deliver and evaluate stroke specific VR in a feasibility randomised controlled trial (RCT) in one English county.

## **Method**

A qualitative interview study with key stakeholders sought to explore barriers to and unmet needs for support for stroke survivors intending to return to work. The findings, two case studies and an expert panel informed the development of a stroke specific VR intervention. Its potential effectiveness in influencing occupational status at 12 months post baseline was measured in a feasibility RCT. Intervention content was analysed and the stroke survivors and employers who received it were interviewed about its usefulness and acceptability.

## **Results**

18 key stakeholders identified barriers to VR in existing service design and delivery. Stakeholders identified the need for individualised,

responsive, timely and flexible intervention including support for family members and employers.

46 people, with mainly minor and moderate strokes, were recruited to the feasibility trial and 23 randomised to stroke specific VR. Delivery and compliance with intervention was feasible. Only one participant withdrew. Follow-up was feasible at three, six and 12 months post baseline as indicated by an overall response rate of 73.9%.

Twice as many participants returned to work in the intervention group. Data collection on income and benefit status was problematic due to missing data. Secondary measures included quality of life, function, mood and participation.

A proforma was successfully used to record and measure intervention content, which showed that stroke specific VR is an individually tailored complex intervention involving cross sector working.

12 stroke survivors and six employers interviewed following the trial, valued this flexible, individualised intervention which positively influenced return to work experiences and outcomes.

## **Discussion**

Stroke severity influenced participation and a different model may be needed for those with severe stroke and those unable to return to an existing job.

Employer contact was not always possible or desired by the stroke survivor.

Funding, targeting and implementing this type of intervention requires further consideration.

### **Conclusion**

Early intervention can potentially influence job retention rates in people with mild and moderate stroke but a larger trial is needed to demonstrate effect.

# Table of Contents

	Page No.
<b>Chapter 1 Introduction and Literature Review .....</b>	<b>1</b>
1.1 Introduction .....	1
1.2 Background.....	1
1.2.1 The definition and epidemiology of stroke.....	1
1.2.2 The Impact of stroke on work and employment .....	3
1.2.3 Stroke rehabilitation .....	5
1.2.4 Vocational rehabilitation.....	6
1.2.5 Policy drivers – Return to work after stroke.....	6
1.2.6 Vocational rehabilitation, stroke and the ICF.....	11
1.3 Literature review.....	16
1.3.1 What factors influence return to work after stroke? .....	17
1.3.1.1 Impairments and bodily functions and structures ...	18
1.3.1.1.1 <i>Cognitive and language function</i> .....	18
1.3.1.1.2 <i>Emotional functions</i> .....	22
1.3.1.1.3 <i>Neuromuscular and movement related functions</i> .....	24
1.3.1.1.4 <i>Energy levels (fatigue)</i> .....	25
1.3.1.1.5 <i>Stroke location</i> .....	26
1.3.1.2 Activity limitations and participation restriction .....	27
1.3.1.2.1 <i>Functional ability</i> .....	27
1.3.1.3 Environmental factors .....	29
1.3.1.3.1 <i>Support and relationships</i> .....	29
1.3.1.3.2 <i>Services, systems and policies</i> .....	30
1.3.1.4 Personal factors .....	34
1.3.1.4.1 <i>Age</i> .....	34
1.3.1.4.2 <i>Gender</i> .....	35
1.3.1.4.3 <i>Race/ Ethnicity</i> .....	37
1.3.1.4.4 <i>Socioeconomic and educational status</i> .....	37
1.3.1.4.5 <i>Type of job</i> .....	38
1.3.1.4.6 <i>Meaning, motivation and the importance of work</i> .....	39
1.3.1.5. Summary of factors influencing return to work after stroke .....	41
1.3.2 What theory underpins VR for stroke survivors? ....	43

1.3.2.1	ABI rehabilitation with added or integrated VR components .....	43
1.3.2.2	VR models that have been adapted for brain injury .....	45
1.3.2.3	Case coordination / resource facilitation models....	47
1.3.3	What is the evidence for effectiveness of VR interventions to facilitate return to work for stroke survivors? .....	49
1.3.4	What outcome measures are used to evaluate VR for stroke survivors and how effective are they? .....	58
1.4	What does the current literature tell us and what are its limitations? .....	60
1.5	Aims of study.....	67
<b>Chapter 2: A stakeholder interview study to inform intervention development.....</b>		<b>69</b>
2.1	Introduction .....	69
2.2	Aims .....	70
2.3	Research questions .....	71
2.4	Method .....	71
2.4.1	Sampling method .....	72
2.4.2	Instrument.....	74
2.4.3	Ethical Considerations .....	75
2.4.4	Procedure .....	75
2.4.5	Data Analysis.....	76
2.5	Results .....	78
2.5.1	Sample.....	78
2.5.2	Stakeholder interview data analysis.....	79
2.5.3	Research question: What are the barriers to VR? .....	80
2.5.3.1	Theme 1 - Service design, delivery and resources .....	80
2.5.3.2	Theme 2 - Influence of the workplace .....	83
2.5.3.3	Theme 3 - Stroke survivor factors .....	85

2.5.4	Research question: What do key stakeholders require from stroke specific VR to enable successful return to work? .....	87
2.5.4.1	Theme 1 - Service design, delivery and resources .....	87
2.5.4.2	Theme 2 - Influence of the work place .....	89
2.5.4.3	Theme 3 - Stroke survivor factors .....	90
2.6	Discussion.....	91
2.6.1	Interpretation of results .....	91
2.6.2	Limitations of stakeholder interview study.....	98
2.6.2.1	Sampling bias .....	98
2.6.2.2	Time of political and economic change .....	100
2.7	Conclusion .....	101
<b>Chapter 3</b>	<b>Intervention Development and Description .....</b>	<b>102</b>
3.1	Introduction .....	102
3.2	Process of intervention development .....	102
3.3	Evidence used to inform intervention development..	105
3.3.1	Use of existing clinical guidelines.....	105
3.3.2	Use of existing research literature.....	106
3.3.2.1	Liaison with employers.....	106
3.3.2.1	Role of support and vocational focus in rehabilitation.....	107
3.3.3	Summary of findings of qualitative stakeholder interview study which informed intervention development .....	108
3.4	Vocational training and mentorship of the research OT .....	109
3.5	Case study pilots and input of the expert panel.....	111
3.5.1	Feedback on case study pilots from expert panel .....	111
3.5.1.1	Fatigue and sustainability of return to work.....	111
3.5.1.2	Liaison with General Practitioners (GPs) .....	112
3.5.1.3	Liaison with Employers .....	113
3.5.1.4	Intervention .....	113
3.5.1.5	Role of the orthoptist.....	114

3.5.2	Case study post-intervention interview findings ...	114
3.5.2.1	Case study 1 - Thematic analysis .....	115
3.5.2.1.1	<i>Intervention content</i> .....	115
3.5.2.1.2	<i>The value of a phased return</i> .....	116
3.5.2.1.3	<i>Intervention delivery</i> .....	116
3.5.2.1.4	<i>Suggestions for future delivery of intervention</i> .....	116
3.6	Development of a model of early stroke specific VR intervention.....	117
3.7	Intervention description .....	122
3.7.1	Assessment of the individual.....	122
3.7.1.1	Initial interview .....	122
3.7.1.2	Standardised assessment.....	123
3.7.1.3	Observation.....	123
3.7.1.4	Job analysis and worksite assessment .....	124
3.7.2	Goal setting and intervention planning.....	125
3.7.3	Individualised intervention sessions and homework tasks .....	126
3.7.4	Provision of information .....	129
3.7.5	Provision of psychological support.....	130
3.7.6	Liaison with other services and agencies.....	132
3.7.7	Work preparation .....	134
3.7.8	Planning return to work .....	134
3.7.9	Review and monitoring of return to work.....	136
3.7.10	Maintenance of work return and ongoing support .....	136
3.7.11	Gradual withdrawal of the intervention, discharge and evaluation .....	137
3.8	Discussion.....	137
3.9	Limitations .....	142
3.10	Conclusion .....	142
<b>Chapter 4</b>	<b>Feasibility Randomised Controlled Trial .....</b>	<b>143</b>
4.1	Introduction .....	143
4.2	Research question .....	143
4.3	Aims .....	144



4.4	Method .....	144
4.4.1	Design.....	144
4.4.2	Sampling frame.....	145
4.4.3	Recruitment, selection and consent.....	146
4.4.4	Randomisation.....	150
4.4.5	Blinding.....	150
4.4.6	Usual care.....	150
4.4.7	OT led stroke specific VR.....	151
4.4.8	Data collection .....	154
4.4.8.1	Baseline data collection .....	154
4.4.8.2	Follow-up data collection.....	154
4.4.8.3	Primary outcomes .....	155
4.4.8.4	Secondary outcomes .....	156
4.4.8.4	Justification for inclusion of standardised measures used in feasibility RCT.....	157
4.4.8.4.1	<i>Mood – Hospital Anxiety and Depression Scale (HADS).....</i>	157
4.4.8.4.2	<i>Instrumental Activities of Daily Living - The Nottingham Extended Activities of Daily Living Scale.....</i>	157
4.4.8.4.3	<i>EQ-5D .....</i>	158
4.4.8.4.4	<i>Work – Work Limitations Questionnaire (WLQ25).....</i>	159
4.4.8.4.5	<i>Work - Work Productivity and Activity Impairment Instrument (WPAI).....</i>	159
4.4.8.4.6	<i>Participation – Sydney Psychosocial Reintegration Scale (SPRS-2).....</i>	160
4.4.8.4.7	<i>Cognition - Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ).....</i>	161
4.4.8.4.8	<i>Disability – Stroke Impact Scale (SIS) Version 2.0 .....</i>	162
4.4.8.4.9	<i>Stroke Severity - National Institutes of Health Stroke Scale (NIHSS) .....</i>	162
4.4.8.4.10	<i>Stroke Type - Bamford Classification .....</i>	163
4.4.8.4.11	<i>Measurement of confidence about return to work.....</i>	165
4.4.9	Piloting the questionnaire.....	165
4.4.10	Follow-up data collection procedure .....	167
4.4.11	Data analysis .....	168
4.5	Results .....	168
4.5.1	Recruitment of participants .....	168

4.5.2	Characteristics of the sample.....	171
4.5.2.1	Demographic characteristics.....	171
4.5.2.2	Occupational characteristics.....	172
4.5.2.3	Health and stroke characteristics.....	173
4.5.3	Feasibility of recruitment.....	175
4.5.4	Spectrum of disease amongst participants.....	177
4.5.5	Feasibility of randomisation.....	177
4.5.6	Feasibility of blinding.....	178
4.5.7	Compliance with intervention.....	178
4.5.8	Services received by intervention and control group participants.....	179
4.5.9	Feasibility of data collection.....	181
4.5.9.1	Questionnaire Completion.....	181
4.5.9.2	Completion of standardised measures.....	183
4.5.9.3	Missing baseline data - Bamford Classification and NIHSS.....	189
4.5.10	Outcome measurement.....	190
4.5.10.1	Primary outcome.....	190
4.5.10.2	Secondary outcome measures.....	193
4.5.10.2.1	<i>HADS</i> .....	193
4.5.10.2.2	<i>EQ-5D</i> .....	195
4.5.10.2.3	<i>NEADL</i> .....	197
4.5.10.2.4	<i>SPRS</i> .....	198
4.5.10.2.5	<i>WPAI</i> .....	200
4.5.10.2.6	<i>WLQ</i> .....	201
4.5.10.3	Non-standardised question outcomes.....	203
4.5.10.3.1	<i>Time taken to return to work</i> .....	203
4.5.10.3.2	<i>Sustainability of Work Return</i> .....	205
4.5.10.3.3	<i>Feasibility of determining sustained return to work</i> .....	207
4.5.10.3.4	<i>Hours of work returned to post-stroke</i> .....	209
4.5.10.3.5	<i>Roles and Responsibilities</i> .....	212
4.5.10.3.6	<i>Workplace accommodations made by employer</i> .....	215
4.5.10.3.7	<i>Type of Work place accommodations made by employer</i> .....	215
4.5.10.3.8	<i>Receipt of benefits post-stroke</i> .....	216
4.5.10.3.9	<i>Income before and after stroke</i> .....	218
4.5.10.3.10	<i>Reasons for returning to work</i> .....	221
4.5.10.3.11	<i>Measuring confidence about work return</i> .....	223
4.6	Feasibility of estimating effect size in order to power a definitive trial.....	226

4.7	Discussion.....	227
4.7.1	Feasibility of recruitment .....	228
4.7.2	Randomisation .....	235
4.7.3	Delivery of intervention .....	237
4.7.4	Usual care as a control .....	237
4.7.5	Feasibility of blinding.....	238
4.7.6	Primary Outcome .....	239
4.7.6.1	Occupational Status.....	239
4.7.6.2	Income status.....	240
4.7.6.3	Benefits status .....	241
4.7.6.4	Characteristics and suitability of standardised secondary outcome measures used .....	241
4.7.6.4.1	<i>Stroke Impact Scale .....</i>	241
4.7.6.4.2	<i>Cognitive screening.....</i>	241
4.7.6.4.3	<i>Euro Qol: EQ-5D .....</i>	242
4.7.6.4.4	<i>Hospital Anxiety and Depression Scale (HADS).....</i>	243
4.7.6.4.5	<i>Nottingham Extended Activities of Daily Living Scale (NEADL).....</i>	243
4.7.6.4.6	<i>Sydney Psychosocial Reintegration Scale – 2 (SPRS-2).....</i>	244
4.7.6.4.7	<i>Work Limitations Questionnaire (WLQ).....</i>	244
4.7.6.4.8	<i>Work Productivity and Activity Impairment Instrument (WPAI).....</i>	245
4.7.6.4.9	<i>Comparison of work measures (WPAI and WLQ).....</i>	246
4.7.6.5	Dealing with missing data .....	247
4.7.6.6	Feasibility and acceptability of non- standardised questions .....	247
4.7.6.6.1	<i>Questions with poor completion rates .....</i>	247
4.7.6.6.2	<i>Sustaining work return.....</i>	249
4.7.6.6.3	<i>Workplace accommodations .....</i>	251
4.7.6.6.4	<i>Confidence about return to work .....</i>	252
4.7.6.6.5	<i>Reasons for returning to work .....</i>	254
4.7.7	Overall questionnaire response rates and loss to follow-up.....	254
4.8	Limitations of feasibility RCT .....	256
4.9	Conclusion and recommendations for definitive trial/ future research .....	258
<b>Chapter 5</b>	<b>Content analysis of stroke specific vocational rehabilitation.....</b>	<b>260</b>

5.1	Introduction .....	260
5.2	Aim .....	262
5.3	The research question .....	262
5.4	Content analysis.....	263
5.4.1	Method.....	263
5.4.2	Sampling method .....	263
5.4.3	Instrument.....	263
5.4.3.1	Development of the proforma.....	263
5.4.4	Procedure .....	265
5.5	Data analysis.....	265
5.6	Results .....	266
5.6.1	Sample.....	266
5.6.2	Content analysis .....	267
5.6.2.1	Delivery of intervention .....	267
5.6.2.1.1	<i>Timing and duration of intervention .....</i>	<i>267</i>
5.6.2.1.2	<i>Distribution of OT Time .....</i>	<i>268</i>
5.6.2.2	Intervention content .....	269
5.6.2.2.1	<i>Work preparation.....</i>	<i>270</i>
5.6.2.2.2	<i>Return to work process .....</i>	<i>271</i>
5.6.2.2.3	<i>Current issues .....</i>	<i>272</i>
5.6.2.2.4	<i>Dealing with psychological issues .....</i>	<i>273</i>
5.6.2.2.5	<i>Mobility.....</i>	<i>274</i>
5.6.2.2.6	<i>Physical intervention .....</i>	<i>275</i>
5.6.2.2.7	<i>Cognitive/ Executive skills .....</i>	<i>276</i>
5.6.2.2.8	<i>Instrumental Activities of Daily Living (IADL).....</i>	<i>277</i>
5.6.2.2.9	<i>Liaison.....</i>	<i>277</i>
5.6.3	Context of intervention .....	279
5.6.3.1	Location of intervention .....	279
5.6.3.2	Method of travelling to work .....	280
5.6.3.2	Use of other services .....	281
5.6.4	Outcomes of intervention .....	282
5.7	Feasibility of using the proforma .....	285
5.8	Discussion.....	287
5.8.1	Use of the proforma .....	287
5.8.2	Development and future use of the proforma.....	290

5.8.3	Content of intervention .....	292
5.8.3.1	Dealing with psychological issues .....	292
5.8.3.2	Employer involvement.....	293
5.8.3.3	Family involvement .....	294
5.8.3.4	Context of intervention .....	295
5.8.3.5	Timing and duration of intervention.....	296
5.8.3.6	Recording outcomes of intervention.....	297
5.8.3.7	Identifying potentially effective components linked with outcomes.....	298
5.8.3.8	Implementing the model of early stroke specific VR OT .....	302
5.9	Limitations and strengths of the study.....	302
5.10	Conclusions.....	303
<b>Chapter 6</b>	<b>The acceptability and usefulness of early stroke specific vocational rehabilitation: views of trial participants and their employers .....</b>	<b>305</b>
6.1	Introduction .....	305
6.2	Aims .....	308
6.3	Research Questions.....	309
6.4	Method .....	309
6.4.1	Sampling Process .....	310
6.4.1.1	Trial Participants .....	310
6.4.1.2	Employers .....	310
6.4.2	Instrument.....	310
6.4.3	Ethical considerations .....	311
6.4.4	Data Collection.....	311
6.4.5	Data Analysis .....	312
6.5	Results .....	312
6.5.1	Sample.....	312
6.5.2	Timing of interviews .....	314
6.5.3	Themes and key findings .....	315
6.5.4	Intervention content .....	316
6.5.4.1	Support .....	316
6.5.4.2	Provision of information and education .....	318

6.5.4.3	Provision of feedback.....	321
6.5.4.4	Communication with the workplace.....	322
6.5.4.5	Perceptions of assessment.....	323
6.5.4.6	The value of a phased return .....	325
6.5.5	Intervention delivery.....	330
6.5.5.1	Continuity of the intervention.....	330
6.5.5.2	Timing of intervention.....	330
6.5.5.3	Duration of intervention .....	331
6.5.5.4	Accessibility of therapist.....	334
6.5.5.5	Therapist's personal qualities and knowledge.....	335
6.5.5.6	Individualised intervention.....	336
6.5.5.7	Integration and liaison with other services .....	336
6.5.6	Intervention outcomes.....	337
6.5.6.1	Influence of intervention on outcomes .....	337
6.5.6.2	Influence of stroke on intervention outcomes.....	340
6.5.7	Intervention future .....	341
6.5.7.1	Who should receive the intervention? .....	341
6.5.7.2	When should intervention be delivered? .....	341
6.5.7.3	Suggested improvements for future intervention..	342
6.5.7.4	Who should fund the intervention?.....	343
6.6	Discussion.....	344
6.6.1	Perceptions of intervention content.....	344
6.6.2	Perception of relationship between therapist and employers .....	347
6.6.3	Perceptions of intervention delivery .....	349
6.6.4	Perceived influence of intervention on outcomes .....	350
6.6.5	Funding and future provision of intervention .....	353
6.7	Implications for clinical practice and broader implementation issues.....	355
6.8	Strengths.....	357
6.9	Limitations.....	358
6.9.1	Sample size .....	358
6.9.2	Researcher bias.....	359
6.10	Conclusion .....	360

<b>Chapter 7</b>	<b>Discussion .....</b>	<b>363</b>
7.1	Introduction and overview of thesis .....	363
7.2	Key findings.....	363
7.3	Discussion of key findings .....	365
7.4	Strengths.....	370
7.5	Limitations.....	372
7.6	Implications for future research.....	377
7.7	Summary of key recommendations.....	386
7.8	Clinical implications.....	388
7.9	Policy implications.....	389
7.10	Conclusion .....	391
<b>References</b>	<b>.....</b>	<b>393</b>

## List of Figures

<b><u>Figures</u></b>	<b>Page</b>
Figure 1. Diagram of ICF .....	12
Figure 2. ICF summarising factors influencing return to work after stroke .....	42
Figure 3. Diagram of intervention development process .....	105
Figure 4. Model of relationship of early stroke specific VR to other services .....	119
Figure 5. Model of Early Stroke Specific VR OT .....	121
Figure 6. Design of the feasibility RCT .....	149
Figure 7. CONSORT flow diagram .....	170
Figure 8. Number of questionnaires returned per participant.....	182
Figure 9. Numbers of participants in intervention and control groups in work at all time points (self-reported).....	190
Figure 10. Primary outcome – full and partial data combined (number of participants from intervention and control groups in work at each time point).....	192
Figure 11. HADS anxiety and depression caseness.....	195
Figure 12. EQ-5D thermometer self-report measure of health status (median scores) .....	196
Figure 13. EQ-5D median scaled scores.....	196
Figure 14. NEADL median scores .....	198
Figure 15. SPRS overall classification.....	199
Figure 16. WLQ percentage productivity loss (median scores).....	203
Figure 17. Time taken to return to work (days) .....	204
Figure 18. Sustainability of return to work.....	205
Figure 19. Hours worked 3 months post-baseline .....	210
Figure 20. Hours worked 6 months post-baseline .....	211
Figure 21. Hours worked 12 months post-baseline .....	211
Figure 22. Roles and responsibilities at 3 months post-baseline .....	213
Figure 23. Roles and responsibilities 6 months post-baseline .....	214



Figure 24.	Roles and responsibilities at 12 months post-baseline .....	214
Figure 25.	Frequency of accommodations made by employer.....	215
Figure 26.	Type of accommodations made by employer .....	216
Figure 27.	Proportion of people claiming benefits at some point during trial (%) .....	216
Figure 28.	Frequency of participants claiming at benefits.....	217
Figure 29.	Average annual income (£) .....	218
Figure 30.	Percentage wage loss post-stroke between intervention and control groups at all time points.....	220
Figure 31.	Reasons for returning to work at 3 months.....	221
Figure 32.	Reasons why people returned to work at 6 months.....	222
Figure 33.	Reasons why people returned to work at 12 months.....	222
Figure 34.	Confidence measure – overall total (median scores).....	223
Figure 35.	Confidence in ability to work (median scores) .....	224
Figure 36.	Confidence in ability to find work (median scores).....	224
Figure 37.	Confidence in ability to manage condition (stroke) in a work environment .....	225
Figure 38.	Confidence that working would not make condition (stroke) worse .....	225
Figure 39.	Overall breakdown of OT time spent .....	269
Figure 40.	Intervention content.....	269
Figure 41.	Work preparation .....	271
Figure 42.	Return to work process.....	272
Figure 43.	Current issues .....	273
Figure 44.	Dealing with psychological issues .....	274
Figure 45.	Mobility .....	275
Figure 46.	Physical Intervention .....	276
Figure 47.	Liaison .....	279
Figure 48.	Method of travelling to work.....	280
Figure 49.	Use of other services.....	282
Figure 50.	Flow diagram of PhD study .....	363

## List of Tables

<b><u>Tables</u></b>	<b>Page</b>
Table 1. Interagency guidelines for vocational assessment and rehabilitation after ABI (Tyerman & Meehan 2004).....	10
Table 2. Formal interviews .....	78
Table 3. Informal interviews.....	79
Table 4. The barriers to VR access and service development.....	87
Table 5. What stakeholders require from stroke specific VR to enable successful return to work .....	91
Table 6. Summary of intervention components .....	152
Table 7. Baseline and follow-up outcome measures .....	156
Table 8. NIHSS scoring system.....	163
Table 9. Bamford Classification.....	164
Table 10. Demographic characteristics .....	171
Table 11. Occupational characteristics.....	172
Table 12. Health and stroke characteristics.....	174
Table 13. Reasons for failure to fit inclusion criteria .....	176
Table 14. Reasons for declining to participate in return to work study .....	177
Table 15. Services received by intervention and control group participants – number, percentage and range .....	180
Table 16. Number of questionnaires returned at each time point.....	183
Table 17. Hospital Anxiety and Depression Scale completion rates .....	184
Table 18. EQ-5D completion rates .....	184
Table 19. NEADL completion rates .....	185
Table 20. Work Productivity and Activity Impairment Instrument completion rates .....	185
Table 21. Sydney Psychosocial Reintegration Scale completion rates .....	186
Table 22. Work Limitations Questionnaire completion rates .....	188

Table 23.	Numbers of participants in intervention and control groups in work at all time points (self-reported).....	190
Table 24.	Primary outcome – full and partial data combined (number of participants from intervention and control groups in work at each time point).....	193
Table 25.	HADS total anxiety scores.....	193
Table 26.	HADS total depression scores.....	194
Table 27.	NEADL scores.....	197
Table 28.	SPRS overall classification.....	200
Table 29.	WPAI scores - overall work impairment percentage.....	201
Table 30.	WLQ productivity loss percentage scores.....	202
Table 31.	Time to return to work (days).....	205
Table 32.	Work status pattern per participant.....	208
Table 33.	Average Annual Income (£).....	219
Table 34.	Percentage wage loss post-stroke between intervention and control groups at all time points.....	220
Table 35.	Baseline characteristics.....	266
Table 36.	Delivery of intervention related to stroke severity.....	268
Table 37.	Overall outcomes for intervention group – number who returned to full time and part time work at some point during the feasibility trial.....	283
Table 38.	Overall outcomes – type of work returned to at some point in the trial.....	284
Table 39.	Overall outcomes at some point in the trial according to stroke severity.....	285
Table 40.	Trial participants interviewed: demographic information.....	313
Table 41.	Employers of trial participants: Demographic information.....	314
Table 42.	Time (days) to interview.....	315
Table 43.	Overarching headings and themes.....	316
Table 44.	Key findings to inform intervention in a definitive trial.....	360
Table 45.	Summary of key findings of each component study.....	364

Table 46.	Summary of key recommendations .....	386
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## List of Appendices

<b><u>Appendices</u></b>	<b>Page</b>
APPENDIX 1: Map of existing services to support stroke survivors back to work in Derbyshire .....	1
APPENDIX 2: Interview schedule for stakeholder interviews .....	2
APPENDIX 3: Thematic map - stakeholder interview study .....	6
APPENDIX 4: Participant interview schedule .....	7
APPENDIX 5: VR training description .....	9
APPENDIX 6: Case study participant intervention presented to expert panel.....	11
APPENDIX 7: The rehabilitation process – original and adapted (Wade, 2005).....	17
APPENDIX 8: Baseline questionnaire booklet.....	18
APPENDIX 9: Content analysis proforma.....	60
APPENDIX 10: Content analysis proforma – explanatory notes .....	62
APPENDIX 11: Employer interview schedule.....	68
APPENDIX 12: Template for trial participant interview data analysis .....	71
APPENDIX 13: Template for employer interview data analysis.....	73
APPENDIX 14: Thematic map - post-trial interview study .....	74
APPENDIX 15: List of publications and presentations arising from this study .....	75

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# **CHAPTER 1 INTRODUCTION AND LITERATURE REVIEW**

## **1.1 Introduction**

This introduction provides an overview of the definition and epidemiology of stroke, the impact of stroke on work and employment, stroke rehabilitation, vocational rehabilitation (VR), policy drivers for return to work after stroke and the International Classification of Functioning Disability and Health (ICF). These topics provide the context for the study and the literature review which follows identifies gaps in the current research and why this study was needed.

## **1.2 Background**

### **1.2.1 The definition and epidemiology of stroke**

The World Health Organization (WHO) defines stroke as 'rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin' (WHO MONICA Project Investigators, 1988). Stroke is the leading cause of disability in Europe (Saka et al., 2009). Over half of all stroke survivors are left with a disability and stroke has a greater disability impact on an individual than any other chronic disease (Stroke Association, 2015). Stroke can cause unilateral paralysis or weakness, sensory loss, vestibular, visual, cognitive, perceptual and speech and language disturbances (Zerwic et al., 2002). It can also result in difficulty swallowing, loss of bladder and bowel control and one in four stroke survivors experience extreme



fatigue (Stroke Association, 2015). A third of stroke survivors become depressed (Hackett et al, 2009).

Approximately 152,000 people have a stroke each year in the UK (Townsend et al., 2012). This figure was calculated using statistics from England and Scotland assuming incidence in England is similar in Wales and Ireland. Stroke is the third most common cause of death, after heart disease and cancer (British Heart Foundation, 2005). Even though the overall stroke incidence has been declining in developed countries, there is evidence that stroke in young adults is on the increase (Sultan & Elkind, 2013). At the same time, prevalence of stroke has increased due to an improvement in stroke survival (Lee et al., 2011) and prognosis in young stroke patients tends to be better than for older people (Sultan & Elkind, 2013). A quarter of strokes in the UK, occur in those under 65 years of age (Daniel et al., 2009).

The economic impact of stroke on society is highlighted by Saka et al. (2009) who estimate costs of £8.9 billion a year in the UK. This includes direct treatment costs of £4 billion which account for 5% of UK NHS costs and productivity losses of £1.5 billion including benefits payments of £841million. Costs are expected to increase due to improved survival and an ageing population and workforce leading to further lost productivity (Arauz, 2013).

### **1.2.2 The Impact of stroke on work and employment**

Given the number of working age people affected by stroke, the impact of stroke on work and employment both at an individual and societal level is of great interest.

Work fulfils basic needs, is important to a persons' financial, psychological and emotional well-being and plays a part in developing self-esteem, social status and a personal sense of achievement, independence, freedom and security (Brusco & Baldwin, 2011).

However, the terms work, employment and vocation are often used interchangeably in the stroke rehabilitation literature and there is considerable variation in whether studies include competitive full time paid employment, part time work, voluntary work, homemaking and being a student in their definition of work.

Two small UK studies were reported in the same paper by Corr and Wilmer (2003) looking at the needs of 26 stroke survivors aged 34-55 years and the support received by six stroke survivors aged 38-62 years in returning to work. They found that returning to work was an important issue for participants. Work was highly valued and perceived as a key to participating in society and yet a gap in service provision in this area was identified.

In a much larger study, McKeivitt et al. (2010) surveyed 1251 stroke survivors in the UK, one to five years post-stroke, to establish their long term needs. They found that 52% reported a reduction in or loss of work activities and 18% reported a loss in income. In a systematic review of

78 studies looking at the social consequences of stroke for working-aged adults, Daniel et al. (2009) found that 77 of these reported data on return to work after stroke. In four studies that reported the prevalence of financial difficulties, this affected between 24% and 33% of the populations studied. Less than 40% of stroke survivors in the UK return to work despite this being a primary goal for many (Stroke Association, 2006). A more recent report by the Stroke Association on the financial impact of stroke (Stroke Association, 2012), which presented the findings of a survey of 2200 stroke survivors and carers across the UK, found that 69% of 25-59 year olds were unable to return to work. This is cited as the most recent UK figure in the State of the Nation Stroke Statistics (Stroke Association, 2015).

A Finnish survey of 46 people under 65 years old four years after stroke or subarachnoid haemorrhage found that not returning to work had a significant negative impact on quality of life (Niemi et al., 1988).

However, the 58 item questionnaire developed in this study was constructed using previous literature and clinical experience and it was not standardised. It covered working conditions as one of four domains (the others being activities at home, family relationships and leisure activities). The authors used the differences in pre-stroke and post-stroke answers and a simple coding system (-1 = deterioration, 0=restoration and 1= improvement) to estimate changes in quality of life, which was not a sophisticated or reliable method of measurement. However, their findings were supported in a more recent postal survey of 141 people in the Netherlands, two to four years after subarachnoid

haemorrhage (Passier et al., 2011). The authors found that work was a major issue for participants and not returning to work was associated with reduced life satisfaction measured using a validated life satisfaction tool (LiSat-9). Half of the respondents were dissatisfied with their work situation and a return to work was strongly associated with satisfaction with life overall.

In the UK the introduction of the Employment (Repeal of Retirement Age Provisions) Regulations (Legislation.gov.uk, 2011) means that employers can no longer discriminate on the grounds of age and the default retirement age of 65 years has been removed. The Office for National Statistics (2013) reported that the number of people in work aged over 65 had reached 1 million for the first time and attributed this to more people staying on at work. The consequence of this is that the incidence of people having a stroke while in employment is increasing

### **1.2.3 Stroke rehabilitation**

Stroke rehabilitation is defined as an interdisciplinary, holistic approach that addresses medical, functional and psychosocial issues (Zorowitz, 1999) and involves a team including a physician, nurses, physiotherapists, occupational therapists (OTs), speech and language therapists, social workers, psychologists, the family and the stroke survivor.

The profile and quality of stroke rehabilitation in the UK has improved over the last 25 years as a result of investment in both services and research. National multidisciplinary guidelines have been developed

and performance is evaluated in the regular National Sentinel Stroke Audits. A coherent policy for the management of stroke patients in the UK has been developed and is supported by well organised specialist services. However, further work is required to increase the level of therapy input in stroke rehabilitation settings and the evidence base for the nature, duration and effectiveness of complex rehabilitation (Kalra & Walker, 2009).

#### **1.2.4 Vocational rehabilitation**

VR is defined as a process whereby those disadvantaged by illness or disability, can be enabled to access, maintain or return to employment (Tyerman & Meehan, 2004). Wadell et al. (2004) defined it as identifying and overcoming health, personal/ psychological and social/ occupational obstacles to recovery and work. So the focus can be work retention and the prevention of people leaving the workforce through drawing up return to work plans for employees that are off sick (TUC, 2002). It can also include accessing employment for the first time or retraining and finding a new job if an individual is unable to return to their previous occupation (Holmes, 2007).

#### **1.2.5 Policy drivers – Return to work after stroke**

The ageing population and rise in retirement age have placed getting people off benefits and back into work high on the UK government agenda (DWP 2004, DWP 2005, Black 2008, DWP 2008, Marmot Review 2010, Black & Frost 2011, DWP 2013, NICE 2013, NHS England 2014, DWP 2015a & 2015b). One of the key objectives proposed by the Marmot Review (2010) was to create fair employment

and good work for all as part of a strategy for reducing health inequalities. The review suggests that one way to achieve this is to enable those who are disadvantaged in the labour market (e.g. with physical and mental health problems) to obtain and retain work. Active management of return to work was also a key recommendation of the NICE guidelines for Stroke Rehabilitation (2013) and recognised in 'The five year forward view' (NHS England, 2014), which states that the NHS will help develop and support workplace incentives to reduce sickness-related unemployment.

In 2008, Black called for an integrated approach to working-age health and for the NHS to have a role in ensuring that people with health conditions, who have the capacity to work, are afforded the opportunity to do so. In its response, the Government said it would do everything it could to support people with health conditions to remain in or return to work (DWP 2008). The Welfare Reform Act (Legislation.gov.uk, 2007) had already changed Incapacity Benefit into Employment and Support Allowance with the emphasis on moving people off benefits and into employment. Approximately 2.7 million people were estimated to be claiming Incapacity Benefit prior to this. Fit notes replaced the traditional sick note, providing opportunities for general practitioners to make recommendations about a phased return to work, in line with Dame Black's recommendations. However, a recent survey of participating organisations who collect fit notes in one region of England (n=498) found that they have not achieved their potential in helping employees return to work. This was largely because the way they are completed

and their content did not appear to meet the needs of employers (Coole et al., 2015). Employers in this study found fit notes that were legible and included information on the health condition and its' impact on the employee's ability to work together with clear advice on return to work useful. Funding from the Department of Health and Department for Work and Pensions for 'Fit for Work' pilot schemes, recommended by Black (2008) and they were extended until 2013. A final evaluation report on these schemes (2010 – 2013) was recently published (DWP, 2015a). These schemes provide personalized back-to-work support for people off sick from work on health grounds but focus on those conditions which consume the greatest proportion of the benefits bill, i.e. musculoskeletal and mild to moderate mental health conditions, rather than more complex neurological disability. In 2011, Black and Frost completed an independent review of sickness absence recommending that the government should fund an Independent Assessment Service (IAS) to provide in-depth assessments on an individual's physical and/or mental function when they have been on sickness absence for four weeks and provide advice about how they could be supported to return to work (DWP, 2013). This service, renamed the Health and Work Service, has been rolled out in England and Wales during 2015 and is the way the Fit for Work pilot schemes are being implemented and made more widely available. General practitioners have been able to refer to this service from March 2015 and employers will be able to refer from autumn 2015 (DWP 2015b). The service is being delivered by Health Management Limited in

England and Wales whereas it is being implemented by the NHS in Scotland. The service is not available in Northern Ireland.

In terms of clinical guidelines, the interagency guidelines for vocational assessment and rehabilitation after acquired brain injury (ABI) comprehensively outline what should be provided (Tyerman & Meehan, 2004) (See Table 1). These recommendations are echoed in the 'Vocational Assessment and Intervention for People with Long Term Neurological Conditions: Recommendations for Best Practice' (BRSM, 2010) although neither are stroke specific. VR is also quality requirement 6 in the National Service Framework for Long Term Neurological Conditions (Department of Health, 2005). It requires people to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities. 'Return to work' is also a quality marker in the National Stroke Strategy (Department of Health, 2007) and a key recommendation of the Stroke Rehabilitation Guidelines (NICE, 2013). The NICE guidelines state that return to work issues should be identified as soon as possible after someone has a stroke and then they need to be reviewed regularly and actively managed. This includes assessment of job demands, impairments to work performance which then informs tailored intervention including education about the Equality Act (2010) and support available (e.g. Access to Work), worksite visits, liaison with employers, reasonable accommodations and a graded return to work.



This plethora of UK policies and clinical guidelines has focused attention on the importance of work and VR for people who have had strokes.

**Table 1. Interagency guidelines for vocational assessment and rehabilitation after ABI (Tyerman & Meehan 2004)**

<b>Guideline</b>	<b>Recommended action</b>
<b>Vocational assessment to determine readiness to return to work/ study and identify rehabilitation needs</b>	<p>Consider personal and family circumstances</p> <p>Assessment of required motor, sensory and cognitive skills and behavioural/ emotional control</p> <p>Consultation with a close relative</p>
<b>Vocational intervention</b>	<p>Provide education about difficulties likely to affect work or study</p> <p>Facilitate development of skills or behaviours necessary for work or study (e.g. restoring work related routines, building up attention, work/ study tolerance and stamina, extending coping strategies for use in the workplace)</p> <p>Utilise material drawn from, or relevant to, the person's work or study</p>
<b>Preparation prior to work return</b>	<p>Provide explicit verbal and written advice about appropriate timing and gradual build-up of hours and responsibilities</p> <p>Seek client's consent to make contact with employer/ education provider to discuss needs prior to return, including liaison with occupational health adviser where available.</p>
<b>Return to work/ study planning</b>	<p>This plan should be agreed with the client, employer/ education provider and occupational health/ learning support (when involved) and may include:</p> <ul style="list-style-type: none"> <li>• a graded return</li> <li>• short term restrictions on hours and</li> </ul>

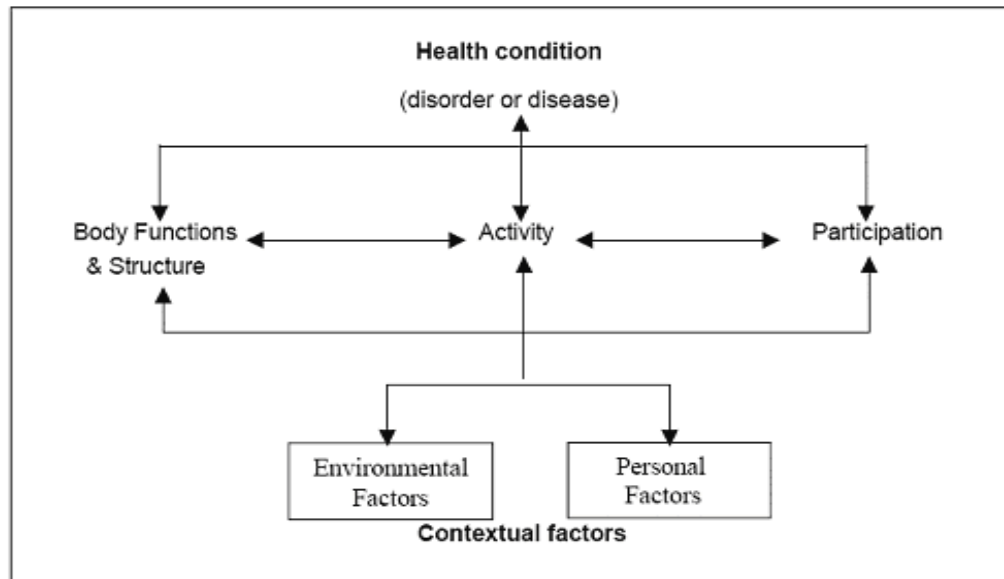
	duties/ study <ul style="list-style-type: none"> <li>• short term flexibility (e.g. frequent breaks)</li> <li>• advice/ support on implementing strategies in the workplace/ place of study</li> <li>• off-site support.</li> </ul>
<b>Support from 'Access to Work'</b>	Involve 'Access to Work' if physical adaptations to workplace or assistance with travel to work are required
<b>Review of return to work</b>	<p>Following return to work/ study progress should be reviewed and further advice/ support provided as required</p> <p>Feedback should be sought from a close relative about how coping with the job/ course may be affecting the individual's personal, family, leisure and social life</p> <p>Ongoing support should be made accessible if difficulties experienced after return.</p>
<b>Longer term support strategy (if needed)</b>	Referral should be made to a Disability Employment Adviser at Job Centre Plus, with the client's consent, to discuss appropriate action

### 1.2.6 Vocational rehabilitation, stroke and the ICF

A systematic review (Daniel et al., 2009), a comprehensive literature review (Wang et al., 2014) and other research studies (Culler et al., 2011; Vestling et al., 2003 & 2005; Hartman-Maeir et al., 2007; Macaden et al., 2010; van Velzen et al., 2011; Wolf et al., 2009) discuss vocation, VR and return to work after stroke in the context of the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) (WHO 2001) (Figure 1). The ICF is based on the biopsychosocial model which provides a coherent view of three different perspectives of health: biological, individual and social. It explores context by looking at the influence of environmental and

personal factors on an individual's ability to execute tasks (activity) and participate in society (WHO, 2002).

**Figure 1. Diagram of ICF**



Although it has been criticised by Wasiak et al. (2007) for its lack of explicitly stated theoretical underpinnings which could potentially limit its translation to return to work research and practice, it is considered a useful framework for describing and understanding the process of return to work with a neurological condition such as stroke.

ICF core sets for stroke (Geyh et al., 2004) and VR (Finger et al., 2012) have been published. These were developed through a consensus process using a combination of systematic review, Delphi exercises with an international multi-professional group of experts and empirical data collection. The core sets consist of brief and comprehensive sets of terminology, a common language that can be used by health professionals, researchers, policy makers, patients and patient

organisations across different countries and cultural contexts to compare research findings and improve stroke care. Examples of terms in the 'body functions' category are 'energy and drive functions' and 'higher level cognitive function'. An example in the 'body structures' category is 'structures of the nervous system' and examples from the 'activities and participation' category are 'focusing attention' and 'moving around using equipment.' The 'environmental' category includes the terms 'individual attitudes of health professionals', 'support and relationships with immediate family' and 'labour and employment services, systems and policies.'

Following a stroke, body functions such as balance and language can be impaired which may affect activities such as walking or using the telephone. This could mean that a person may be unable to participate in society as a worker. Environmental factors, for example, whether their employer has a positive attitude to making reasonable adjustments to assist with return to work and personal factors such as how important work is to the individual will also play a part in whether participation can be achieved.

Grizzell and Smart (2013) advocate the use of the ICF as a tool for underpinning VR services following ABI. They stress its value in viewing disability as a dynamic interaction between the health condition and contextual influences on return to work. Their paper details the way the ICF can be used for assessment purposes to identify the effects of ABI, to inform intervention design, facilitate best practice, to evaluate

programme evaluation to assist with resource planning and service development and as a catalyst for research . It advises that more specialised assessment (e.g. neuropsychological status) will be needed to inform clinical decision making than the ICF framework provides. The importance of overcoming environmental barriers in VR is also highlighted. This view has resonance with the outlook of some OTs who make links between the ICF and the professional language of OTs who base their practice on the relationship between people, their occupations and their environments (Darzins et al., 2006). A recent qualitative interview study of 14 employees with a range of physical and psychological health conditions, 15 employers and 4 occupational physicians from multiple organisations of various sizes and types in The Netherlands explored the role of personal and environmental factors on return to work (Hoefsmit et al., 2014). They found environmental factors including social support from relatives, the belief that work stimulates health, adequate cooperation between stakeholders and the employers' communication skills supported return to work. A positive perception of the working situation (i.e. enjoyment of work) was the only personal factor which stimulated return to work in this study. The suggestion is made that return to work interventions should focus on these broader factors rather than the medical model where focus is on the impairment and the belief that people should recover before returning to work is dominant. This change of emphasis should promote earlier return to work.

A number of alternatives were considered when choosing a theoretical framework to underpin this thesis. These included occupational therapy models, in particular, the Model of Human Occupation (Kielhofner, 1995, Mentup et al.1999), the Canadian Model of Occupational Performance (Law et al., 1997) and the Occupational Adaptation theoretical frame of reference (Schkade and Schultz 1992, 2003). However, the ICF was chosen because it is internationally recognised, it can be used and understood by the range of health professionals that may be involved in VR and has been applied to VR in the body of work described above.

There are many other specific intervention models of VR following ABI described in the literature (Tyerman, 2012). A range of these models will be explored in greater depth in the literature review (section 1.3).

Kroll and Morris (2009) suggest that rehabilitation research is complex and they examine the contribution mixed methodology research can make to address this complexity. They point to the ICF as a way of understanding the processes of rehabilitation and experiences of disability. They propose the biopsychosocial underpinnings of the ICF suggest that rehabilitation research can be seen as being at the intersection of natural and social science thinking. This means that the objective measurement of intervention outcomes and the subjective experience of recovery can both be addressed. The latter preserves the voice of the participants and provides context specific and reflective information. This thinking, alongside guidance on developing and

evaluating complex interventions (MRC Framework 2008) underpins the current study in which qualitative studies precede and follow a feasibility randomised controlled trial to explore the development, delivery and evaluation of stroke specific vocational rehabilitation.

### **1.3 Literature review**

The aims of this literature review are to provide an overview and critical appraisal of literature to answer the following questions:

- What factors influence return to work following stroke?
- What theory underpins VR for stroke survivors?
- What is the evidence for the effectiveness of VR interventions for stroke survivors?
- What factors influence the outcomes of VR?
- What are the limitations of the current literature?

#### *Methodology*

A critical approach was chosen when conducting the literature review (Grant & Booth, 2009). This enabled the analysis and narrative synthesis of literature from a wide variety of sources including policy documents, existing reviews and research using a range of methodologies. A full systematic review would have limited the scope of the literature included and there were no known randomised controlled trials at the outset.

#### *Search strategy and key words:*

The following databases were searched for relevant literature: CINAHL, MEDLINE, ASSIA, EMBASE and PSYCHINFO. Citation tracking was used in seminal papers. The key search terms used were: stroke,

stroke survivor, cerebrovascular accident, subarachnoid haemorrhage, acquired brain injury, work, vocation, employment, work retention, job retention, vocational rehabilitation, work rehabilitation, occupational therapy, workplace accommodation, job modification.

*Inclusion criteria:* Worldwide literature reported in the English language from 1990 onwards.

### *Critical appraisal and synthesis*

Relevant papers were critically appraised using quality checklists that were specifically designed for different types of study/ paper. Checklists for cohort studies, randomised controlled trials, review papers and surveys were selected from Crombie (1996) and for qualitative studies from Taylor (2000). This enabled critical evaluation of the strengths and weaknesses of each individual paper/ study followed by synthesis to answer the literature review questions.

#### **1.3.1 What factors influence return to work after stroke?**

A number of reviews have examined factors that influence return to work (Wozniak & Kittner 2002; Treger et al., 2007; Wang et al., 2014). All conclude that stroke severity is a significant negative predictive factor however the influence of other predictors is considered complex and in need of further exploration. The most recent review (Wang et al., 2014) uses the ICF as a framework to cluster literature and summarise findings. A similar approach will be used in this section but with the addition of more recent studies. Original papers will be evaluated in greater depth.



### **1.3.1.1 Impairments and bodily functions and structures**

#### **1.3.1.1.1 *Cognitive and language function***

A number of studies cite cognitive function as influential in whether a stroke survivor returns to work. Vestling et al. (2003) conducted a retrospective cohort study of 120 stroke survivors in Sweden and found that it was 2.64 times more likely that participants returned to work if they had preserved cognitive capacity. In this study, 26 people had tried to return to work but not succeeded and it was found that 64% of them had impaired cognitive ability. Cognitive ability was evaluated by looking at medical notes and rated as 'severe/moderate' or 'preserved' but it is not clear whether standardised cognitive tests had been completed. The dichotomous scoring method meant those with mild cognitive dysfunction were potentially either excluded or classed as 'preserved' which could have increased the odds ratio (OR).

A prospective cohort study of 140 Finnish patients following first-ever ischaemic stroke (Kauranen et al., 2012) found that the initial cognitive severity of the stroke predicts the later inability to return to work with an OR of 2.252. This is a similar finding to Vestling et al. (2003).

Neuropsychological assessments were conducted within the first few weeks of stroke and at the six month follow-up and were compared with healthy controls. The assessments included executive functions, working memory, language, visual spatial and constructional skills and motor skills.

A Swedish national postal survey (Lindstrom et al., 2009) responded to by 1068 people aged 18-55 and in paid employment before their stroke

relied on self-report of cognitive function and included changes in memory, tiredness, concentration, ability to be engaged in discussions/ talks and complete different tasks in busy and noisy environments. Concentration was chosen from these to represent cognitive function as it was the most strongly correlated with this cluster. The study found that a significantly lower proportion of those with reduced ability to concentrate returned to work.

A prospective cohort study of 143 patients working full time at first stroke onset, using an American stroke data bank (Wozniak et al., 1999), also found a positive association between return to work and absence of cortical neurological dysfunction 7 to 10 days after stroke. However, this was not a statistically significant finding. They defined cortical deficit as including at least one higher cortical dysfunction (neglect, apraxia, homonymous visual field defect, aphasia or anosognosia). However, visual field defects do not appear to be classed under this heading in other studies. A Japanese prospective cohort study of 325 patients after first stroke (Saeki & Toyonaga 2010) classified higher cortical dysfunctions as aphasia, agnosia and apraxia and also found no statistically significant relationship with return to work.

A retrospective cohort study with 72 people following ABI (48 stroke, 24 traumatic brain injury) (Hofgren et al., 2010) used the Barrow Neurological Institute Screen for Higher Cerebral Functions (BNIS) which includes seven subscales (speech and language functions,

orientation to time, place and person, attention and concentration, visuo-spatial problem solving, memory, affect and awareness versus own performance. There were no differences in screening between the diagnostic groups. Those who returned to work scored more highly on this measure but the only significant difference was in the 'affect' subscale and the ability to perceive and express affective responses as part of social skills needed in the workplace. Also no one who had neglect (hemi-inattention) following stroke returned to work.

A prospective cohort study in Australia (Ownsworth & Shum, 2008) assessed executive function in 27 stroke patients and followed up at 12 months to evaluate employment outcome and productivity. The measures of purposive behaviour and self-regulation distinguished the employed from unemployed and productivity was also significantly correlated with these components and planning.

A recent prospective cohort study of 351 patients with first-ever stroke in Japan (Tanaka et al., 2014) found that no attention dysfunction and no aphasia (both diagnosed by neurologist) were significant predictors of return to work. However, 101 were lost to follow-up at the 18 month follow-up which may have influenced results.

Case examples detailing the influence of cognitive impairment on return to work are given in a qualitative interview study with 43 stroke survivors under 60 years old over an 18 month period (Alaszewski et al., 2007). One person, whose job involved long distance lorry driving, found it extremely difficult to concentrate, multi-task and found

background noise distracting. Another interviewee who worked as a nurse found a combination of concentration and speech difficulties meant she was not able to sustain her return to work. In another qualitative study involving focus groups with 37 stroke survivors (Lockett et al., 2005) participants cited difficulties with memory, processing information, vision and speech as barriers to employment. A qualitative interview study with 12 people following ABI (van Velzen et al., 2011) highlighted the cognitive consequences of aphasia and reduced concentration on individuals working in busy workplaces where they experienced difficulties when expected to switch their attention between tasks and perform more than one task at a time. In a study adopting a multiple case study approach (Macaden et al., 2010), a person with ABI (three to 13 years post-injury), a family member, job coach and co-worker were interviewed for each of eight case studies (five traumatic brain injury, two strokes and one subarachnoid haemorrhage). The ability to cope with poor cognitive function was beneficial in sustaining employment. This involved one individual with attention difficulties due to background noise requesting a quiet office for himself and as a result he not only successfully returned to work but also achieved several promotions. A qualitative interview study with 10 stroke survivors identified reduced executive functioning and communication difficulties as barriers to employment (Culler et al., 2011). This meant that one participant took three times as long to prepare for class and their ability to give presentations and conduct meetings was affected.

With specific reference to language, a prospective cohort study of 79 patients who underwent vocationally orientated in-patient rehabilitation following stroke, found that those most likely to return to work were not aphasic (Black-Schaffer & Osberg, 1990). This was a statistically significant finding. In a literature review on aphasia and return to work in younger stroke survivors Graham et al. (2011) found they were less likely to return to work than those without aphasia (28.4% compared to 44.7%). Another more recent survey study of 72 stroke patients (Doucet et al., 2012) also found the presence of language disorders was a statistically significant negative predictive factor for return to work whereas cognitive impairment (memory disorders, psychomotor slowing and frontal lobe syndrome) was not.

In summary, cognitive and language function is clearly an important factor affecting not only work return success but also work outcomes including work retention and the sustainability of work return. However, what is not known about these studies is whether people received support or VR or not. What is evident from the case studies is that people with cognitive impairment can and do work and can be supported in the work environment if adaptations are made to accommodate them. What remains unclear is the extent of cognitive impairment that facilitates or inhibits this.

#### **1.3.1.1.2 Emotional functions**

A large prospective population-based study of 1423 first-ever stroke patients in New Zealand found that, in those who were cognitively competent, psychiatric morbidity at 28 days post-stroke was a strong

independent predictor of not returning to work. This was assessed using the General Health Questionnaire (GHQ-28) which does not refer to any specific diagnosis but psychiatric morbidity after stroke generally alludes to depression (Glozier et al., 2008). However, a prospective cohort study of 441 stroke patients in Australia conducted by the same authors (Hackett et al., 2012) did not find depression at 28 days to be a statistically significant independent predictor of return to work although it still had a reasonably strong effect ( $p=0.03$ ). This may have been because the incidence of depression in the sample was much lower than seen in previous studies and therefore was underpowered. The Hospital Anxiety and Depression Scale (HADS) depression subscale was used. The prospective cohort study by Wozniak et al. (1999) also did not find depression to be associated with vocational outcome. In this study depression was measured using the Center for Epidemiological Studies- Depression Scale (CES-D). This may have been because the measure was not sensitive enough or because it was measured in the acute phase post-stroke which may not be the optimal time.

The impact of post-stroke anxiety on return to work appears to be a neglected area of research. In the Hackett et al. (2012) study the anxiety subscale of the HADS was correlated with the depression subscale and so only the latter was used in the analysis. A Cochrane Review (Campbell Burton et al., 2011) cites prevalence of anxiety after stroke as 20-25% but found no studies which considered intervention (psychological or medical) for anxiety separately from depression. Bertisch et al. (2013) found anxiety to be a primary predictor of

functional impairment after ABI in their correlational study of 54 out-patients in the USA. They recommended it is a potentially modifiable factor that should be considered in clinical and research settings.

However, only 19 participants had had a stroke, 17 had traumatic brain injury and people with a range of other neurological conditions including multiple sclerosis and Parkinson's disease were included in the sample. Kneebone and Jeffries (2013) present a case study of a working stroke survivor who received modified cognitive behavioural therapy which enhanced his ability to manage his anxiety and as a result, his job.

In summary, both depression and anxiety appear to be prevalent following stroke and there is some evidence to suggest they have a negative impact on return to work outcomes. However, in the presence of conflicting evidence, further research is required to clarify this relationship, together with an exploration of efficacious interventions.

#### **1.3.1.1.3 Neuromuscular and movement related functions**

Being able to walk was the most important predictive factor (OR 3.98) in the study by Vestling et al. (2003) and also significant in the study by Tanaka et al. (2014). Lindstrom et al. (2009) found that retaining the ability to run a short distance was a significant factor associated with return to work (OR 2.77). In the retrospective cohort study of 248 stroke survivors in Taiwan (Hsieh & Lee, 1997) found that maximum weakness (measured using muscle function tests on all four limbs) was one of the most significant predictors of return to work. Normal muscle strength (OR 4.5) and the absence of apraxia (OR 4.87) both increased the odds of returning to work after stroke in a retrospective cohort study of 230

stroke patients in Japan (Saeki et al., 1993). Whereas a later study by the same research group found that function of the hemiplegic hand was a significant determinant of early return to work (Saeki & Toyonaga, 2010) but not the hemiplegic leg. Difficulties in using the dominant hand was cited as a barrier to employment in the qualitative interview study by Lock et al. (2005). In a prospective cohort study of 150 stroke survivors in South India (Sreedharan et al., 2013), limb weakness was significantly associated with employment loss. In the qualitative study by van Velzen et al. (2011), the physical consequences of stroke including problems with balance, loss of muscle strength, impairments of the both lower and upper extremities were cited as limiting return to work. All ten participants in the interview study by Culler et al. (2011) cited physical difficulties including the ability to move around the workplace being affected by strength and balance and lifting and carrying requiring bilateral hand use.

In summary, the evidence presented clearly demonstrates that neuromuscular and movement related function, of both the lower and upper limbs following stroke, is an important factor influencing return to work success.

#### **1.3.1.1.4 Energy levels (fatigue)**

A number of qualitative studies found fatigue was perceived as a barrier to returning to work (Alaszewski et al., 2007; Lock et al., 2005; Rubenson et al., 2007; van Velzen et al., 2011; Vestling et al., 2013). A prospective cohort study of 83 first-ever stroke patients in Denmark with a two year follow-up concluded that fatigue appeared to be an



independent determinant of return to paid work (Andersen et al., 2011). It was measured using the Multi-dimensional Fatigue Inventory. It is apparent that stroke survivors and their families perceive fatigue to be an influential factor in the return to work process. However, more quantitative studies with larger sample sizes are required to explore the relationship with return to work outcomes further.

#### **1.3.1.1.5 Stroke location**

Wozniak et al. (1999) examined the influence of stroke location on return to work for 109 stroke survivors in a prospective cohort study and found it was not significantly associated with vocational outcomes at one year. The same result was obtained in a retrospective cohort study of 126 stroke patients in Japan (Saeki & Hachisuka, 2004) and a retrospective survey of 72 stroke patients in France (Doucet et al., 2012). All three studies concluded that stroke location was not as important as other more easily measured factors when predicting return to work. A pre-post treatment observation study of 127 patients with post-acute brain injury evaluating rehabilitation noted an interesting trend ( $p=0.08$ ) in relation to the impact of laterality of stroke on independence level at discharge (Adams et al., 2004). They found that those with right hemisphere strokes were less likely to be independent at discharge but concluded this may have more to do with the syndromes they experience e.g. neglect, aphasia) than simply the side of cerebral lesion.

In the light of the evidence presented, it can be concluded that stroke location is not an important factor in relation to return to work outcome.

### **1.3.1.2 Activity limitations and participation restriction**

#### **1.3.1.2.1 Functional ability**

Functional ability has been shown to be positively associated with return to work in a number of cohort studies (Adams et al., 2004; Black-Schaffer & Osberg 1990; Wozniak et al., 1999; Glozier et al., 2008; Gabrielle & Renate 2009; Busch et al., 2009; Saeki & Toyonaga 2010; Hackett et al., 2012; Doucet et al., 2012; Sreedharan et al., 2013).

Most of these studies used the Barthel Index to measure functional ability (Black-Schaffer & Osberg 1990; Wozniak et al., 1999; Busch et al., 2009; Gabrielle & Renate 2009; Glozier et al., 2008; Saeki & Toyonaga 2010; Doucet et al., 2012) but the Frenchay Activities Index (Hackett et al., 2012) and the modified Rankin scale (Doucet et al., 2012; Sreedharan et al., 2013) were also employed. Wozniak and Kittner (2002) point out that though the Barthel Index is regularly used in studies to identify predictors of return to work it has known ceiling effects and those individuals with a normal score may still have deficits which influence return to work. They suggested using the NIH Stroke Scale as an alternative.

A recent prospective cohort study of 351 stroke patients in Japan examined clinical, functional and occupational factors associated with work return within 18 months of stroke (Tanaka et al., 2014). They adjusted for functional ability at the beginning (measured by Barthel Index and modified Rankin scale) as they considered it a strong predictor of return to work.

Doucet et al. (2012) found, in a retrospective survey of 72 patients admitted after a first stroke to a physical and rehabilitation medicine centre in France that those who had resumed driving had a significantly higher rate of returning to work. There was also a significant positive correlation between time to work re-entry and the time to resumption of driving. This could be linked with preserved cognitive function as driving requires high level cognitive skills. The study states that return to work was not significantly associated with a mention of cognitive disorders in medical records on discharge but this indicates that formal cognitive tests were not used in the analysis. Not being allowed to drive due to legal regulations or being unable to drive to work were identified as limiting factors in qualitative studies (Culler et al. 2011; Macaden et al., 2010; van Velzen et al., 2011). This potential link does not appear to have been explored in other stroke studies however it has in traumatic brain injury research where being able to resume driving was found to be important for return to work (Catalano et al., 2006).

In summary, there is robust evidence that functional ability is a strong predictor of return to work after stroke as measured by a variety of standardised tools. There also appears to be a link between ability to drive, an instrumental activity of daily living, and return to work following acquired brain injury. Stroke specific research would be helpful to clarify the nature of this relationship and explore any mediating factors.

### **1.3.1.3 Environmental factors**

#### **1.3.1.3.1 Support and relationships**

External support from others was found to be a significant factor (OR 3.66) in returning to work after stroke in the survey by Lindstrom et al. (2009). Unfortunately the authors only asked if someone was receiving support and did not explore further who was providing it. They also found that stroke survivors not perceiving themselves as a burden impacted positively on work return (OR 3.33).

Specific professional support is cited as a positive prognostic factor for return to work after stroke in the survey by Doucet et al. (2012). This study concluded that close cooperation was needed between occupational health and rehabilitation services to speed up the process. They also found living alone to be a statistically significant negative prognostic factor compared to those living with a partner. They hypothesised that support from a partner could have ameliorated low mood which in turn enhanced the probability of returning to work.

Qualitative studies also indicate that supportive social networks (including family, friends and work colleagues) facilitate return to work (Alaszewski et al., 2007; Culler et al., 2011; Ellingsen & Aas 2009; Lock et al., 2005; Macaden et al., 2010; Rubenson et al., 2007; van Velzen et al., 2011). Participants found that whether employers, managers and work colleagues were supportive and understanding of their situation was an important factor (Alaszewski et al., 2007; Rubenson et al., 2007; van Velzen et al., 2011). A Norwegian focus group study of four people with cognitive deficits following ABI including stroke and 11 health and

social care professionals with specific experience in work rehabilitation of this patient group (Elingsen & Aas 2009), found that social support in the workplace was a very important facilitator of return to work.

Macaden et al. (2010) found that employment was sustained where employers had personal experience of disability. The positive influence of supportive family and friends has also been highlighted (Alaszewski et al., 2007; Lock et al., 2005; van Velzen et al., 2011).

In conclusion, supportive relationships with family members, professionals and people in the workplace have all been shown to be influential in enabling return to work success.

#### **1.3.1.3.2 Services, systems and policies**

In relation to the workplace there were conflicting findings about the influence of the employing institution. Hsieh and Lee (1997) found that in Taiwan, being in a government job was a significant predictor of return to work. They had compared government with private, self-employment and being a housewife in their retrospective cohort study of 248 stroke survivors discharged from one of the largest academic hospitals in the country. Their interpretation was that the government provides greater job stability. In contrast, a qualitative interview study in the UK (Alaszewski et al., 2007) found that flexibility was the key factor in the employing organisation and that large public sector organisations were not perceived by some participants to be supportive because of the lengthy bureaucratic process required when returning to work. This included having to have a medical and work station assessment and adaptations made. However, in the Doucet et al. (2012) survey,

consulting an occupational health physician increased the likelihood of return to work although this didn't reach statistical significance. The assistance of an occupational physician and occupational specialist in introducing adaptations was also seen as facilitative by participants with ABI in the qualitative interview study by van Velzen et al. (2011). This study was conducted in the Netherlands where the system is very different to the UK. There is a clear distinction between the health care insurance which covers in-patient rehabilitation and social security insurance which people are automatically covered by when they are employed. This means that both the employer and the employee are responsible for the return to work process for the first two years of sick leave. The employer has to pay at least 70% of the employees wage and is obliged to provide modified work on a temporary basis to assist with the return to work process which is supported by an occupational physician or vocational reintegration company. In addition, there is much greater legal protection as the employee cannot be dismissed during this two year period (van Velzen et al., 2015). In theory this should maximise the return to work probability but two years may not be long enough for people with more severe strokes.

The impact on the size of the employing organisation on return to work after stroke was explored in a prospective cohort study with a two year follow-up in Denmark (Hannerz et al., 2012a) which found that the probability of returning increases with the size of the enterprise. This was a very big study which included 13,178 stroke survivors divided according to their place of employment into four sizes of enterprise:

micro (1-9), small (10-49), medium (50-249) and large (>250). They found that larger companies could hold positions open for longer and had the resources to make job modifications which were often needed following stroke. Another possible influential factor could be that larger organisations are more likely to have better access to occupational health and occupational physicians. Hannerz et al. (2012b) also found in a time trend analysis that changes to Danish legislation which reduced sickness absence reimbursed by the state coincided with the return to work rates following stroke being doubled. A similar trend was previously identified in a retrospective cohort study (n=183) (Saeki et al., 1995) where return to work at 18 months after stroke was linked with the cessation of sickness benefits from the government. So in both of these studies, return to work was being influenced by the social security policy and systems which vary massively between countries and appear to be more supportive in some countries than others.

Hackett et al. (2012) found that having health insurance was significantly associated with return to paid work in their Australian study. They interpreted this as being a marker of socioeconomic status because tax breaks offered for private health insurance increase with income. They also suggest that being on a higher income the financial incentive to return to work is greater. A Swedish focus group study (Lundqvist & Samuelsson, 2012) found mixed opinions about health insurance. Some of the 14 participants with ABI found it inflexible and they had to struggle with the regulations in order to get rehabilitation and others felt lucky because their rehabilitation was at a time with

more generous regulations. However it is not made clear whether these participants were among the six who had a stroke and whether regulations had become less generous over time. The influence of health insurance does not generally apply in the UK due to the health care system in place but the sickness absence policy of a company or organisation could affect the time period during which someone receives full or reduced payment and this could in turn influence access to rehabilitation services and work return time frames.

An American study evaluating in-patient VR (n=79) found that a shorter stay in hospital was a significant predictor of return to work after stroke (Black-Schaffer & Osberg, 1990). However, this was an older study and people generally tended to stay in hospital longer for rehabilitation at that time. A more recent ABI study in Sweden (Hofgren et al., 2010) found those who returned to work had a shorter stay in rehabilitation hospital and shorter total length of stay in hospital (acute hospital and rehabilitation hospital). Both studies also found being independent in activities of daily living was important, which may be linked with length of hospital stay. The more recent study does not explain the way in which it was measured only whether participants were independent or not. Authors of an American post-acute brain injury rehabilitation study (Adams et al., 2004) were surprised to find that longer length of stay was associated with higher levels of independence at discharge and they discussed the possibility that the longer stay for those with more severe impairment resulted in greater benefits from therapy input. An alternative mediating factor proposed was that length of stay was



associated with environmental supports such as increased family support or better insurance cover. However, it could be argued that greater family support could reduce length of stay.

The influence of VR on return to work after stroke will be explored in greater depth later in this chapter.

In summary, research demonstrates that the influence of services, systems and policies on return to work after stroke is multifaceted and varies widely according to the country in which the study takes place. The policies and nature of governments, health and social care systems and employing organisations can all have an impact on the availability and accessibility of services and financial support.

#### **1.3.1.4 Personal factors**

##### **1.3.1.4.1 Age**

One retrospective (Hofgren et al., 2010) and three prospective (Busch et al. 2009, Hackett et al. 2012, Hannerz 2011) cohort studies found that being younger increased probability of return to work after a stroke. The Busch (2009) study was conducted in the UK using the South London Stroke Register of 2874 first ever strokes. At one year 35% of stroke survivors had returned to paid work and those over 55 years were less likely to have returned. The Hackett study showed those aged 51 (plus or minus 10 years) were more likely to return than those 55 (plus or minus 10 years). The very large Danish stroke population study (n= 19,985) which only included those under 60 (retirement age in Denmark) and found that 62% were employed at two year follow-up and

being 50 years or older was negatively associated with return to work (Hannerz et al., 2011). The Hofgren study found that mean age of those who returned was 40 (SD 15) whereas for those who did not return the mean age was 50 (SD 11). However, only 13 (18.1%) of those in the Hofgren study returned whereas 202 (75%) returned in the Hackett study. The Hofgren study included people with stroke and traumatic brain injury whereas the Busch, Hackett and Hannerz studies were only stroke which would have had an impact on these results as age group affected by traumatic brain injury was younger. An older review of the literature (Saeki, 2000) also found age was a predictive factor but only when studies included people aged 65 and over. However, this was not the case in the Hackett, Hofgren or Hannerz studies where all participants were under 65. Saeki (2000) suggested that, in those approaching 65 years old, advancing age and socioeconomic factors such as retirement reduced the probability of return to work and this argument probably still holds in light of more recent evidence.

It is evident from a number of large scale research studies across the world that being younger increases the likelihood of return to work after stroke.

#### **1.3.1.4.2 Gender**

A number of cohort studies have found that female stroke survivors are less likely to return to work than males (Adams et al., 2004; Busch et al., 2009; Saeki & Toyonaga 2010, Hannerz et al., 2011; Trygged et al., 2011; Hackett et al., 2012; Sreedharan et al., 2013). However, this contrasts with other studies that did not find gender predictive of a

return to work (Black-Schaffer & Osberg 1990; Hseih & Lee, 1997; Saeki et al., 1993; Glozier et al., 2008; Lindstrom et al., 2009). Biological differences, different pressures or barriers to work or employer discrimination are all possible explanations proposed by Busch et al. (2009) and further exploration is suggested. Adams et al. (2004) also discuss gender discrimination and suggest that psychosocial factors may play a part in that men may strive more towards regaining autonomy and women towards maintaining relationships. Roding et al. (2009) in a survey of 1068 stroke patients found significant differences in perceived deteriorated physical and cognitive function between men and women which were greater in women. These factors have a direct relationship with return to work which could explain gender differences. If it is a matter of perception then maybe reduced self-confidence could also be influential. However this is only one study using self report and relatively more men did not respond to the questionnaire so findings need to be treated with caution. Trygged et al. (2011) offer an alternative explanation, that differences in income between men and women account for the lower probability of women returning to work.

A consensus has not yet been reached on the relationship between gender and return to work after stroke. Sociocultural, psychosocial factors and the perceived functional impact of the stroke itself have all been suggested as possible mediating factors which require further study.

#### **1.3.1.4.3 Race/ Ethnicity**

A study of the socio-demographic differences in return to work after stroke using the South London Stroke Register found that black ethnicity was independently associated with a lower probability of returning to work (OR 0.41; 95% CI 0.19-0.88) (Busch et al., 2009). Glozier et al. (2008) in a prospective cohort study found that being of non-New Zealand European ethnicity (Maori, Pacific, Asian and other) was an independent, age and gender adjusted predictor for not returning to work (OR 0.40; CI 0.17-0.91). The similarity in the statistical findings of these two studies is striking however the reasons for these results are unclear and the impact of ethnicity on return to work warrants further exploration.

#### **1.3.1.4.4 Socioeconomic and educational status**

A Swedish national survey (Lindstrom et al., 2009) found that higher socioeconomic status was associated with an increased probability of returning to work after stroke (OR 2.12). A recent prospective cohort study of 21 individuals with mild stroke conducted in the USA also found that those from lower socioeconomic backgrounds found it more difficult to return to work than those from higher socioeconomic backgrounds (Brey & Wolf, 2015). Another study using data from the Swedish national register of in-patient care for stroke survivors aged 40-59 who were discharged from hospital between 1996 and 2000 (n=7081) (Trygged et al., 2011) found that income and education were independent predictors of return to work. Those who had attended university were 13% more likely to return than those who had just

attended school. Also those in the highest income quartile were twice as likely to return as those in the lowest. This may be partly explained by the type of work people in these higher income and education brackets are engaged in and will be explored more fully in the next section.

#### **1.3.1.4.5 Type of job**

The type of job people do has been found to predict whether they return after stroke. A number of studies have found that white collar work makes the return more likely. Vestling et al. (2003) found the OR for this to be 2.99, Saeki and Toyonaga (2011) found white collar versus blue collar OR to be 2.06 and Tanaka et al. (2014) found both job type (white collar versus blue collar) and work position (managerial versus regular employee) to be a statistically significant predictors of work return. The latter study speculates that people in more skilled employment may have greater opportunity to redesign their working conditions thereby increasing their chances of returning. This argument had previously been made by Hannerz et al. (2011) who found the probability of returning to work after stroke increased with the skill level of the job. They suggested that the possibility of influencing the volume and content of work is higher in white collar work which impacts on the return to work process. So the degree of autonomy at work could be a key factor as it increases in more highly skilled work, professional and managerial positions. This was definitely the experience of a stroke survivor who took part in a qualitative in-depth interview study in the USA (Hartke et al., 2011) and found the work place were open to

spacing and accommodation so that she had more control when she returned to her managerial position. Trygged et al. (2011) also suggest that those in higher paid white collar jobs may find it easier to adjust work tasks than those in blue collar work. In manual work, greater emphasis may be placed on measurement of task completion, speed and productivity. There would also be no control of the pace of work, for example, on a factory assembly line. Unskilled workers in the Brey and Wolf (2015) study perceived significantly less social support ( $p=0.017$ ) and autonomy ( $p=0.049$ ) in work responsibilities than the skilled group. However this was a very small study ( $n=21$ ). Another suggestion made by Hannerz et al. (2011) is that there is a link between jobs which have greater educational requirements and the meaning of work which is discussed further in the next section.

#### **1.3.1.4.6 *Meaning, motivation and the importance of work***

The only quantitative study which evaluates the influence of the importance of work to the individual (Lindstrom et al., 2009) found that if work was perceived as important to stroke survivors they were five times more likely to return to work. This was interpreted by the authors as a positive attitude to work but this appears to oversimplify what is described in more depth in other studies. Vestling et al. (2005) in a survey of 65 stroke survivors and found that financial and intrinsic aspects of work were ranked as the most important. The latter included personal development, freedom to decide (autonomy) and use of knowledge. These took precedence over social aspects of work. However, there were no statistically significant differences between

those who returned and those who did not. Despite these findings the authors recommend further work into motivational factors which may influence return to work rehabilitation. In a qualitative in-depth interview study with 12 stroke survivors of critical factors related to return to work Hartke et al. (2011) found that the financial incentive of returning to work was finely balanced with the fear of losing benefits if return to work was not successful. This was also reported by stroke survivors in the interview study by Culler et al. (2011). Hartke et al. (2011) also found that risk also came into the equation when work was very important to people and they were willing to take risks with their health in order to return. They found that a passion for a particular type of work or a strong work ethic were both very powerful motivators. However, some re-evaluated their work life balance post-stroke and made changes to reduce the risk of work stress on their health. Very similar findings were reported by Alaszewski et al. (2007) where interviewees talked about the value of work to them both financially, socially and in making a contribution to society. They also discussed making changes in the light of work stress which they felt had been a contributory factor in their stroke occurring. For some, returning to work, even if perceived as risky, was a way of demonstrating their progress and a sign of recovery and resilience. The meaningfulness of work and the risk of going back too early for financial reasons were two themes identified by Rubenson et al. (2007). Vestling et al. (2013), in another qualitative interview study about the experiences of returning to work after stroke, found that work held multiple subjective meanings that were important contributors to

motivation to return to work including self-fulfilment and that strong willpower enabled them to face the challenges of returning. Most participants in the van Velzen et al. (2011) interview study said motivation and a strong will to return to work were highly influential. The role of intrinsic motivation in sustaining work return was a recurring theme in a UK multiple case study of eight individuals with ABI (Macaden et al., 2010). An example given was someone who wanted to prove themselves and their restored independence by returning to and maintaining their work role. This was described as an overarching force which enabled participants to overcome their acquired disability. Authors recommended exploiting previous work interests as a way of increasing motivation and therefore sustaining employment.

These studies suggest concepts of motivation and meaning are interwoven in a way that has different implications for different individuals depending on their particular life and work situation.

#### **1.3.1.5. Summary of factors influencing return to work after stroke**

This international body of research highlights a vast array of factors that combine to influence the probability of return to work after stroke. Using the ICF as a structure, the dynamic relationship between these factors is illustrated in Figure 2. The strongest positive predictors are higher functional, cognitive and language ability, being mobile and younger. The presence of post-stroke fatigue appears to have a negative effect. The role of gender and ethnicity warrant further investigation although current evidence appears to suggest that being female and from an

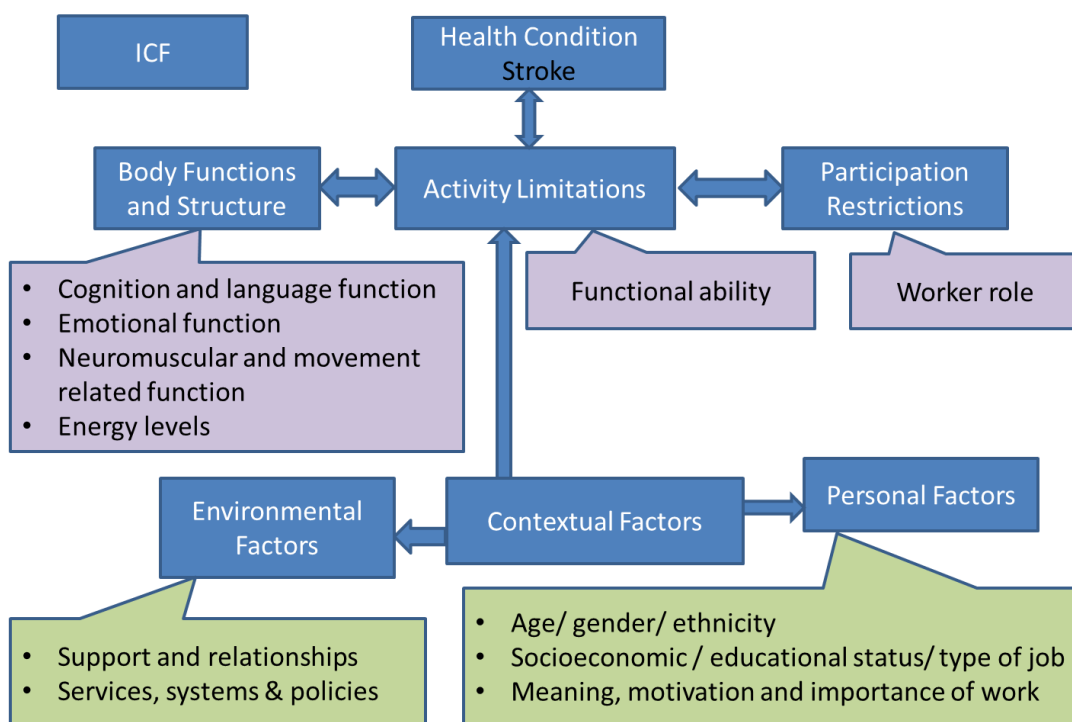


ethnic minority reduces return to work prospects. Further research is also needed to clarify the impact of depression and anxiety. Stroke location is not considered to be important.

Environmental factors such as the support available from family members, professionals and the workplace is considered crucial. The services stroke survivors receive depends on the ethos and policies of the government and employing organisation which vary globally.

Personal factors including higher socioeconomic status, education and job skill levels appear to increase return to work probability. Motivation is more complex and a person's life stage and work situation may lead them to react in a variety of ways influenced by perceptions of risk to health and financial status.

**Figure 2. ICF summarising factors influencing return to work after stroke**



### **1.3.2 What theory underpins VR for stroke survivors?**

A range of theoretical models underpin VR for people following brain injury. There has been greater development and publication of these models in the field of traumatic brain injury than stroke however it could be argued that they are broadly transferable. A number of these models will now be described and discussed.

A recent review of models for VR following traumatic brain injury that have emerged over the last 30 years (Tyerman, 2012) divides them into three main groups; those that are ABI rehabilitation programmes with integrated or added VR components, VR models that have been adapted for brain injury and case coordination/ resource facilitation models. This structure will be adopted for this section.

#### **1.3.2.1 ABI rehabilitation with added or integrated VR components**

An early example of this model is described by Ben-Yishay et al. (1987) for people with severe traumatic brain injury and was cited by Tyerman (2012) as one of the most influential. This programme involved remedial intervention (intensive individual and group work focused on cognitive and social skills) for four days a week for 20 weeks, guided voluntary work trials for 3-9 months with the support of a vocational counsellor and assistance in finding work placements with follow-up support from vocational guidance practitioners. This was deemed to be a successful model as 94% were rated as having gained the ability to be productive with 64% achieving competitive employment and 30% non-competitive employment. However, these figures went down to 50% and 22%

respectively by the third year follow-up so the number rated as unemployable was four times as high. But considering all participants had previously been considered unemployable, this model can still be regarded as effective. The suitability of this model for stroke survivors would depend on the severity of the stroke and whether they were cognitively impaired.

Other models in this category are explored by Hart et al. (2006) in their survey of vocational services for traumatic brain injury. Five out of the 16 services surveyed described themselves as using the 'train and place' philosophy where comprehensive treatment programmes focused on cognitive remediation and work preparation are delivered as part of medical rehabilitation before voluntary work trials and then paid job placement. This survey examined programme characteristics, funding and perceived importance of vocational treatment components but did not evaluate the effectiveness of the models.

The other name given to this model is 'programme based vocational rehabilitation' after traumatic brain injury (Fadyl & McPherson, 2009). This is described as pre-employment vocationally related skills training followed by work placement with transitional support and follow-up at specific time points. Fadyl and McPherson (2009) rate the quality of the research evidence for effectiveness of this model and conclude it is weak.

The above studies are both American but a UK example of this model is the 'Working Out Programme' designed for people following ABI who

have been unable to return to work (Tyerman, 2012). This also provides vocational assessment, work preparation, voluntary work trials and supported work placements as an extension to a general brain injury rehabilitation programme. In the development stage of this programme 50% of 40 people who participated following severe traumatic brain injury, returned to paid employment or vocational training with another 35% to 'permitted' (while claiming benefits) or voluntary work with outcomes maintained at two year follow-up. However, it is not clear how long after the brain injury they commenced participation in the programme. The programme was expanded to include ABI but the proportion of people with strokes is not stated. The outcomes of this small study were later updated to 64% in paid employment or vocational training but this was a conference paper (Tyerman, 2012) and full details do not appear to have been published. The proportion returning to paid work as opposed to vocational training is also omitted.

#### **1.3.2.2 VR models that have been adapted for brain injury**

Supported employment is one VR model that has been adapted for use following brain injury. This involves job placement in competitive employment, on-the-job training and long-term support through on-the-job coaching which is gradually withdrawn as person becomes more competent (Wehman, 2012). It was pioneered in the field of learning disabilities and subsequently modified for use with other populations (Wehman, 2012) but evidence for use following ABI is lacking (Wehman et al., 2009). One paper, directly applicable to stroke (Wehman et al.,

1991), is a descriptive case study of three individuals, one of whom had a stroke and successfully returned to work.

This VR model is described as adopting a 'place and train' philosophy by Hart et al. (2006). Six of the 16 services in the USA survey were using this model. This supported employment model is also described by Fadyl and McPherson (2009) who found weak evidence for its effectiveness in the field of brain injury. It is aimed at people with severe disability who would be unlikely to manage without this high level of support in the workplace.

In the UK this model has been adopted with enthusiasm in the field of mental health and is more commonly known as 'individual placement and support' (IPS). Evidence for effectiveness is strong and it has been integrated into UK mental health services (Schneider, 2003). This review of the cost effectiveness of supported employment largely refers to studies conducted in the USA and includes those in the field of learning disabilities as well as mental health. The focus of these global programmes appears to be assisting people to move towards competitive employment through job placement rather than work retention (Schneider, 2003). Caution is recommended when thinking about transferability to other contexts including different countries and health and social care systems. In addition, there is limited evidence of its use following ABI. Elements of this model were adopted by Rehab UK and Momentum in the UK in a study of 232 clients (22% stroke) but pre-placement work preparation meant it was a hybrid of the two

models described above (Murphy et al., 2006). Time since injury ranged from seven months to 35 years although a third of participants commenced six months to two years post-injury. Almost all (92%) were claiming Incapacity Benefit while on the programme and so were classed as unemployed. Outcomes after an average of 50 weeks were 41% in paid competitive employment, 15% mainstream education/training, 16% in voluntary work, 15% discharged to other treatment and 13% withdrew from the programme. Authors do discuss that the study sample are not a representative group as those whose needs could have been addressed by less intensive support and those with highly complex difficulties that were deemed to preclude work return were excluded. However, the precise details of this screening process are unknown.

### **1.3.2.3 Case coordination / resource facilitation models**

Models in this group have case coordination as a core feature. The vocational case coordinator model after ABI was evaluated by Malec and Moessner (2006) who replicated a previous study which had demonstrated effectiveness (Malec et al., 2000). Key elements of this model included early intervention, a hospital based vocational case coordinator who assists the participant to develop a vocational plan and a smooth transition from medical to community based services. Other important features are on-the-job assessments, coaching and support, work accommodations, education of employers and colleagues and regular on-going follow-up. The 2006 cohort study of 138 people with ABI (84% unemployed and the rest failing in employment and average

of 3.5 years since injury) found that one year after placement, 80% of participants remained in community based employment, 56% with no support, very similar results to the earlier study. Better outcomes were linked with earlier intervention and not injury severity.

Five of the 16 services surveyed by Hart et al. (2006) used a case coordination approach. They describe it as a combination of medical rehabilitation and supported employment with an emphasis on case management. Fadyl and McPherson (2009) actually call it a case coordination model where VR is part of an overall rehabilitation programme. The case coordinator assesses and refers to various aspects of VR according to the individuals need and then monitors progress. They highlight unique features of this model as a focus on early intervention and continuity of care and the coordination of VR with other rehabilitation services. They state that there is moderate evidence for the effectiveness of this model after ABI.

The Australian Commonwealth Rehabilitation Service, a major provider of VR services, uses a client-centred case management model. A rehabilitation consultant worked one to one with individuals with ABI (27% stroke), throughout the programme, to involve them in planning their own rehabilitation (O'Brien, 2007). The overall outcome rate of paid employment for those completing this programme was 50%.

In the UK, the case coordination approach is used by community brain injury teams who employ case managers to coordinate all aspects of patient and family intervention (Phillips et al., 2010). However, this is

not so for stroke services which points to a potential gap in provision (Grant et al., 2014).

The above studies appear to use the words case coordination and case management interchangeably. A study by Trexler et al. (2010) introduced another term, 'resource facilitation', but state it is also known as case management. This small prospective randomised controlled trial evaluates the impact of resource facilitation on 22 people with ABI including 13 with stroke. Return to work was one of the outcomes of interest and participation in resource facilitation led to 64% employment compared to only 36% in the control group. Another example of a case coordination approach being evaluated is a work-place intervention tested out alongside usual rehabilitation (Ntsiea et al., 2014). This study will be discussed further in the following section.

### **1.3.3 What is the evidence for effectiveness of VR interventions to facilitate return to work for stroke survivors?**

There is little evidence for the effectiveness of VR for stroke survivors because few studies describe and evaluate interventions to support return to work after stroke. Treger et al. (2007) point to a considerable lack of research and knowledge of effective assessments and VR interventions following stroke in their review.

In a systematic literature review, Baldwin and Brusco (2011) highlighted that at the time of this review no randomised controlled trials had been carried out to evaluate the effectiveness of VR for stroke survivors. The six studies included in the review were retrospective single cohort



designs and they concluded there were insufficient high quality trials to make recommendations to support or refute the use of VR to increase work return rates following stroke. In the review the authors included a study of constraint-induced movement therapy (Mennemeyer et al., 2006) which they justified on the basis that the aim of the study was to report employment rates. However, constraint -induced movement therapy cannot be classified as VR intervention. They also included a retrospective audit of a UK project for people with a range of neurological conditions (Bisiker & Millinchip, 2007) and found the lowest percentage of people returning to work by diagnosis were those following stroke (26% n=6). The numbers were very small and it would be difficult to generalise findings from a practice evaluation like this. Baldwin and Brusco (2011) generally found intervention descriptions lacking or variable in quality.

A randomised controlled trial of a six week workplace intervention for stroke survivors with follow-up at three and six months was conducted by a physiotherapist in South Africa (Ntsiea, 2013). The author chose to call it work place intervention because it focused on facilitating return to a job held prior to stroke and she differentiated this from VR defined as finding work for someone who is out of work. This contrasts with the UK definition of VR which is process to enable people disadvantaged by illness or disability to access, maintain or return to work (Tyerman & Meehan, 2004) and also similar definitions stated in the introduction to this study. The study population included 41 males and 39 females whose average age was 45 years with an av

average stroke duration of 4.6 (SD 1.8) weeks. The overall return to work rate was 20% at three months and 40% at six months. At three months 27% of those who received the intervention had returned to work whereas only 12% of the control group returned. At six months these figures had increased to 60% and 20% respectively. The intervention, described in detail in this doctoral thesis, was delivered by an occupational therapist and a physiotherapist. The six week programme began with an assessment of the work skills of the individual using the 'Therapist Portable Assessment Lab' (Valpar International Corporation, 1992) and the job demands using the 'Job Content Questionnaire' (Karasek et al., 1998), this was followed by separate interviews with the stroke survivor and the employer about perceived barriers and enablers of return to work. A joint meeting then took place to develop a return to work plan. An initial worksite visit was conducted with the stroke survivor, assessing their work ability in situ. Adaptations were made to the environment and emotional support and advice on coping strategies to compensate for mobility and upper limb limitations and fatigue management were provided. This was followed by a series of weekly work visits to monitor progress and make any necessary adjustments. Participants also continued with their rehabilitation programme at the hospital which included physiotherapy, occupational therapy, speech and language therapy and social work as required. Final interviews were then conducted with stroke survivors and employers. This intervention would only be generalizable to stroke survivors returning to paid work where there is an employer for rehabilitation staff to liaise

directly with. It is not clear how long the rehabilitation programme at the hospital continued for and how intensive this intervention was. The control group received usual care which is described very briefly as the general rehabilitation programme provided to all participants as hospital in-patients or out-patients, where job requirements were taken into account but no work place visits took place.

Trexler et al. (2010) conducted a prospective randomised controlled trial of resource facilitation on community participation following ABI in the USA that looked at vocational status as one of their outcomes.

Resource facilitation is also known as case management and involves the coordinated management of resources to improve outcomes.

However, this was a very small trial with only 22 participants, seven of whom had traumatic brain injury, seven had intracranial haemorrhage, six cerebral infarcts and two had other diagnoses. At follow-up 64% of the resource facilitation group were employed compared with 36% of controls even though the former group were significantly more impaired in terms of participation at the outset. Despite the small numbers and the median time since injury in the intervention group being 52 days and 85 days in the control group, this study concluded that resource facilitation services that have a clear focus on return to work may have a substantial impact on participation and unemployment following brain injury. The intervention had increased access to VR services and specialised brain injury out-patient rehabilitation. The authors say that significantly more people in the resource facilitation group were referred to VR but that not all were found to need supported employment or job

coaching. Apart from this, no further description of the VR services or specialised brain injury rehabilitation they received is given and so it is not possible to draw any conclusions about the effectiveness of these services in isolation from resource facilitation or in comparison with each other. The small sample size and mixed range of diagnoses of participants make the results difficult to generalise.

An American post-acute brain injury rehabilitation programme for people with ABI was evaluated for 127 people following stroke (Adams et al., 2004). The intervention included assessment of cognitive, behavioural, emotional and social function leading to individualised treatment programmes to reduce the impact of impairments on daily life including work. An interdisciplinary team, including vocational specialists, provided a combination of individual and group intervention and counselling for relatives to address emotional adjustment issues. Simulation of tasks in a clinic setting preceded worksite analysis leading to job accommodations, ongoing support for employee, employer/ supervisor and a gradual return to work duties for those employed before stroke or assistance in finding a different job for those unable to return. Out of the 183 stroke survivors who commenced the programme, 24% withdrew or were discharged for other unspecified reasons. Fifty people were excluded including six because they were 65 years or older at discharge and an additional six as they were not productive prior to stroke. Following discharge from the programme 58% were classed as productive which included those in competitive, modified or supported employment, and education but not homemakers

and those doing voluntary work. Follow-up at one year was achieved for 70% of participants (n=90) and there only appeared to be a slight deterioration in productivity for this group (52%). The main limitation of this research is that it is a retrospective pre-post treatment observational study so there was no control group and vocational intervention was just one component of a generic brain injury rehabilitation programme.

Chan (2008) described hospital and community based occupational therapy return to work services for stroke survivors in Singapore. These programmes included work and driving assessments, work simulation, work site visits, recommendations for work adjustments, retraining for alternative jobs at a specialised vocational assessment unit, sheltered workshops or day care centres. Job trials, job placements and skills courses can be offered through these services. The scope of intervention appears to be comprehensive and generic. A survey was conducted at the specialised vocational assessment unit in 2005. Only 7% (n=29) of the clients seen at this unit were stroke survivors. The effectiveness of the unit was measured using a retrospective study of data records during 2004 when 55% of stroke survivors seen were able to return to work. There was no control group but 70% of those who returned to open employment (seven stroke survivors) had needed active assistance from the unit. The role of the unit in retraining blue collar workers in clerical/ white collar work is emphasised. Three case examples are provided highlighting the influence of individual factors such as motivation and job characteristics on outcome. The outcomes

of the other services mentioned in this paper were not investigated in this study.

Wehman et al. (1991) used a brief case study report format to describe a supported employment approach for a stroke survivor in Canada. A work capacity evaluation was carried out and the person was assigned a supported employment specialist, also known as a job coach. A phased return was negotiated and a number of adaptations made to the work environment including provision of equipment. The intensive nature of training and compensatory strategies provided at the job site is emphasised but it is not clear how long this individual was seen for and how much time the job coach spent at the workplace. The role of supported employment in helping those who have been failed by traditional VR is highlighted. However, the individual in the case study was deemed to be eligible for the supported employment on discharge from hospital but the criteria for this were not specified. Due to descriptive nature of this paper, the findings may be transferrable to similar cases but cannot be generalised.

Black-Schaffer and Osberg (1990) provide a brief description of a vocationally orientated in-patient stroke rehabilitation programme in the USA and its impact on return to work. It describes frequency of therapy sessions (occupational therapy, physiotherapy and speech and language therapy 10 times a week each) and states that VR assessment and counselling and neuropsychological testing were part of the programme but does not give any detail about what this involved.

It reports goals were set and therapy geared towards vocational needs of the patients. This description of rehabilitation which took place in the late 1980's appears very intensive but the setting means the results are not generalizable in today's health care systems where the focus has moved to out-patient and community based rehabilitation. However, 49% of participants had returned to work at a mean of 3.1 months after being discharged and approximately five months after their strokes. Due to lack of follow-up, whether this early return was sustained was not investigated.

Another American cohort study (Kempers, 1994) describes a Functional Occupations Programme for a very different group. Stroke survivors (n=39) had been out of their occupational role for more than a year when they entered this VR programme. The programme was designed for people 'post-injury' with physical disabilities and stroke only constituted 24% of the total number of patients seen. An interdisciplinary out-patient programme is described which included assessment, work preparation by building up skills needed using real or simulated work tasks. Work hardening including feedback and upgrading of work activities took place weekly using individual programmes and addressed deficits in work performance. VR specialists matched clients' abilities with job demands and assisted with appropriate job selection and placement. The average duration of the programme for stroke survivors was 10.25 weeks with an average of 14 hours intervention over three, four or five days per week. Following this programme 20% of participants returned to work and 20% to voluntary

work. There was no control group and follow-up of these outcomes was not carried out. Interestingly, they highlighted that 58% of the sample were blue collar workers and therefore state that return to work rates compare favourably to other studies where people in white collar work have a greater chance of returning. However, they do not provide a specific number/ proportion of those in blue collar work that returned.

McMahon and Crown (1998) also evaluated a VR programme in the USA using the data of 200 stroke patients over a four year period. A brief and very general description of the programme is outlined including assessment, vocational counselling, work trial assessment, job placement, job seeking and job maintenance skills training to assist with work preparation and job retention support including job coaching, employer education and job accommodations/ modifications. Results showed that 30% of the sample returned to paid work (21% with the same employer), 10% went onto voluntary work and 9% were engaged in sheltered work. In terms of job type, 31% of the sample was in the professional occupational group and 21% in the clerical and service job category. The potential influence of job type on outcome is acknowledged. The duration and intensity of the intervention are not described. Basic percentages are reported and further statistical evaluation of outcomes does not appear to have taken place.

In summary, VR intervention is not described in sufficient detail, in the available research literature, for it to be replicated. Evaluation of intervention programmes is very basic and mainly consists of cohort



studies where there are no control groups as a means of comparison or random allocation of intervention. The two trials (Trexler et al., 2010; Ntsiea 2013) are not comparable as one evaluates resource facilitation and the other a workplace intervention delivered by rehabilitation therapists. They are also delivered in two very different cultural contexts (USA and South Africa). There is insufficient high quality evidence to support or refute the effectiveness of VR in returning stroke survivors to work. Outcome measures used to evaluate intervention will be addressed in the next section.

#### **1.3.4 What outcome measures are used to evaluate VR for stroke survivors and how effective are they?**

Wasiak et al. (2007) point out, in their review of the literature, that one of the factors limiting return to work research is the lack of consistent and comprehensive measurement of work return. They also assert that one of the most important indicators of work participation is the worker's productivity following return to the work place, suggesting the Work Limitations Questionnaire (Lerner et al., 2001) as one measure that can be used to capture this. Even though return to work is a very important outcome for people following a stroke (Treger et al., 2007), there are no standardised stroke specific work return to work measures.

One of the difficulties in measuring outcomes of return to work studies is the lack of a clear definition of employment (Baldwin & Brusco, 2011). For example, whether it only means paid work, whether it is full or part time and whether other forms of productive activity like being a student, volunteer or homemaker are also included.

Most studies use work or vocational status as their primary outcome measure. Return to work rates which vary from 0-100% are cited across studies in reviews carried out by Treger et al. (2007), Daniel et al. (2009) and Baldwin & Brusco (2011). However, only a small proportion of studies reviewed are intervention studies. There is a lack of consensus in definitions of work status, some studies include voluntary work or return to a homemaker or student role in addition to paid work which makes it difficult to compare outcomes. For example, Black-Schaffer (1990) included full-time work, part-time work, homemaking and full-time university students in their definition of work, whereas McMahon and Crown (1998) excluded homemakers, students and volunteers from their definition of employment. Kempers (1994) defined work as all forms of productive activity irrespective of reimbursement and so worker, homemaker, student and volunteers were included. Two studies included sheltered work as one of their outcomes (Chan 2008, McMahon & Crown 1998) but whether this is paid or not is not made clear. Of the two trials, Trexler et al. (2010) included those employed or in education for two years prior to injury/ stroke, whereas Ntsiea (2013) only included those in paid employment. Pre-stroke vocational status is not always reported (Kempers 1994, Chan 2008) yet in some studies only those employed prior to their stroke met the inclusion criteria for the VR programme (Trexler et al., 2010).

The time points at which outcomes are measured are also hugely variable. It is not always evident how long after stroke or intervention

data was collected and follow-up is absent in many studies (Baldwin & Brusco 2011).

O'Brien and Wolf (2010) used a telephone administered Occupational Outcome Questionnaire at 6 months to determine work outcomes in an American study of 98 people following mild to moderate strokes. It was not made clear whether they had received intervention to assist with work return or not. They found 63% had returned to work but of those returning 56% reported performing at 75% of their ability or less. This study highlights that using work status alone is a very simplistic outcome measure and being back at work does not guarantee productivity.

#### **1.4 What does the current literature tell us and what are its limitations?**

The majority of research on return to work after stroke has focused on the analysis of predictive factors. There appears to be a consensus that stroke severity is a consistent and robust negative predictor but there are conflicting findings with respect to the multitude of other factors and acknowledgement that the interaction of factors and outcome is highly complex. The ICF has been used as a framework to organise existing literature and a model for illustrating this intricate relationship.

In their methodological review, Wozniak and Kittner (2002) highlighted that some studies have tried to build multivariate models in order to predict return to work (e.g. Hsieh & Lee 1997; Saeki et al., 1993; Saeki et al., 1995) and that these have potential value in looking at who

cannot return to work for social security administration purposes. But they point out their limitations in that some stroke specific deficits are not included in these models and yet would have a direct influence on return to work outcome, for example, if a school bus driver had hemianopia or a college lecturer had aphasia. They also propose that, in order to develop interventions that improve vocational status after stroke, it would be useful to develop explanatory models which focus on potentially modifiable factors such as mood, social support and job characteristics. These factors have been included in a number of subsequent studies (Glozier et al., 2008; Lindstrom et al., 2009; Vestling et al., 2005). They also recommended the inclusion of quality of life measures to quantify the personal cost of not being able to return to work after stroke. Some cohort studies have included quality of life measures, for example, the WHO Quality of Life questionnaire (Gabrielle & Renate 2009) and life satisfaction (Eriksson et al., 2009; Hartman-Maeir et al., 2007; Roding et al., 2009) and explored their relationship with return to work.

In the last decade, there has been a growth in qualitative research focusing on the experience of returning to work after stroke and ABI. Some of this work has contributed to a deeper and broader understanding of factors influencing return to work as described earlier in this chapter (Alaszewski et al., 2007; Culler et al., 2007; Ellingsen & Aas 2009; Hartke et al, 2011; Lundqvist & Samuelsson 2012; Macaden et al., 2010; Lock et al., 2005; Rubenson et al., 2007; van Velzen et al., 2010; Vestling et al., 2013).

However, other qualitative studies have examined the longer term issues in relation to changing jobs and retirement as a result of stroke. A qualitative interview study in the UK with 13 stroke survivors between three months and eight years post stroke (Gillworth et al., 2009) goes further to explore the experiences of people who have decided to make a career change and those who were unable to return and decided to take early retirement as a result of their stroke. Another study which looks at the longer term impact of stroke on work is a single in-depth narrative analysis of one person's journey back to work from three to six years after stroke. Issues of reconciling past and present identity and the transition to alternative employment after leaving the pre-stroke job were explored (Gustafsson & Turpin 2012). Another UK study where 19 stroke survivors and 12 informal carers were interviewed as part of a larger longitudinal study, also investigated the impact of being able to resume previously valued activities, including work, post-stroke on an individual's sense of self and identity (Robison et al., 2009). In a similar vein, an American interview study of 12 right hemisphere stroke survivors and 13 primary caregivers (Koch et al., 2005) discovered that making changes to employment, for example reduced hours, changing to a new position or finding a new job with a different employer or 'forced' or elective retirement could have either a positive or negative psychosocial impact depending on the individual circumstances. The impact on career development for people with disabilities is discussed. The effect on the caregivers employment was also revealed as some

had to reduce their working hours and others delayed their own retirement in order to support their spouse financially.

One qualitative study specifically explored the views of six stroke survivors in Sweden on the rehabilitation and work rehabilitation they had received (Medin et al., 2006). The general view was that rehabilitation was principally focused on bodily and functional recovery and not promoting return to work and that where professionals had not taken action, they had to take control of the situation themselves which could be seen as a positive occurrence. This was achieved in a number of ways including gradually returning to work on their own terms, discussing how work return could be supported with their workplace. They used their initiative and took action to return on a trial basis and engaged in problem solving if this was not successful in order to make it so. This is one of the few studies which has explored the perspective of stroke survivors on the work rehabilitation they received. However, caution in interpreting the results is urged by the authors as all of the participants had returned to work and they infer this may be because they had fewer deficits and the numbers were very small. The role of motivation and support were also discussed. Another Swedish study which investigated the views of younger stroke patients, approximately two years post-stroke, on experiences of the rehabilitation process involved in-depth interviews with five individuals (Roding et al., 2003). Using grounded theory, an hypothesis was generated that young stroke survivors feel frustrated and invisible because the rehabilitation setting does not acknowledge their age-specific difficulties. In contrast, a

qualitative interview study with 10 people recruited from a work rehabilitation clinic in Sweden for people with ABI (Rubenson et al., 2007) commented favourably on the service they had received from the team, in particular the OTs who facilitated discussions with groups of people in the same situation so they could share their experiences of returning to work and help each other. The role of support in engendering a sense of belonging during a year of rehabilitation for nine people aged 42-62 years following stroke interviewed was highlighted in another Swedish interview study (Erikson et al., 2010). This was linked with increased participation in work. In a cohort study of 83 stroke patients under 50 (Teasell et al., 2000) the specific rehabilitation needs of younger stroke survivors are emphasised including the need for a focus on return to work.

The views of employers of people with stroke on the return to work process have rarely been explored. Culler et al. (2011) interviewed seven employers of people with a range of disabilities including stroke some of whom described the advantages of support from VR staff. Eighteen employer stakeholders were interviewed in a study by Coole et al. (2013) who found that employers welcomed advice from health care professionals as they felt they lacked knowledge and experience in supporting stroke survivors into work.

Treger et al. (2007) reviewed the literature on return to work following stroke and pointed out the lack of knowledge about effective assessments and interventions in VR following stroke. They criticised

current research for not fully describing the interventions being offered, their utility or cost effectiveness.

Daniel et al. (2009) reviewed the literature on the social consequences of stroke for working age adults and difficulty returning to work is cited as one of these. Criticism is levied at existing studies for failing to describe the intervention offered. In the more recent systematic review of the effect of VR on return to work rates post stroke (Baldwin & Brusco 2011), only six studies, all single cohort design, were included and even these were rated as methodologically poor by the reviewers. The review states that unless standardised terminology and definitions are agreed and high quality trials carried out, no conclusions can be drawn about the effectiveness of VR on return to work after stroke. Even though two randomised controlled trials have taken place since this review (Trexler et al., 2010; Ntsiea 2013), they were not conducted in the UK and have evaluated two different interventions (resource facilitation and workplace intervention). The former was not only aimed at returning people to work but also increasing participation in home and community activities. This highlights that existing research in this field has been conducted in a number of countries including the USA, South Africa, Australia, Japan, Taiwan, Singapore, Sweden, Denmark and The Netherlands all of which have very different health and social care systems to the UK. For many the role of insurance has resulted in greater involvement of employers in the return to work process from a legal and financial perspective. The need for the development and evaluation of stroke specific VR in the UK is therefore evident.



So in summary, the majority of literature on return to work after stroke has focused on predictive factors which has been presented and critically evaluated in this chapter using the ICF headings as a structure. This has illustrated that although stroke severity is a robust predictor, it is a complex interplay of impairment, personal and environmental factors that impact on a stroke survivors ability to return to activities which enable participation in society as a worker. There have been a number of reviews (Treger et al., 2007; Daniel et al., 2009 and Baldwin & Brusco, 2011) that have all reached the conclusion there is insufficient evidence that VR is effective for people following stroke. Almost all quantitative intervention studies have been of a cohort design with just two randomised controlled trials to date (Trexler et al., 2010; Ntsiea et al., 2014).

Models of return to work interventions have been developed in the field of traumatic brain injury (Hart et al., 2006; Fadyl & McPherson, 2009) and sometimes these have been broadened for use following ABI (Adams et al., 2004; Malec & Moessner, 2006; Wehman 2009). Only one stroke specific model (Ntsiea et al., 2014) has been proposed in the literature to date and was the workplace intervention evaluated in the trial conducted in South Africa.

In the last ten years there has been a growth in qualitative research on return to work after stroke and much of it has been conducted by rehabilitation researchers in Scandinavia. It explores the facilitators, barriers and experience of returning to work and work rehabilitation.

Some of the longer term issues (e.g. promotion, career change and retirement) from the perspective of stroke survivors and their families are also examined. Very little work has been done to investigate return to work after stroke from the point of view of employers and other stakeholders.

The NIHR (2008) report on rehabilitation for long term health conditions, including stroke, suggested that new services like VR are evaluated before they become too assimilated so that comparison with local provision can be made. It also called for qualitative research on service user experiences of rehabilitation and their involvement in evaluation studies so that the extent to which their needs are being met can be captured. So the case for mixed methodology studies has been made clear and this study will combine a feasibility randomised controlled trial with a preceding stakeholder interview study and a post-intervention interview study with trial participants to evaluate the intervention from their perspective.

## **1.5 Aims of study**

The aims of this PhD study are listed below:

- To explore barriers to VR for stroke survivors in one county (Derbyshire).
- To establish what key stakeholders require from stroke specific VR

- To design, develop and deliver stroke specific VR in a feasibility randomised controlled trial comparing it with usual care
- To describe and analyse the content of the trial intervention
- To evaluate the effectiveness of stroke specific VR from the perspective of stroke survivors and their employers
- To evaluate whether the newly developed intervention was useful and acceptable to stroke survivors and their employers who participated in the trial
- To ascertain which components of intervention were perceived by trial participants and their employers to be most and least useful in promoting successful return to work

## **CHAPTER 2: A STAKEHOLDER INTERVIEW STUDY TO INFORM INTERVENTION DEVELOPMENT**

### **2.1 Introduction**

Existing qualitative research has illustrated some of the barriers to returning to work after stroke and what stroke survivors and their supporters feel would facilitate this transition (Lock et al., 2005; Alaszewski et al., 2007). Lock et al. (2005) in a qualitative study of 37 stroke survivors and 12 supporters (eight wives, one husband, one partner, one mother and one mother-in-law), found the rehabilitation process itself too short in duration and not sufficiently focused on return to work. Negative staff attitudes and infrequent liaison between rehabilitation staff and employers were barriers to work return. They also highlighted employer attitudes and willingness to make adaptations, social structural factors such as access, transport and societal attitudes including the lack of awareness of stroke in younger people. In addition, 'personal factors', which included individual impairments such as fatigue, difficulties with memory and processing and personal qualities such as determination were also important (Lock et al., 2005). Similarly, Alaszewski et al. (2007), in a qualitative interview study involving 43 stroke survivors under 60 years old, found both environmental (flexible work environment and supportive social networks) and personal factors including residual disability and the unique value and meaning of work to each individual were facilitators of return to paid employment.

However, evidence for the effectiveness of vocational rehabilitation (VR) intended to overcome such barriers following a stroke is scant (Treger et al., 2007). Whilst barriers to work return per se are well researched, barriers to accessing support to overcome them, such as VR are neglected in the literature. Prior to developing and delivering stroke specific VR in a feasibility randomised controlled trial in Derbyshire, exploratory research was needed to investigate existing return to work services and the barriers which limit access to them in the county. It was also an opportunity to explore key local stakeholder's perceptions of what post-stroke VR intervention should include and address. A stakeholder is someone with a vested interest in the success of an organisation or outcome of a service being delivered (Investor Glossary, 2012). In the context of this study, stakeholders included those with a vested interest in delivering, managing or commissioning services that advised or supported stroke survivors in a return to work after stroke and those in receipt of these services (stroke survivors and employers).

## **2.2 Aims**

The aim of the stakeholder interviews was to explore the existing barriers to VR in one geographical area (Derbyshire) and to find out what stakeholders required from stroke specific VR to enable successful return to work. This information was then used to design and develop the trial intervention. The county of Derbyshire was chosen as it has a city (Derby) and a mix of towns and villages. This ensured representativeness in terms of encompassing both an urban and rural

population and stakeholders from a variety of sectors. It is also the county in which the feasibility trial intervention was to be delivered.

### **2.3 Research questions**

1. What are the barriers to VR service developments in Derbyshire?
2. What do key stakeholders require from stroke specific VR to enable a successful return to work?

### **2.4 Method**

Qualitative interview methods were used to address the research questions. Prior to the interviews, services providing advice or support to stroke survivors wishing to return to work in Derbyshire were mapped as part of a larger study (Sinclair et al., 2014) and a number of key stakeholders and organisations were identified. In initial discussions and scoping work other data collection methods were considered, for example, a postal survey but this was not a practical possibility as one key stakeholder, a stroke coordinator with a role in strategic development of stroke services across the county, indicated that the provision of VR was both complex and evolving. Therefore a method of investigation was needed that would explore the relationships between services and how stroke survivors were able to access and utilise them, including any barriers faced. As at the time, no directory of stroke services existed, a comprehensive postal survey of current provision was not viable and the organisational and contextual factors relevant to service developments difficult to investigate. Therefore, qualitative interviews were considered to be the best method of exploring existing provision from the dual perspective of those both providing and

receiving it. Interviews provide the opportunity to pose open ended questions to a small, select group of individuals whereas surveys generally ask closed questions of large samples (Silverman, 2005). Interviews allow perceptions, knowledge and experience of the barriers to VR and opinions about what kinds of services are both needed and desirable to be explored. The underlying belief is that knowledge is situated and contextual so the purpose of the interviews was to ensure the relevant context could be brought into focus so that meaning and understanding could be created (Mason, 2004). In this study both formal and informal interviews were conducted. Informal interviews sometimes followed on from formal ones to provide more detailed information about how a service was operationalised. They were used because they can be conducted in busy work environments where a number of people are present. Informal conversations with team members and observations of services in action provided greater contextual understanding.

#### **2.4.1 Sampling method**

Robson (2002) describes the principle of purposive sampling as the researcher using their judgement to build up a sample which enables the needs of the project to be met. The reason why this method was selected is that people were specifically chosen in order to explore their viewpoint as either providers or recipients of services to support return to work so that the research questions could be answered from multiple perspectives. Therefore it was not convenience sampling, where people were selected in an opportunistic way, nor total population sampling

because the latter was neither practical nor necessary (Holloway & Wheeler, 1996). Instead, a sampling frame was created during a mapping exercise which identified services in Derbyshire that offered advice or support to stroke survivors hoping to return to work (Sinclair et al, 2014). Key stakeholders from a variety of employing organisations, professions and geographical locations in the county were then purposively selected as interviewees from this sampling pool (Appendix 1). Sampling began with key NHS and Social Services providers involved in delivering services in the city of Derby because it is the hub of the county and the participants were recruited for the trial from the Royal Derby Hospital. Further interviewees were then identified using snowball sampling, which is a variation of purposive sampling, where interviewees are used as informants to identify other members of the population of interest (Robson, 2002). During initial interviews, interviewees were asked to identify their counterparts providing services in the northern part of the county and for details of relevant stakeholders in the NHS, other statutory services (e.g. Department of Work and Pensions - DWP), the charitable (e.g. The Stroke Association, Headway) and independent sectors (e.g. organisations providing occupational health services to major employers in the area) whom they felt were addressing the needs of stroke survivors intending to return to work. People were selected for interview from the suggestions made during snowballing and the sampling pool in a way that ensured comparisons could be drawn between city and county providers and also across public, private and third sectors. In addition,



the perspective of stroke survivors who had returned to work and their employers who had experienced supporting them in this process was explored. These stakeholders were also identified through snowball sampling as a result of their connections with service providers, voluntary or employer organisations.

#### **2.4.2 Instrument**

A semi-structured interview schedule was devised (Appendix 2) based on systems methodology (Checkland & Scholes, 1999). In systems theory, services are seen as complex human activity systems which can be understood in terms of the relationships between their structure, process and outcomes. The rationale for choosing this methodology was the recognition that the transfer of knowledge from research to practice is not a linear process and that complex contextual factors such as existing organisational structure and process can significantly impact on outcome and therefore need to be understood (Currie & Suhomlinova, 2006). Questions were developed using the mnemonic 'CATWOE' (Customers, Actors, Transformation, Worldview, Ownership, Environmental) used in systems methodology to explore the perspective of interviewees (Sinclair et al., 2014). The questions evolved from a UK national mapping study of VR for people with long term neurological conditions (Playford et al. 2011). A semi-structured approach was chosen because it allows the interviewer to use the schedule flexibly (Holloway & Wheeler 1996). In this study, both providers and service users were interviewed. Semi-structured interviews promote a natural flow in conversation and the interviewer

can clarify, probe and delve deeper on responses elicited (Robson, 2002). This is helpful when trying to expose barriers as the natural tendency of service providers is to eulogise about the success of their provision (Hart et al., 2005).

### **2.4.3 Ethical Considerations**

The study was approved by the Leicester and Rutland Research Ethics Committee. Informed consent was sought and participants agreed to have an audio-taped interview. Data source was anonymised and all data was stored in accordance with the Data Protection Act (1998) following University of Nottingham Research Governance procedures.

### **2.4.4 Procedure**

Face to face interviews were conducted between July 2010 and June 2011. The majority were conducted by the author (MG). However, two employer interviews and one stroke survivor interview were conducted by one of two other research occupational therapists (OTs) working on the project. Interviews lasted approximately one hour and formal interviews were recorded using a digital voice recorder in a location chosen by the interviewee. They were then transcribed verbatim and transcripts checked for accuracy. Audio files and transcripts were stored on the university computer and were password protected for data security. Field notes were taken during informal interviews, stored securely and used in data analysis.

#### **2.4.5 Data Analysis**

Thematic analysis was used (Braun & Clarke, 2006). This is a foundational method of qualitative analysis for identifying, analysing and reporting patterns and themes within the data. It was selected in preference to other qualitative data analysis methods as it was not intended to generate new theory as is the case when using grounded theory and constant comparative methods but it is more in-depth than content analysis which is more suited to dealing with open responses in questionnaire data (Robson 2002). Phenomenological approaches were also not appropriate as it was not the purpose to carry out an in depth exploration of people's lived experiences but to find out their views and desires (Polit et al., 2001). Therefore, thematic analysis was chosen because it provides a rich and detailed account of the data in order to answer the research questions.

The six phases involved in thematic analysis (Braun & Clarke, 2006) are outlined below.

1. *Familiarising yourself with the data*: Reading and rereading the data and making notes on initial ideas
2. *Generating initial codes*: Coding interesting features of the data in a systematic way, collating data relevant to each code
3. *Searching for themes*: Collating codes into initial themes, gathering all the data relevant to each potential theme

4. *Reviewing themes*: Checking if themes work and creating a thematic map of the analysis
5. *Defining and naming themes*: Ongoing analysis to refine the specific nature of each theme and the generation of definitions and names for each theme
6. *Producing the report*: Final opportunity for analysis, the selection of compelling extract examples, relating the analysis back to the research questions and literature in a scholarly report

Analysis was deductive (top down) and driven by an analytical interest in a specific area (the barriers to existing support available for people returning to work after stroke and what stakeholders require from stroke specific vocational rehabilitation). Coding took place for the research questions outlined above which reflects a 'theoretical' rather than an 'inductive' approach to data analysis. Themes were identified at an explicit and semantic (surface) rather than latent (interpretative) level. Three researchers were involved in this process including the author and they completed phase one of analysis independently i.e. they read and reread the data and made initial notes in the margins of the transcripts. Then they moved onto phase two and generated initial codes and collated data relevant to each code. These codes were then collated into broader themes during phase three. Then the three researchers worked together to review, refine and name the themes (phase four and five) which were then related back to the research questions (phase six) (Braun & Clarke, 2006).

## 2.5 Results

### 2.5.1 Sample

Interviews were conducted with 18 key stakeholders (17 interviews) in Derbyshire (Table 2). The largest professional group interviewed were OTs providing stroke rehabilitation, with a range of post-qualifying experience and each representing teams working in different settings including in-patients, out-patients, community and occupational health services. In this county OTs took a lead role in delivering vocational rehabilitation. Other professionals and interviewees were employed in the NHS, Social Services and the independent sector. One of the stroke survivors was recruited from a young stroke support group run by the charitable sector, one was working in the NHS and the third in the private sector. The employers of two of the stroke survivors who participated in this stakeholder study were also interviewed.

**Table 2. Formal interviews**

<b>Interviewees</b>	<b>Number</b>
OTs	4
Stroke survivors	3
Stroke coordinators	2
Clinical Neuropsychologists	2 (interviewed together)
Speech and Language Therapist	1
Life Skills Adviser	1
Stroke Consultant	1
Occupational health adviser	1
Commissioner of NHS services for older people (previously responsible for stroke services – acute and rehabilitation for Primary Care Trust)	1
Employers	2

Informal interviews also took place with a further seven people working in the DWP, NHS, Social Services and education (Table 3).

**Table 3. Informal interviews**

<b>Interviewee</b>	<b>Number</b>
Disability Employment Adviser	1
OTs	2
Social worker	1
Speech and language therapist	1
Stroke support worker	1
Education coordinator	1

### **2.5.2 Stakeholder interview data analysis**

Three main overarching themes identified by the three researchers through the process of thematic analysis described above were: 'service design, delivery and resources', 'the influence of the workplace' and 'stroke survivor factors'. These final themes were named after reviewing and discussing a larger number of initial themes including 'idiosyncratic local configurations', 'partnerships and problems', 'service design', 'referrals' and 'referral gaps' (to services supporting return to work after stroke), 'resource demands', 'implications for patients', 'stroke survivor perspectives', 'the challenges of stroke', 'managing the managers', 'employers/ managers perspective/ work situation'. A thematic map (Appendix 3) illustrates data analysis.

The findings are described below in relation to the research questions about barriers to vocational rehabilitation, service developments to overcome these barriers and what stakeholders require from stroke

specific vocational rehabilitation. Direct quotations are used to illustrate specific points made during the interviews.

### **2.5.3 Research question: What are the barriers to VR?**

#### **2.5.3.1 Theme 1 - Service design, delivery and resources**

Access to support and advice regarding return to work after stroke was deemed to be restricted due to high demand for and limited capacity within existing services. Staff from two different out-patient services said they had a twelve-week waiting list at the time of the interview.

Entry criteria to some services meant those with more severe strokes were prioritised and those with milder strokes were not given the opportunity to access rehabilitation following discharge from hospital. In one out-patient service, referrals for those with more complex needs and requiring both occupational therapy and physiotherapy were accepted but those solely having cognitive problems and no mobility issues might miss out. The quotation below from a service provider demonstrates an awareness of the limitations of the acute stroke service in dealing with the return to work issues of people who have a mild stroke.

‘The turnover is so fast in the acute stages and I find this particularly with younger stroke patients, they’re sent home because they’re, you know, walking about and they can feed and dress themselves. They are independent from that point of view but actually they’ve got a lot of high level cognitive deficits so when they try to go back to work, they haven’t got the

concentration or their memory is not so good, they can't process things as well. And of course that impacts hugely on their working'. RTW-SI-D-116:166

Referral to existing services relied on a mixture of formal and informal networks and this depended on those in the network knowing what was available. An example of a formal network was NHS staff who worked in acute, out-patient and community stroke services with the same patients. Informal networks exist across organisations, for example, NHS and the DWP (Job Centre Plus) or charities (e.g. Headway) where therapists refer people and liaise as needed. Many of these informal networks were described as 'historical' by the participants, having been built up over many years. Paradoxically they were also described by the same people as 'ever changing', in terms of the services available. This is because new organisations spring up or change their names frequently. This especially applied to those larger organisations that had won contracts with the DWP and subsequently subcontracted local provision to smaller organisations (e.g. Remploy and the Shaw Trust). Another example of existing networks were residential courses provided by the DWP, accessed through a Disability Employment Advisor at Job Centre Plus and delivered by educational establishments. These were for people who had been unable to return to previous jobs, were claiming state benefits and required retraining and new skills in order to be able to find alternative work.



A care pathway can be defined as a plan of care that is developed and used by a multidisciplinary team and is applicable to more than one aspect of care (Kwan & Sandercock, 2003). Moving people along the stroke pathway from acute to out-patient and community based services relies on staff making appropriate referrals and, as illustrated below, people can slip through the net. There was no care pathway specific to return to work.

'He wasn't ever on our waiting list or anything, he somehow got missed, so he went back (to work) unsuccessfully.' RTW-SI-D-104:125

Geography also played a part in potentially restricting access to advice and support for return to work after stroke. There were differences in provision between the city and county and also between the north and south of the county. City based services saw approximately 72 working age stroke patients a year whereas each small community hospital in the county saw only 10. As a result, the city was in a position to offer both group and individual VR interventions for people with neurological conditions including stroke. The city services acted as a hub and were seen as specialists in vocational and neurorehabilitation. They also acted as a resource to county providers. Some patients from the county were referred to the city so that they could access these specialised group interventions.

'Our actual operational policy is that we are a resource of information, a specialist resource for other areas and we do have

other therapists ring up for advice... there are areas that haven't got neuro services.' RTW-SI-D-104:630

Commissioning can influence the provision of vocational rehabilitation. Some providers saw VR as part of the rehabilitation package but others felt that return to work was not seen by commissioners as a priority outcome for health services (e.g. the heavy workshop OTs). At the time of the interviews one NHS return to work service was under threat of closure because the commissioners did not share the view of providers that preparing people to return to work was an important aspect of rehabilitation.

### **2.5.3.2 Theme 2 - Influence of the workplace**

Company size and policy was seen to influence availability and access to occupational health and VR services. The opportunity for redeployment and retraining were seen as greater in larger companies. However, occupational health was seen to be geared more towards injury rather than complex neurological conditions like stroke. The occupational health business model adopted by larger independent sector providers appeared to reduce accessibility to stroke survivors and other providers. This is illustrated by the quote below.

'When I say we do telephone assessments, we call them 'call-backs' rather than telephone calls because we, our day is split into four hundred minutes clinical time so ten call backs, forty minutes ago, through-out the working day, twenty minutes to do the actual assessment, twenty minutes to do the actual report. If

we need any further time outside that, it's in our time.' RTW-SI-D-115:1009, 1041

Most assessments took place over the telephone and at a distance from the employee and the workplace and the tight schedule above, meant they had no time to liaise with NHS health professionals involved in the employees rehabilitation. Other VR providers expressed their frustration and dissatisfaction with this situation. However, the person providing the occupational health service felt it was satisfactory.

The difficulty in finding work in the current economic climate was raised and the possibility that some employers pressurised employees into taking medical retirement following a stroke therefore depriving them of the opportunity to take time to access VR and return to work.

'..we've had a few people here who were at work and had a stroke, then before they knew it they'd been signed off... medical retirement and they end up losing their job, and then six months after that they think, 'oh actually I think I could have done my job', in a way it's a bit too late..' RTW-SI-D-106:135

Self-employed people had a tendency to rush back to work as soon as possible, often for financial reasons, as illustrated by the quotation below and may miss out on VR.

'...that's a very common problem that comes up, we have a lot of people who are self-employed and of course they drive themselves back to work quite quickly if at all able.' RTW-SI-D-116:213

### **2.5.3.3 Theme 3 - Stroke survivor factors**

Stroke survivors and service providers highlighted that reduced confidence and self-esteem, reduced motivation, depression and anxiety were potential barriers to work return. It is possible they will also influence the uptake of or engagement with VR services as illustrated by the quotations below.

‘..we’ve got a young person in our service at the minute who could potentially get back to work but her anxiety is such a state.. she cries if we talk about work..’ RTW-SI-D-104:165

‘I realise now, I must have been depressed but no one ever picked up on it, you know, just stripped of my personality completely... my confidence had gone completely.’ RTW-SI-D-103:393

The presence of cognitive or significant speech and language difficulties can also make it difficult for people to access VR as return to work may be considered challenging by the health professionals involved, as indicated below.

‘Especially if you get someone back and there are cognitive problems. Cognitive problems are a big issue to overcome.’ RTW-SI-D-102:362

People turn down services and may want to forget they have had a stroke or not want to address the impact the stroke has had on their ability to work.

'We ring people up and I would say a good 50% say, 'No, we don't need any support services at the moment, we are fine.'

RTW-SI-D-108:393

The influence of partners and family members on return to work and VR can be variable. Some may discourage this by being very over protective and others may push someone to return to work before they are ready for financial reasons.

'I've got some people who can't, like the relatives will almost reinforce the fact that they 'oh he can't get back to work, he's not well.' RTW-SI-D-104:865

'we always seem to have quite a few who are self-employed and it may be that the relatives, their spouses, who are pushing them to go back and don't quite realise the hidden disabilities.' RTW-SI-D-104:765

A summary of barriers to VR (access and service development) as perceived by stakeholders is summarised in Table 4.

**Table 4. The barriers to VR access and service development**

<b>Barriers to accessing VR</b>
<ul style="list-style-type: none"> <li>• High demand and limited capacity of existing services</li> <li>• Stroke severity – people with milder strokes miss out on services</li> <li>• Referrals rely on historical networks and up-to-date knowledge of available services</li> <li>• Geographical variation - city/ county and north/ south of county - more specialised services in city and south of county</li> <li>• Work place occupational health and rehabilitation geared more towards common health conditions (e.g. musculoskeletal injuries) and not complex neurological conditions such as stroke</li> <li>• Stroke survivor factors e.g. reduced confidence and motivation, presence of depression and anxiety reducing uptake of VR</li> </ul>
<b>Barriers to VR service development</b>
<ul style="list-style-type: none"> <li>• Health service commissioning not recognising return to work as a priority outcome</li> </ul>

**2.5.4 Research question: What do key stakeholders require from stroke specific VR to enable successful return to work?**

**2.5.4.1 Theme 1 - Service design, delivery and resources**

Specialist stroke and VR knowledge was seen as essential in facilitating return to work and finding appropriate alternative work.

A multidisciplinary approach was seen as a desirable way forward for VR including the involvement of general practitioners. The view that a person's work status needed to be given a higher priority by clinicians while the stroke survivor is still in hospital was expressed.

Appropriate timing of VR was perceived as important. Some felt early intervention was needed following a mild stroke but others felt that later intervention is required for those with more severe disability. The

difficulties of predicting the right time was highlighted. Flexibility and responsiveness were seen as important aspects of VR service delivery.

‘Just going out there, it’s all coming from me, they’ll not seem to be getting anything from it and then all of a sudden it just clicks into place, timing.’ RTW-SI-D-105:359

A suggestion was made by one interviewee that review appointments with the stroke consultant could be the trigger for referral to services related to work return if the stroke survivor had not yet accessed them.

The idea of commissioning VR services using a lead provider model was explained by one interviewee. This would involve one organisation being commissioned to provide and coordinate the service on the understanding that they build in collaboration with other organisations. This interviewee saw ‘return to work’ as an intervention that required an integrated effort from the NHS, social care, the DWP and education.

Sharing resources with the traumatic brain injury service was one idea proposed in order to make more efficient use of what is currently available. The case management approach adopted by the traumatic brain injury service was seen as beneficial and an example the stroke service could follow. Case management is defined as ‘a collaborative process which assesses, plans, implements, coordinates, monitors and evaluates the options and services required to meet an individual’s health care, educational and employment needs, using communication and available resources to promote quality, cost effective outcomes’ (CMSUK, 2012). Case managers, based in health care, work

collaboratively within the multidisciplinary team to achieve desired vocational outcomes.

#### **2.5.4.2 Theme 2 - Influence of the work place**

More support and education for employers and managers, as part of VR, was deemed desirable in order to facilitate successful return to work. A quotation from a stroke survivor illustrates this point.

‘I think that employers need to be aware of what to expect from the post-stroke patients. She (my manager) had no idea.’ RTW-SI-D-103:683

Some service providers had concerns about legal issues and were looking into consent paperwork to ensure any communication with the work place would only take place with the stroke survivors’ permission.

Improved communication between occupational health departments and providers and NHS rehabilitation services was felt necessary.

Employers also expressed their lack of knowledge about stroke and need for support as illustrated by the following quotations:

‘Yes, I think (we need) someone to talk to, to make sure we are doing the right thing. Because you know, what do we really know about someone having a stroke, not an awful lot.’ RTW-EMP-02:402

‘The way I handled it, I let her (employee with stroke), get herself well. I didn’t investigate what actually happened to her and nor



was I given any instruction as to what her capabilities was when she came back to work...but should I have gone and found out myself, that's what I question' RTW-EMP-11:97, 229

#### **2.5.4.3 Theme 3 - Stroke survivor factors**

An individualised approach was considered necessary, tailored specifically to the needs of each stroke survivor. Preparation for work return, including the management of invisible disabilities like fatigue and changes to personality was part of this. One interviewee said that expectations of services have to be managed carefully if the stroke survivor does not have insight into their condition as this will influence the feasibility of returning to work.

Mentorship by other stroke survivors as part of VR was advocated and some services offered group work and had witnessed the power of peer support, specifically in relation to work related activity.

More support is felt to be needed for partners and families of stroke survivors in preparation for return to work. Education of the family was seen as a vital part of VR by some service providers.

'quite often we get a referral for the carer who is struggling, doesn't understand, not coming to terms, feeling angry because, you know, they've lost their supporter, almost their own carer. Their whole life changes.' RTW-SI-D-108:650

A summary of what stakeholders require from stroke specific VR is given in Table 5.

**Table 5. What stakeholders require from stroke specific VR to enable successful return to work**

- Specialist knowledge of stroke and VR
- Multidisciplinary approach including involvement of general practitioners
- An individualised, timely, flexible and responsive service
- Integration of services across the NHS, social care, the DWP and education
- A case management approach to VR as used in traumatic brain injury services
- Provision of support and information for the partners, families, employers and managers of stroke survivors returning to work
- Mentorship, peer support and group work with other stroke survivors to increase confidence and prepare for work return
- Work preparation including management of fatigue and other 'invisible' disabilities connected with stroke

## **2.6 Discussion**

### **2.6.1 Interpretation of results**

The identified themes provide some degree of insight into the barriers to VR that stroke survivors in Derbyshire experience and these findings add to what has been found in previous literature. These related to the way stroke and other non-stroke specific services were designed and delivered, the resources available, the work situation stroke survivors found themselves in and influential individual factors. Interview data revealed information about the structure, process and outcomes of existing services and ideas flowed about how return to work services could be developed to overcome current barriers.

Unlike this stakeholder study, most of the previous literature has focused on barriers to work return rather than VR but Deshpande &

Turner-Stokes (2004) commented on insufficient specialist VR services for stroke survivors in the UK. Medin et al. (2006) also found, in a qualitative study of stroke survivors, that return to work was not the focus of existing rehabilitation services and that the stroke survivors interviewed had initiated and coordinated this themselves. One of the stroke survivors in this study also perceived that she had been discharged home from hospital and left to get on with it. Lock et al. (2005) found that very few participants identified factors in the rehabilitation process that enabled employment. Negative attitudes of health care professionals and limited duration of rehabilitation were two difficulties raised. In contrast to this last point, a number of rehabilitation service providers interviewed in the current study said that people could be seen for up to two years post-stroke and there did not appear to be a clear exit strategy. This could explain the long waiting lists and yet no one suggested that this needed to be reviewed.

On the issue of stroke severity, the pattern of those with mild strokes being discharged quickly from hospital without being referred for rehabilitation was previously identified by Wolf et al. (2009) in a large database survey of 7740 people admitted to a neurology service in the USA. This problem was also raised in this study and the possibility of work issues being picked up at a six week review appointment with the stroke consultant suggested as one possible solution.

When exploring what key stakeholders required from stroke specific vocational rehabilitation, findings had some resonance with previous

studies, for example, the desire for employer involvement in VR (Vestling et al., 2003; Lock et al., 2005). A qualitative interview study with employers highlighted that they would welcome advice from clinicians as they often lacked knowledge and experience of how to support a stroke survivor in returning to work (Coole et al., 2012). Education about stroke, the impact of the stroke on the individual, legal issues with respect to disability management (especially in smaller companies) and awareness of existing support services were all identified as necessary. The role of the work place and individual factors has also been explored in previous research. Vestling et al. (2005) recommended that working conditions and motivational factors must be considered when engaging in work rehabilitation. Lindstrom et al. (2009), in a population based survey of factors influencing work return for 1068 Swedish stroke survivors aged 18-55, found that external support from others and a positive attitude to return to work increased the likelihood of success. Glozier et al. (2008) conducted a prospective population based incidence study of early psychiatric morbidity following first stroke in New Zealand (n= 1423) and stressed the importance of managing the emotional and physical consequences of stroke to optimise return to work. Tanaka et al. (2011) conducted a multicentre prospective cohort study to examine clinical, functional and occupational factors associated with early work return and highlighted the need for cognitive rehabilitation to enable the latter, an issue which links with the perceived challenges of cognitive deficits by some interviewees in the current study. The evidence to support cognitive

rehabilitation as part of VR will be examined in the next chapter. Lock et al. (2005) proposed that VR should include work on increasing self-esteem, confidence, fatigue management and advice on finances.

Stroke survivor factors are well researched in relation to predicting successful return to work, for example, physical, cognitive and psychosocial difficulties (Vestling et al., 2003; Lindstrom et al., 2009; Tanaka et al., 2011) but the influence of these factors on access to or uptake of VR has not been explored.

When investigating what stakeholders require from stroke specific VR to enable successful return to work, issues such as appropriate timing of VR intervention have not been addressed adequately in previous literature. The quotation in the results section about 50% of people turning down a service may be an indication that sometimes the offer of support comes too early and it is not until someone has been at home for a while they start to realise the impact of the stroke on everyday life and their need for support. Offering VR at a stage when the individual is ready to think about work and balancing this with the challenge of keeping a job open and avoiding the pressure from an employer to take medical retirement can be tricky. This kind of flexibility is difficult to achieve when referrals to certain services are made at specific points in time, for example, prior to discharge home from hospital.

Support for families in relation to work return has been called for by a number of researchers (Lock et al., 2005; Vestling et al., 2003;

Lindstrom et al., 2009) and this is reiterated by interviewees in this study.

A number of issues arising from the interview data resonate with recommendations made in the interagency guidelines for vocational assessment and rehabilitation after acquired brain injury (Tyerman & Meehan, 2004) (See Table 1 in Chapter 1). However many service providers interviewed were unaware of these guidelines and this highlights the known challenge of raising awareness and implementing evidence and new knowledge in practice (Currie & Suhomlinova, 2006). One of the barriers to implementation is that these guidelines are only recommendations and there is no audit to act as an incentive to bring greater weight and impetus to operationalising them as there are for other clinical guidelines like those of the Royal College of Physicians (Intercollegiate Stroke Working Party, 2012). The contrast between rhetoric and reality is evident in the comments made during interviews of service users, providers and commissioners. The guidelines recommended vocational assessment to determine readiness for return to work taking into account individual difficulties, personal and family circumstances. Vocational interventions including education and the building up of work skills and coping strategies follow on from assessment. Close liaison with the employer and occupational health to plan and action the return to work needs to take place with a clear review and monitoring system which includes seeking the views of relatives about how someone is coping. The delivery of VR in the NHS is seen as the job of psychologists and OTs but the limitations of current

NHS provision in meeting the needs of those with acquired brain injury who wish to return to work are noted by the authors (Tyerman & Meehan, 2004). Referral to the Disability Employment Advisers at Job Centre Plus is recommended if longer term adjustments and support are needed. The NSF for Long Term Neurological Conditions (2005) makes similar recommendations emphasising the importance of coordination across the agencies involved in supporting a return to work including the NHS, DWP, independent and voluntary sectors. Despite these recommendations, the Care Quality Commission (2011) found that only 37% of NHS Primary Care Trusts were providing support with return to work but since this time, a strategic decision to disband Primary Care Trusts meant the role of commissioning health services has become the responsibility of Clinical Commissioning Groups led by general practitioners (Ham, 2012). Interviewees in this stakeholder study, including a commissioner, have suggested that the NHS cannot achieve return to work outcomes singlehandedly and that interagency working is still deemed to be the most promising way forward. The Health and Well Being Boards (Ham, 2012), operationalised in 2013, present an opportunity for integrated working across health and social care which could facilitate services such as VR where joint funding initiatives offer a solution. This was the conclusion drawn following a qualitative interview study about VR services after stroke with 16 health and social care commissioners across three counties in England (Radford et al., 2013a). But in the mapping exercise of services offering return to work advice or support to stroke survivors related to this work

(Sinclair et al., 2014), two joint health and social care funding initiatives identified at the project outset were axed during the 10-month mapping period. Such service innovations, often established with short term funding (in this case Stroke Strategy monies) in response to aspirational targets, unmet need or to bridge service gaps appear to be 'partnerships on paper' but the mechanisms to make them work in practice have often been ill thought through and are not underpinned by evidence for effectiveness, making them particularly vulnerable.

In May 2013, a UK government policy entitled 'Making sure health and social care services work together' was issued (DH & Lamb, 2013) followed by The Care Act (UK Government, 2014) which made it law. Funding has been provided to support the process of joining up health and social care services for the benefit of patients and a commitment to make evidence-based integrated care a reality by 2018. Whether this will apply to return to work services as well as 'care' services across all age groups remains to be seen. Integration of health and the DWP would be more helpful and potentially lead to better outcomes in return to work services. This could work if a specialist vocational hub were created in the NHS which acted as a single point of referral early on after stroke and then joint working with other organisations like the DWP was built in as part of the commissioned contract with funds to ensure this happened in a systematic rather than ad-hoc way. However, even in countries where medical insurance creates a legal obligation for this kind of joint working (van Velzen et al., 2011; van Velzen et al., 2015; Doucet et al., 2012), it does not always lead to a multi-



stakeholder/ biopsychosocial approach. The involvement of occupational health physicians can lead to a medical model being adopted. In addition, the outsourcing of occupational health by large employers (both public and private) means the business model described in the findings of this interview study can potentially limit liaison between occupational health and rehabilitation services. This could, in turn, reduce the return to work potential of people with more complex conditions like stroke. Therefore this complexity would need to be addressed in any collaborative cross sector commissioning arrangements along with the issue that return to work is not currently an indicator for performance in the NHS outcomes framework (Department of Health, 2011).

## **2.6.2 Limitations of stakeholder interview study**

### **2.6.2.1 Sampling bias**

One limitation of the stakeholder interview study is that purposive snowball sampling can lead to bias in the people selected for interview. In this study most interviewees were from public services and mainly NHS employees. Within this group there was a strategic bias towards OTs as they were seen to be the key providers of VR for stroke survivors in this county. In other areas, there may be greater involvement of other professional groups like physiotherapy. Efforts were made to recruit general practitioners to this stakeholder study, especially in the light of the transition towards their developing role in commissioning services but unfortunately this was not successful. In addition, attempts were made to find stakeholders outside of the NHS

and Social Services, providing advice and support to stroke survivors wishing to return to work but it was more difficult to identify and recruit these people. For example, suggestions were made by interviewees about approaching human resources and occupational health departments of large employers in the area but getting access proved difficult without personal contacts. The occupational health adviser working for an independent provider of occupational health services for four major employers in the area was recruited via the NHS occupational health employee who was interviewed. This was because they had previously worked together and so it was made possible by personal introduction. More employer and stroke survivor interviews may have enhanced this study and in a future study it would be helpful to extend the scope of stakeholders to interview partners or family members of stroke survivors about their role and needs during the process of work return.

Geographically, the sample was biased towards those working in Derby city. Again, as the NHS and Social Services employees in the city were used as a starting point in the interview study, they tended to recommend others in the city that would be useful to interview. Names and contact details of counterparts in the north of the county were obtained and interviews arranged but the number of people recruited was limited. This was, in part, connected with plans for the trial intervention to be delivered in Southern Derbyshire so this was the most relevant context for informing intervention development.

### **2.6.2.2 Time of political and economic change**

There was a general election during the interview study and due to change in government and government policy, the DWP were in a time of transition. The work schemes 'Workstep' and 'Work Preparation' were replaced by the specialist disability employment programme 'Work Choice' in 2010 and 'The Work Programme', a mainstream employment programme was introduced in 2011 to replace 'Flexible New Deal' and 'Pathways to work' (DWP, 2013). The practical implications of this transition were not fully realised at the time of the interviews.

Another factor that created uncertainty at the time of the interviews was the impact of the credit crunch and the economic downturn on services being provided by the public sector. This appeared to affect social services more than the NHS. For example, a life skills advisory service was terminated as part of funding cuts in social services as it was seen as a 'luxury' service and the life skills adviser we had interviewed was made redundant. The contract of another interviewee seconded by social services into a stroke support worker post was not renewed and she returned to her previous position whereas two NHS funded support workers were kept on. These decisions, taken by the local authority demonstrate that in times of economic hardship, return to work services are not seen as a priority and resources are focused on services for the majority and for those with high level care needs. This was evident from the interview data and a move towards the use of personalised budgets to fund services was indicated. This is also part of the integration agenda and will potentially mean those with more severe disabilities

and greater personal care needs will shape the nature of service provision.

## **2.7 Conclusion**

This stakeholder interview study has highlighted a number of potential barriers to VR and service developments for supporting stroke survivors in a return to work in Derbyshire. Many of these relate to the way the services are currently designed, delivered and resourced. Other barriers arose due to the work situation stroke survivors find themselves in and factors connected with the impact of the stroke on the individual. Key stakeholders highlighted the necessary components of stroke specific vocational rehabilitation. It is suggested that a case coordinated approach to VR be adopted which enables an individualised, flexible and responsive service to be delivered. The OT, based within existing rehabilitation services would deliver and coordinate vocational intervention across sectors and agencies commencing in the acute phase at the appropriate time for each individual and continuing for a period of time after a person has returned to work to ensure that work is sustained. Alongside this, support for employers and families of stroke survivors should also be provided by the therapist to enhance the possibility of success. Work preparation including the management of invisible disabilities, such as fatigue, should be a key feature of intervention. These important findings directly informed the development of the stroke specific VR intervention delivered in the feasibility randomised controlled trial. The intervention development process and the intervention itself are described in detail in Chapter 3.

## **CHAPTER 3 INTERVENTION DEVELOPMENT AND DESCRIPTION**

### **3.1 Introduction**

In order to design a stroke specific vocational rehabilitation (VR) intervention for the feasibility randomised controlled trial which would meet the needs of stroke survivors in the locality, the Medical Research Council (MRC) guidelines for developing and evaluating complex interventions were used (MRC, 2008). There are three stages to this process; identifying the evidence base, developing a theoretical understanding of the likely process of change and modelling the process and outcomes of the intervention. This chapter will describe, in detail, the development process and the stroke specific VR intervention which was created for delivery in the feasibility trial.

### **3.2 Process of intervention development**

The MRC (2008) defines complex interventions as those that contain several interacting components. This could be in relation to a number of dimensions including the interaction between components within the experimental and control interventions, the degree of flexibility and tailoring of the intervention and the number and variability of the outcomes. All of these dimensions apply to the intervention developed in this study.

An overview of the three stage process in the development of the trial intervention recommended by the MRC (2008) will now be given. The first stage was identifying the evidence base. In this feasibility study,

relevant research literature and existing clinical guidelines were explored and used as a foundation for the intervention development.

The second stage was identifying or developing appropriate theory. The MRC guidelines acknowledge that it is not always clear from the beginning of the development process what the theoretical basis for change is and how it will be achieved. It is suggested that primary research is conducted, for example, stakeholder interviews with those proposed to be targeted by the intervention or involved in its development or delivery. A stakeholder interview study with providers and recipients of support to return to work in Derbyshire was conducted and views sought on what was required from the trial intervention to enable successful return to work. This study was reported in Chapter 2. The way the findings were utilised in the intervention development process are described in this chapter.

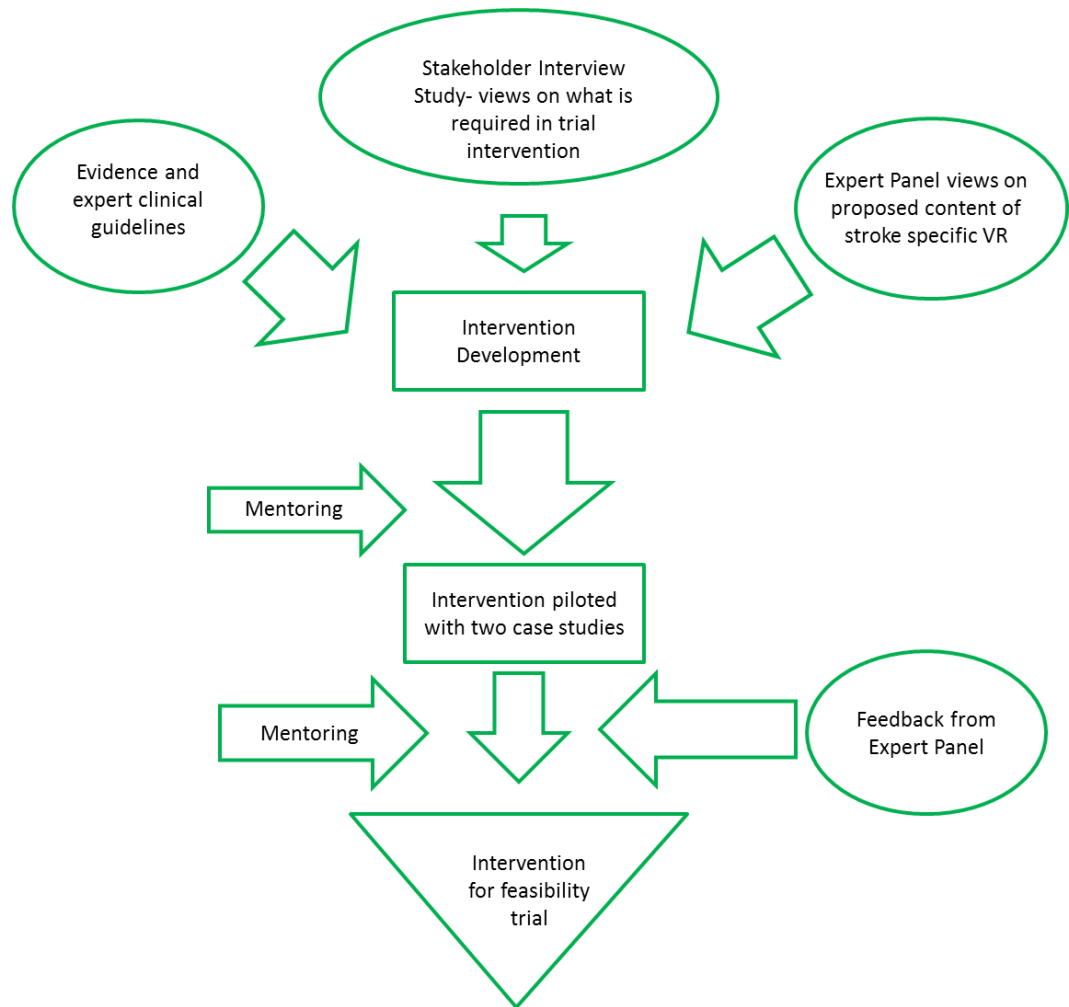
The third stage was modelling the process and outcomes of the intervention. The method used for this stage involved identifying and defining the key components and outcomes of the intervention using existing literature, clinical guidelines and input from a panel of experts (Richards & Hallberg 2015). A proforma, previously used in a study of VR for people with traumatic brain injury (TBI) (Phillips et al., 2010), used to record intervention components was presented to an expert panel to elicit their views on its suitability for people following stroke. The detail about how the proforma and therefore components of the intervention were altered in response to this feedback is described in

Chapter 5. One of the expert panel, an experienced occupational therapist (OT) working in out-patient neurorehabilitation, became a mentor to the research OT for the development stage and throughout the feasibility trial. Initially the intervention was delivered to two case study participants by the research OT and an account of the intervention presented to the expert panel for their feedback. The case study participants were also approached by an independent researcher to be interviewed about their experience of the intervention. The interview schedule is in Appendix 4. The interviews were recorded verbatim and analysed using thematic analysis (Braun & Clarke, 2006). The third MRC stage also included the development of a model of intervention which describes how this intervention interacts with other services/ agencies and the key stages of the intervention process. This model is described later in this chapter.

The stroke specific VR intervention developed for the trial will then be described in detail including the evidence on which it is based the specific actions and activities involved which will enable replication in future research and clinical practice. The reporting of the intervention is informed by the TIDieR checklist and guidelines for describing interventions (Hoffman et al., 2014).

The diagram below (Figure 3) illustrates the intervention development process.

**Figure 3. Diagram of intervention development process**



### **3.3 Evidence used to inform intervention development**

#### **3.3.1 Use of existing clinical guidelines**

A decision was made to base the development of stroke specific VR on interagency guidelines for vocational assessment and rehabilitation after acquired brain injury (ABI) (Tyerman & Meehan 2004). At the time of publication these guidelines reflected current best evidence and a consensus of expert opinion on mechanisms facilitating a return to work for people following ABI. They reflect the complex nature of service delivery in VR and highlight the need for development of these services



and cross sector working. They were supplemented by more recent evidence to develop the stroke specific intervention for this study.

Key features of the intervention described in these guidelines (Tyerman & Meehan, 2004) included vocational assessment, vocational interventions including education and skills development, specific verbal and written advice on graded return to work including a return to work plan and the support of 'Access to Work' (Department of Work and Pensions (DWP) provision) where appropriate. Liaison with the employer and family of the individual returning to work were seen as central to the process. The need for ongoing support following return to work was highlighted along with longer term adjustments and support from Disability Employment Advisers where appropriate. These features are echoed in the Vocational Assessment and Intervention for People with Long Term Neurological Conditions: Recommendations for Best Practice (BRSM, 2010).

### **3.3.2 Use of existing research literature**

Information gleaned from research literature was used to supplement above guidelines when developing the intervention.

#### **3.3.2.1 Liaison with employers**

A review by Treger et al. (2007) highlighted the influence of employer attitudes on return to work and stated that the success of VR depends on this. Vestling et al. (2003) conducted a retrospective correlational study using medical records and a postal questionnaire. They suggested that explicit discussions about return to work need to occur

within the rehabilitation team and with the patient and their relatives. In a qualitative study of 37 stroke survivors and 12 of their supporters, using focus groups, Lock et al. (2005) concluded that liaison with employers is needed to educate them on the needs of stroke survivors returning to work.

### **3.3.2.1 Role of support and vocational focus in rehabilitation**

In a national postal survey, in Sweden, where 1068 out of 1425 eligible working age stroke survivors responded (Lindstrom et al., 2009), conclusions were drawn about the importance of external support and positive attitudes and interventions aimed at increasing motivation, self-efficacy and social support in facilitating successful return to work.

Glozier et al. (2008) conducted a correlational study in New Zealand using a register of 1423 stroke survivors. They concluded that the emotional and physical consequences of stroke need to be managed appropriately to optimise recovery and return to work in young adults.

Hart et al. (2006, 2010), exploring vocational interventions and supports for people with traumatic brain injury, found that emotional and cognitive adjustment appeared to require more intense intervention and that job coaching and support following return to work were also rated as important by participants. The use of phone and email contact to supplement face to face intervention was described and this level of detail about the nature of intervention delivery is lacking in many studies to date. Lock et al. (2005) stated that health professionals involved need to express a positive attitude towards return to work and rehabilitation needs to be longer in duration, not coming to an end when

minimal function regained. They also suggested that rehabilitation may need to include work on/ or referral for increasing self-esteem, confidence, management of fatigue, reduction of functional impairment and advice on finances. Fadyl & McPherson (2009), in their review of evidence about VR following TBI point to a consensus in the literature that individualized vocational intervention is important and evidence that the therapeutic relationship between individual rehabilitation staff and their clients is critical to outcome. Waddell and Burton (2004) highlight the role of transitional work arrangements, adjustments, or accommodations involving making changes to the individual's usual work tasks, equipment or organisation in facilitating (early) return to work. This is reiterated by Hart et al. (2010) who also highlight family/ significant other intervention to support work goals following TBI.

Further research evidence used to underpin individual components of the trial intervention is highlighted later in this chapter as part of the detailed intervention description. Hoffman et al. (2014) recommend describing activities used in intervention.

### **3.3.3 Summary of findings of qualitative stakeholder interview study which informed intervention development**

A number of key stakeholders, including stroke survivors, employers, NHS and social care service providers and commissioners, statutory (DWP), voluntary (Stroke Association) and independent sector (private sector occupational health) service providers, were interviewed about existing services to support people back into work after stroke in Derbyshire and what they felt would be required in the stroke specific

VR intervention being developed for the trial. The selection of these key stakeholders and a full account of the interview study findings are described in Chapter 2. Their recommendations for the trial intervention were:

- Specialist knowledge of stroke and vocational rehabilitation
- Multidisciplinary approach including involvement of general practitioners
- An individualised, timely, flexible and responsive service
- Integration of services across the NHS, social care, the DWP and education
- A case management approach to VR as used in TBI services
- Provision of support and information for the partners, families, employers and managers of stroke survivors returning to work
- Mentorship, peer support and group work with other stroke survivors to increase confidence and prepare for work return
- Work preparation including management of fatigue and other 'invisible' disabilities connected with stroke

These recommendations were taken into consideration when developing the intervention.

### **3.4 Vocational training and mentorship of the research OT**

In order to fulfil the requirement for specialist knowledge of stroke and VR, the research OT attended a three day training course delivered by Harrison Associates which built on her previous knowledge and skills

and this learning was applied to the development of the intervention for this study. The research OT delivering the intervention had 25 years post-qualifying experience across a range of conditions including stroke. This particular training course was chosen as it is highly regarded in the field of VR in the UK and was led by an OT who is the author of a key textbook on the subject and has experience of delivering VR in both the public and independent sectors (Holmes, 2007). It covered the return to work process, assessment of the worker and job analysis, work preparation, work modifications, planning a phased return to work, reviewing and problem solving, outcome evaluation and referring to other agencies if unable to return to work (Holmes, 2010) (More detail of course content is provided in Appendix 5). A combination of seminars, course participant group work and the use of case studies encouraged active learning, the application of knowledge to real world scenarios and practical preparation for delivering vocational rehabilitation.

Another influence on development and delivery of this specialised intervention was the mentorship of the research OT by a member of the expert panel. A senior OT from a local neurorehabilitation out-patient department with experience of VR and stroke assumed the role of clinical mentor and regular meetings took place where the intervention for the study participants was discussed. Foci included the need for specialised assessments, agreeing specific goals for intervention, the influence of insight and motivation and practical ideas for intervention. Advice was sought on the duration and intensity of intervention and the

need for a more intensive approach when cognitive difficulties existed. In complex cases, maps were drawn to look at all the people, agencies and services involved and the impact of contextual factors on outcomes.

### **3.5 Case study pilots and input of the expert panel**

Intervention provided for the two case study participants is described in Appendix 6. This information was presented at a meeting of the expert panel who consisted of two stroke survivors with experience of working in the public and independent sectors and other local and national experts in stroke and/ or vocational rehabilitation. They included ten experienced OTs working in the NHS, independent sector and research, an NHS rehabilitation consultant and an NHS speech and language therapist.

The intention was that the two case study participants would be treated in the same way as trial participants and would be interviewed regarding their perceptions of the intervention following its completion.

#### **3.5.1 Feedback on case study pilots from expert panel**

Members of the panel were asked for their feedback on intervention provided at the expert panel meeting.

##### **3.5.1.1 Fatigue and sustainability of return to work**

Fatigue was discussed in relation to the challenge of making return to work sustainable. Concerns were expressed that Case Study 1 was going to bed at 8.30pm due to fatigue caused by increasing hours at work and not being able to take a rest in the day time as he had done

earlier in the phased return. Some members of the panel felt this was not sustainable and the issue of pacing and working with participants to help them achieve a healthier balance between activity and rest was discussed. The impact of diabetes on tiredness was also raised and whether this might also be an issue for Case Study 1.

This feedback ratified the use of information provision and education on fatigue management and highlighted the importance of considering the presence of medical conditions, apart from the stroke, which can impact on fatigue levels and ability to work.

#### **3.5.1.2 Liaison with General Practitioners (GPs)**

Diabetes management and the advice people receive from their GPs was discussed. Members of the group gave feedback based on their own experiences of how to effectively establish a two way dialogue with GPs. Some OTs on the panel said they phoned GPs if they needed specific information about the medical condition or to establish when the GP thought someone should to return to work. Opinions about the best time for someone to return to work were felt to differ between GPs and Consultants. One participant suggested attending GP appointments with the patient. Other panel members suggested providing letters, written to the GPs, for the patient to take to their GP appointment.

This ratified the plan to liaise with GPs regarding participation of their patients in the trial and with respect to intervention being provided where appropriate.

### **3.5.1.3 Liaison with Employers**

As Case Study 2 did not want the research OT to have direct contact with her employer but had been happy to pass on a letter outlining a proposed phased return to work plan, discussion took place about the value of liaison with employers. The research OT was asked how much she would push for direct liaison/ meetings with employers and she felt it was dependent on the individual patient involved. It was suggested by one panel member that the research OT may need to use her clinical skills to persuade someone that this would be a good idea whereas another member said that in her experience some patients would not grant permission for contact with their employer to be made and that this should be respected. One panel member cited her experience of working with employers in Australia where liaison with employers is a routine part of the process due to different legislation. She felt that some employers do not understand stroke and would need to be reminded of their legal obligations. Another panel member felt that providing employers with information is helpful.

This feedback ratified the promotion of direct employer liaison when appropriate and when consented to by trial participant.

### **3.5.1.4 Intervention**

The role of support workers was raised and whether some of the intervention outlined in the presentation could be delivered by rehabilitation support workers as was the case in one of the panel member's services. This was felt to be a useful future consideration for



roll out. However, within the given resources of the research project this was not possible during the feasibility trial.

The role of work simulation tasks was also raised, e.g. the suggestion that cooking tasks could have been carried out at home with Case Study 2 in preparation for return to her work in catering. This sanctioned the use of work simulation in the home environment in order to assess and prepare participants for work return.

#### **3.5.1.5 Role of the orthoptist**

The role of the orthoptist was discussed as Case Study 2 was seen by an orthoptist and Case Study 1 was not, even though both had been diagnosed with hemianopia. One medical panel member said that all patients with visual problems should routinely be referred for a follow-up assessment with the orthoptist.

This endorsed liaison with other services and encouraged referral to existing services as part of the intervention. If direct referral is not possible then the research OT could advise participants to ask their GP to make referrals.

#### **3.5.2 Case study post-intervention interview findings**

In addition, an interview with the participant in Case Study 1 was conducted by an independent researcher. It was not possible to conduct an interview with Case Study 2 as this person disengaged from the intervention and research and could not be contacted. The reason for this was not known.

### **3.5.2.1 Case study 1 - Thematic analysis**

Themes identified from the data are illustrated by direct quotations from the transcript.

#### **3.5.2.1.1 *Intervention content***

Case study 1 affirmed that, for him, the intervention included the right mix of support and guidance with respect to visual problems, driving, fatigue and work return.

‘Well I think in essence I think that the thing I got from it was that there was somebody there that you could discuss things with, that had a little bit of experience as to what you were going through. That was really the essence of it’.

He also commented that while he was self-employed, he thought employer liaison would be useful to educate them about the physical and mental impact of the stroke and its’ impact on the work role.

‘I think that is an area (liaison with employer) where it could be very effective because there is nothing out there at the moment is there? Nothing at all’

‘I think it is a good idea if somebody somewhere was doing it (assessment of capability to do the job). I think that is probably one of the benefits, one of the biggest benefits of this thing really’.

#### **3.5.2.1.2    *The value of a phased return***

Due to previous experience of medical ill health, the participant was already familiar with the concept of a phased return but felt the stroke was different in that he was surprised by the level of tiredness he experienced. He described the importance of taking it easy during the first month and accepting help from family members in running the business, then building up his hours, days and duties at work gradually.

#### **3.5.2.1.3    *Intervention delivery***

He felt the timing and duration of intervention were appropriate to his needs.

He explained that he had not received any other post-stroke support from the NHS but had appreciated the support and follow-up from the research OT.

‘I really didn’t get any follow up from anywhere else’.

#### **3.5.2.1.4    *Suggestions for future delivery of intervention***

The participant said that he could see advantages in a return to work service being sited outside the NHS or at least with a ring fenced budget if within the NHS to enhance its effectiveness.

‘Well if it was a bit more independent, then it would probably be more aggressive and more effective but I don’t think, but then maybe you can do that within the NHS I don’t know. It depends on the management style doesn’t it and who is running it and all of that sort of stuff’.

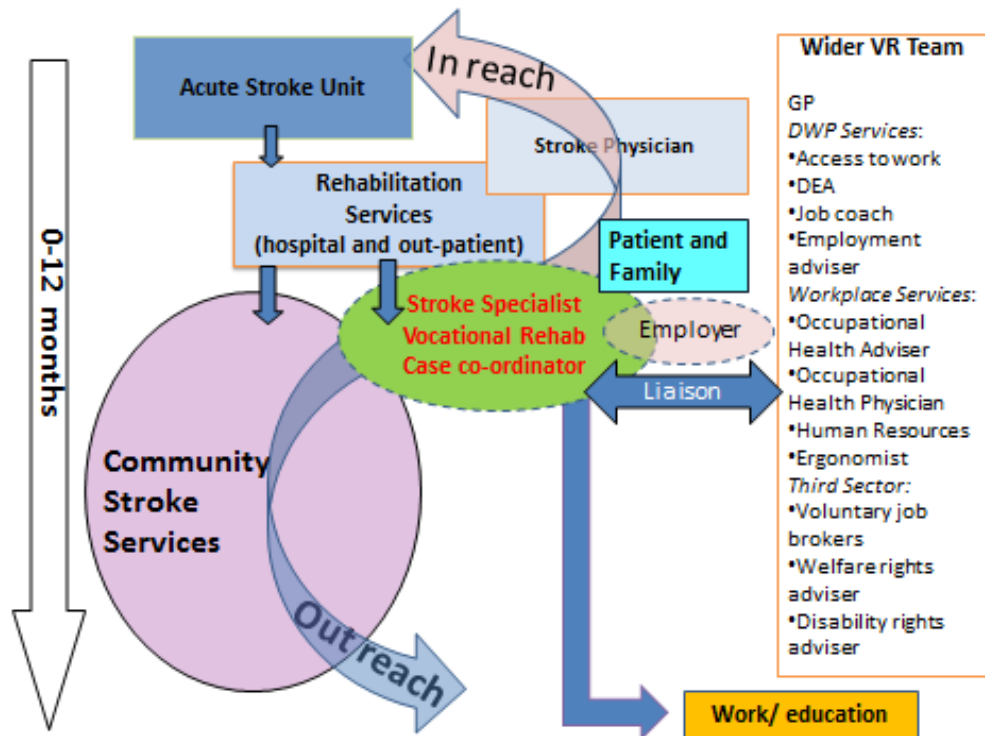
### **3.6 Development of a model of early stroke specific VR intervention**

As a result of the development activity above, a model of early stroke specific VR intervention was created to describe the intervention. There are two aspects of an intervention model to consider, its relationship to other services (where it sits) and what it does. These are depicted in Figure 4 and 5 respectively. The first shows the OT situated and working between acute stroke services and community services. In-reach involved participants being seen on the acute and rehabilitation stroke wards as early as possible following stroke. Some were seen within a couple of days, others within the first few weeks or months post-stroke. Intervention usually commenced within the first 30 days. In-reach involved liaison with rehabilitation staff on the stroke wards and neurological out-patient rehabilitation services. Out-reach encompassed liaison with intermediate care/ early supported discharge teams, community stroke services (e.g. speech and language therapy) and the wider VR team. This was through liaising with staff working with the trial participants about their progress in rehabilitation and potential difficulties in relation to preparation for work return. Examples of this included liaison with speech and language therapists about the communication difficulties and the potential impact on the persons work role. Liaison took place with out-patient physiotherapists about mobility/ physical recovery from stroke and OTs/ clinical neuropsychologist with respect to cognitive difficulties and any intervention being provided to coordinate intervention and avoid overlap. It also involved making referrals to services such as the clinical neuropsychology service or the

neurological out-patient therapy service if additional specialised assessments or interventions were deemed to be required. For example, cognitive assessments, memory group intervention or the self-management group. Liaison with the stroke support service also took place if advice was needed on finances or additional psychological support was required by the stroke survivor or family members. With respect to the wider VR team, the OT contacted the Disability Employment Advisor at Job Centre Plus and attended appointments with the stroke survivors who were looking for a new job or for advice on the availability of training. Meetings with voluntary job brokers were also arranged and information sought about community projects, for those looking for voluntary work as preparation for return to paid work. Advice on 'Access to work' services, how they could be contacted and what they could offer was provided. The OT communicated with the GP with respect to intervention being provided and the time frame for work return for some individuals. Liaison with the stroke physician took place, for example, if there were concerns about changes in mood during initial assessment and intervention. The OT also attended occupational health appointments with participants and joined meetings between the participant and human resources managers when appropriate. For people who anticipated difficulties with their line managers, the disability rights adviser at a local charity was contacted and asked to attend return to work planning and review meetings. Sometimes, trade union representatives were also contacted and involved in this process. The OT acted as a case coordinator in a way previously described by Fadyl

and McPherson (2009). The OT also liaised with family members and the employer where appropriate.

**Figure 4. Model of relationship of early stroke specific VR to other services**



The flow diagram in Figure 5 depicts a model of the process and nature of the intervention itself in three key stages. In stage one it shows the OT intervenes early to ensure work is on the agenda and jobs are not relinquished but kept open. Assessment of the individual, the impact of the stroke and a detailed job analysis and liaison with family members takes place at this stage. Plans are made to prepare the individual for work return by providing information and education and liaising with the employer where appropriate. The participant is encouraged to keep the channels of communication with the workplace open and the OT offers to mediate if difficulties arise. Activities are undertaken at home,

relevant to work or simulated to build up the stamina and skills required to return to work. These include physical, cognitive or communication based activities depending on how the stroke has affected someone and what the demands of their job are. Liaison with any other services the person is receiving takes place to ensure there is no overlap and approach to VR is smoothly coordinated.

The second stage involves planning and implementing a phased return to work. This might involve a worksite visit and negotiation of realistic timing and any work place accommodations to ensure success.

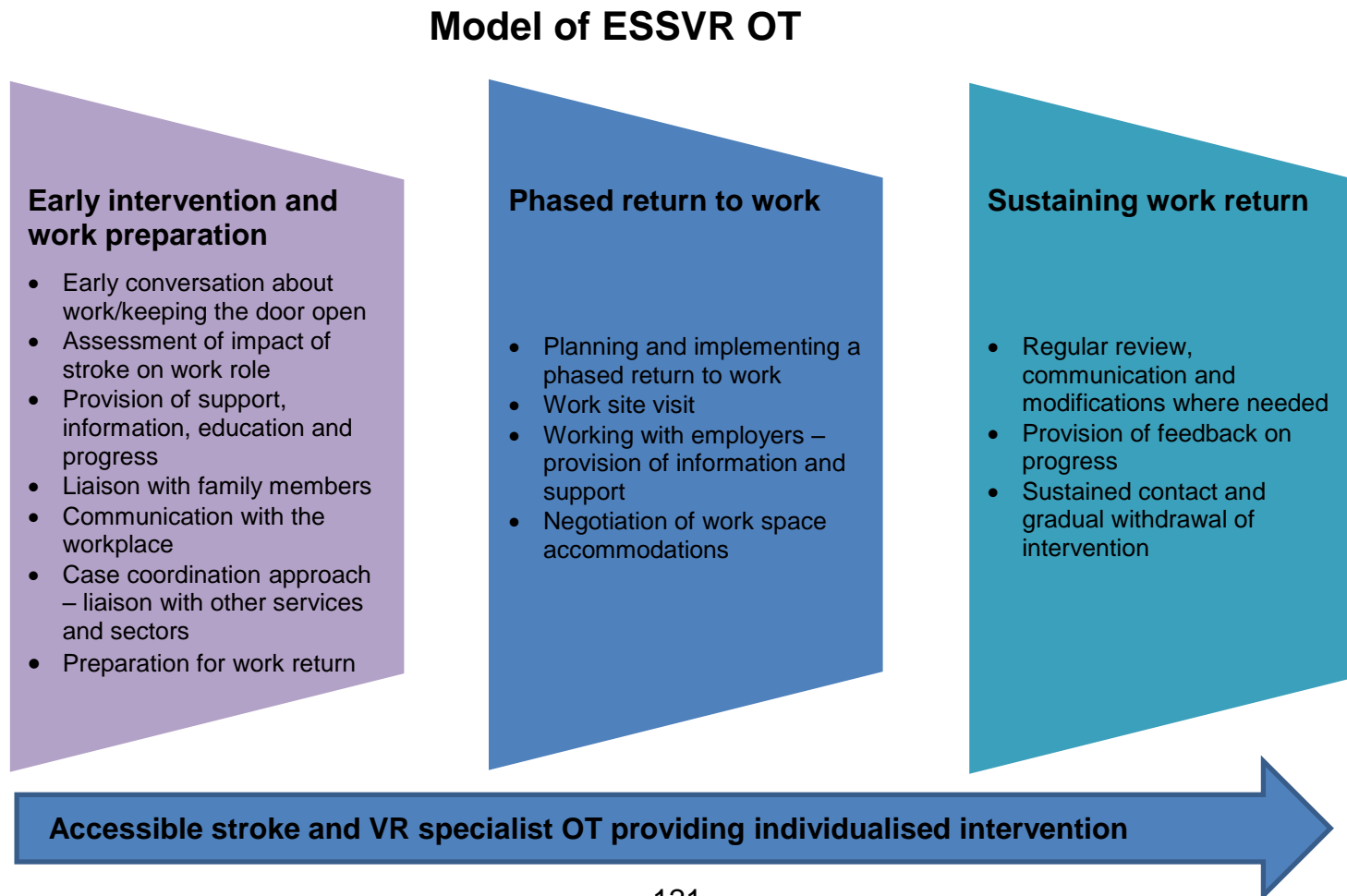
Information and education for employers is part of this stage to increase the employer's understanding of the impact of the stroke on the individual and how this might influence their ability to meet job demands.

In stage three, following work return, the focus is on sustaining work by implementing regular reviews and making modifications if needed.

Feedback is provided on progress and this contact is sustained for a period of time according to need and complexity and withdrawn gradually.

Throughout the three stages, psychological support would be provided to the individual and their employer and matters arising are dealt with flexibly. Liaison with other services and agencies is ongoing.

**Figure 5. Model of Early Stroke Specific VR OT**





This model of intervention was tested in the feasibility randomised controlled trial described in Chapter 4. The analysis of the intervention content is described in Chapter 5.

### **3.7 Intervention description**

The components of the intervention delivered in the trial are described in detail using the TIDieR guidelines (Hoffman et al., 2014) and examples given about how intervention was tailored to individual recipients.

#### **3.7.1 Assessment of the individual**

Assessment of the individual involved a combination of an initial interview, standardised measures and observation of mood, function, cognition, stroke impact, work, participation and readiness for work return. This was the first stage of the intervention process which helped to identify the difficulties the person was experiencing and how these might impact on their ability to return to work. It also helped to develop a therapeutic relationship with the patient (Sumsion, 1999). Chan et al. (2008) describe an occupational therapy return to work programme for stroke rehabilitation in Singapore. Vocational assessment is described as a key feature involving cognitive and work assessments.

##### **3.7.1.1 Initial interview**

An initial interview was conducted at the beginning of intervention period to explore participants' perceptions of the impact of the stroke and their needs and expectations regarding work return and intervention. This was carried out in a similar way to a semi-structured

interview where information was gathered by asking questions about the person's health (in relation to the stroke), how they were currently functioning (including difficulties they are experiencing due to the stroke) and what their job entailed (Ross, 2007).

### **3.7.1.2 Standardised assessment**

Standardised assessment took place either whilst in hospital or at the patient's home. A number of measures included as baseline assessments for the trial were used to inform the initial assessment of the participants post-stroke function, mood, cognition, participation and work status. These measures are described in detail in chapter 4.

These provided specific information about the person's mental, health and functional status to inform intervention. More detailed cognitive assessments were conducted when required by the research OT (e.g. Behavioural Assessment of the Dysexecutive Syndrome, Rivermead Behavioural Memory Test) and referrals were made to clinical neuropsychology and neurological out-patient rehabilitation services when more comprehensive cognitive assessments were required. This arrangement with existing services worked well and enhanced the intervention by making specialist expertise available to the participant to support their return to work.

### **3.7.1.3 Observation**

Observational assessment was used, during the initial interview and subsequent intervention sessions to complement information gleaned from standardised tests, to assess verbal communication, mood and the

impact of the stroke on their mobility, cognition, speech and ability to work.

Participants were observed during work site visits, meetings held with employers and during interaction with family members during home visits. This enabled the potential influence of relationships on recovery to be assessed and educational needs identified so that specific support and information could be provided to employers and family members.

#### **3.7.1.4 Job analysis and worksite assessment**

An analysis was carried out of the demands of the job and workplace that the participant was returning to, looking in detail at the roles and responsibilities (Holmes, 2010). The participant was asked to describe their job and the skills and tasks required. Where available, a written job description was requested. Where possible, when participants consented, a visit was made to the workplace to meet the line manager/ employer (and sometimes work colleagues) and an assessment was made of the demands of the work environment (physical, cognitive and social) (Ross, 2007). An analysis was made of the match between job demands and the ability of the individual to meet these (Holmes, 2010) in light of the impact of the stroke and the support available to bridge the gap. An example of this would be looking at someone whose job comprised working in the office and travelling to work sites with uneven ground. If they were initially unable to manage site visits due to reduced balance and mobility, then telephone calls, emails with photographs were used as a substitute and the participant was still able to offer advice to colleagues on site based on this information. If a site visit was

essential then a colleague could be asked to help out and cover until such a time that the stroke survivor could safely walk on uneven ground. These accommodations were also helpful in reducing fatigue in the initial stages of work return as driving to the worksites was tiring.

These assessments were used as the basis for identifying challenges faced and guiding person-specific information provision, goal setting and intervention planning. By discussing the findings of these assessments with the participant, employer and others involved in supporting the return to work, it was possible to negotiate priority areas of intervention based on facilitating a successful return to work. It also informed the individualised nature of the intervention as it related to the impact of the stroke and the job.

### **3.7.2 Goal setting and intervention planning**

Drawing on evidence for the effectiveness of goal setting in rehabilitation (Wade 1999, Hartigan, 2012) for increasing motivation (Conneeley, 2004), long and short term goals were identified and agreed between therapist and participant and where appropriate, their employer. These goals related to the returning to work and the rehabilitation needed to prepare for this for example, a short term goal of walking around the block near home to improve stamina was set to prepare for the longer term goal of walking around a worksite when back at work. These were documented in emails or letters to the individual and copied to relevant health professionals (i.e. GP), employers and others (e.g. occupational health) where consent was given.

Goals were regularly reviewed and modified throughout the return to work process noting feedback on progress, self-evaluation and monitoring. Feedback and encouragement from the therapist were important elements of intervention with the purpose of maintaining motivation and building self-efficacy in relation to work return (Vestling et al., 2005; Locke & Latham, 2002).

### **3.7.3 Individualised intervention sessions and homework tasks**

Individualised intervention sessions focused on providing education or preparing the person for return to work by promoting the use of specific skills and abilities (physical/ motor, sensory, cognitive, social, emotional) required for the individual's job. For example, fatigue management, increasing stamina and strength, sensory re-education, multi-tasking, increasing concentration, memory strategies, verbal and written communication.

The intervention targeted difficulties identified in the literature through stroke survivors' lived experience of returning to work (Lock et al., 2005; Robison et al., 2009).

For example, Flinn & Stube (2010) conducted focus groups with 19 stroke survivors living in the community, looking at the impact of fatigue. They found that fatigue management was important in preparing for work return. They used education and a number of fatigue management strategies including energy conservation and problem solving. Participants indicated that exercise such as walking or water aerobics were helpful strategies in reducing fatigue.

A Japanese study of 30 people with post-stroke hemiplegia demonstrated that increasing level of daily activity and exercise (mainly walking) improved their physical fitness (Fujitani et al., 1999) which might also be advantageous in preparation for work return.

Sensory loss following a stroke can be addressed using sensory re-education (Yekutieli & Guttman, 1993). This small scale controlled trial evaluated the use of retraining of sensory function of the hand in stroke patients and found it to be effective. This may be an important element of VR depending on the job type. Risk assessment and education about managing sensory loss is vital in cases where sensation does not return or remains altered.

A Cochrane Review by Pollock et al. (2011) found limited evidence to support the use of compensatory visual scanning training for people with visual loss following stroke. Also an earlier review by Wolter & Preda (2006) proposed the use of assistive technology for people with visual deficits using computers following stroke. These interventions could both be of potential value in preparing people for work return.

Wehman et al. (2009) discussed the evidence for effectiveness of cognitive rehabilitation in the context of VR for individuals with ABI and identified two key models of remediation and compensation. Evidence cited as two meta-analyses of cognitive rehabilitation following traumatic brain injury and stroke (Cicerone et al., 2000; Cicerone 2005) which were actually systematic literature reviews drew the conclusion that compensatory treatment can result in significant improvement in

health outcomes and remediation can lead to improvement on laboratory tests but this does not necessarily transfer to everyday function. This review was updated to include literature up to 2008 and authors concluded that there was substantial evidence to support interventions to improve attention, memory, and executive function (Cicerone et al., 2011). However, in contrast, recent Cochrane Reviews concluded there is no evidence to support or refute cognitive rehabilitation following stroke to improve spatial neglect (Bowen et al., 2013), memory deficits (das Nair & Lincoln, 2007), attention deficit (Loetscher & Lincoln, 2013) or executive dysfunction (Chung et al., 2013). In this feasibility study, some remedial work was done using planning activities as homework in preparation for work return but mainly a compensatory model of cognitive rehabilitation was adopted. This involved collaboratively developing strategies for managing cognitive difficulties at work. Examples of these were use of a notebook and mobile phone to prompt and compensate for memory difficulties and taking regular breaks or changing activities to enhance concentration on work tasks.

Homework tasks were provided that encouraged practice between intervention sessions, for example, planning activities, maths tasks, reading, exercise/ walking (use of Wii Fit), computer activities, using public transport, shopping, cooking and social activities including social networking. Some participants were asked to keep a diary of activities and use visual analogue scale scores to record levels of fatigue and concentration in relation to the activities. The process and outcome of

executing these tasks were then discussed with the participant and feedback was provided by the therapist. Further homework tasks were then set in light of discussion and feedback.

Homework assignments are recognised as an important element of cognitive behavioural therapy (CBT) where they have been found to be associated with significantly improved outcomes (Thase & Callan, 2006). The ability of the therapist to match the difficulty of homework tasks with patient readiness to ensure the tasks are relevant and achievable is important in conjunction with reviewing homework and providing feedback (Thase & Callan, 2006). These were features of the VR intervention in this feasibility study.

#### **3.7.4 Provision of information**

Verbal and written information, including relevant leaflets, booklets and websites, were provided for individuals and where appropriate, family members, managers/ employers and work colleagues. Information was specifically tailored to individual needs (e.g. information on the impact of stroke and how to manage fatigue, visual problems, cognitive and emotional difficulties, communication problems, driving and returning to work). Some information was given to the participants to read at their leisure, other information was used during intervention sessions as a means of giving advice and education. The Stroke Association (Stroke Association, 2014) and Different Strokes (Different Strokes, 2014) both provide useful literature and the latter produces booklets specifically about work and stroke for stroke survivors, friends and family members and employers.



McKevitt et al. (2011) found in their survey of 1251 stroke survivors in the UK that there was an unmet need for stroke information reported by 54% of the population. Gillworth et al. (2009) also found that information and support was not provided and advice about return to work sometimes misguided as a result of health professionals being over protective. The therapeutic value of returning to work with support was not emphasised enough leading to people losing their jobs and going onto state benefits. The need for information for young people following stroke to be personalised was highlighted in a survey of 200 members of young stroke groups affiliated with the Stroke Association in the UK. Participants felt this would help facilitate participation in society (Low et al., 2003).

### **3.7.5 Provision of psychological support**

Psychological support was provided to participants, family members and managers/ employers to assist with adjustment and re-evaluation following the stroke, preparing for work return and throughout the return to work process. This involved asking how participants felt during sessions, listening to their concerns and providing encouragement and positive reinforcement as they tried to regain skills and confidence. People were referred to the stroke support service if they needed more psychological and social support (e.g. those who lived alone and did not have any family support). Participants who appeared depressed were encouraged to seek appropriate help from their GP (e.g. medication or referral to Improving Access to Psychological Therapy Services (IAPTS) / CBT intervention). Although evidence to support the use of

psychological interventions in influencing return to work is limited; several studies have found a relationship between the presence of psychological support and positive work outcomes. Appropriate management of the emotional consequences of stroke are recommended by Glozier et al. (2008) who conducted a prospective population based stroke incidence study of the influence of psychiatric morbidity on return to paid work in New Zealand. They suggested that this management would optimise recovery and enable successful return to work in younger stroke survivors. The final results from an Australian cohort study looking at psychosocial outcomes in stroke failed to confirm the hypothesis about early depression after stroke being independently associated with inability to return to work but there was still a reasonably strong effect (adjusted OR 2.32). The authors concluded that this because depression rates were lower than expected in the study (Hackett et al., 2012). Hartke et al. (2011) in their qualitative study of 12 stroke survivors returning to work found that psychological factors, such as interpersonal support from therapists, family and the workplace were central to enabling work return. A similar conclusion about supportive social networks was reached by Alaszewski et al. (2007) in a qualitative interview study of 43 stroke survivors. In a retrospective survey of 72 stroke patients following admission to a French physical medicine rehabilitation centre, Doucet et al. (2012) found that professional support and having a supportive partner reduced the risk of mood disorders and enabled work re-entry. In a Swedish national survey of younger stroke survivors (Lindstrom et al.,

2009) it was found that external support from others concerning their work situation was associated with a greater chance of returning (OR 3.66). Anxiety was the most commonly reported psychological problem (66%) in a retrospective study of 83 stroke survivors aged under 50 (Teasell et al., 2000). In the same study 48% of participants were anxious about work return and dealing with this was seen as an important role for rehabilitation staff. Support from health care professionals, family, employers and co-workers was reported to improve self efficacy, with respect to work return, in an in-depth qualitative interview study of six stroke survivors (Medin et al., 2006). These studies collectively suggest that support from family members, employers and health professionals all have a mediating effect.

### **3.7.6 Liaison with other services and agencies**

Liaison took many forms including face to face meetings, telephone calls, emails and letters. It took place with other professionals and services throughout the intervention process. As a result of the stakeholder interview study the research OT developed knowledge of locally available services and this provided a roadmap for cross professional/ sector working. This included liaison with other rehabilitation professionals (OTs, physiotherapists, speech and language therapists, clinical neuropsychologist, rehabilitation consultants), the GP and other agencies (e.g. stroke support service, Disability Employment Advisers at Job Centre Plus, occupational health and human resources departments, union representatives, disability rights charity providing an advice and advocacy service). Community

resources were also utilised to support participants back into work, for example, voluntary sector services that broker voluntary work and community projects (art workshops and yoga classes for stroke survivors).

Doucet et al. (2012) suggested that early involvement and close cooperation with occupational health was a positive prognostic factor for increasing the speed of return to work following stroke. Medin et al. (2006) also found that cooperation between rehabilitation professionals was helpful in the return to work process but that this liaison was perceived to be infrequent.

In a systematic review of return to work after stroke, Treger et al. (2007) found that rehabilitation professionals were not sufficiently attentive to the transition from acute care to community reintegration. An important aspect of the role of the OT in this study was to act as a link between the two, initiating contact in the acute phase following stroke and maintaining this as the person returned home and went back to work. Trexler et al. (2010) demonstrated in a small prospective randomised controlled trial of resource facilitation intervention for work return that return to work rates were increased when resources were coordinated for people following ABI. In the current study the research OT used a case-coordination model of intervention (Fadyl & McPherson, 2009), working alongside usual care but also referring to services or utilising community resources to enhance the participants' ability to return to work.

### **3.7.7 Work preparation**

Where possible, work tasks were simulated in the home environment or community settings. So, for example, some participants used a computer at home to simulate activities they would be required to do at work. For some participants it was possible to obtain work samples from the employer (e.g. report and letter templates and relevant information needed to complete these) and feedback from the line manager was sought on how accurately or successfully these tasks were executed. Other simulated activities involved building physical stamina and standing/ walking ability or driving/ using public transport to prepare for the journey to work or the physical demands of the job itself. This required grading, which enables adjustment, both physically and psychologically, to occur and capacity for work to increase (Holmes, 2007). Participants were encouraged to gradually build their general activity levels and re-establish routines to assist with preparing for work return (e.g. getting up at the same time as they would for work).

### **3.7.8 Planning return to work**

This initially involved discussing work options and asking participants when they felt able to return to work and what hours and days and tasks they thought they would or would not be able to manage. This led to a more structured process of planning a phased return to work which involved liaising and meeting with employers, occupational health and human resource departments where appropriate and if the participant consented. Tailored information about how the stroke had affected the individual was given to people at the workplace (directly at meetings or

by the participant if they did not want the therapist to meet their employer). A booklet about stroke and work, written especially for employers, by the charity 'Different Strokes' was also provided (Different Strokes, 2014).

A return to work plan was developed, brokered, negotiated and agreed with the individual and their employer which included transitional arrangements, reasonable adjustments and work place accommodations during the phased return to work. Ross (2007) states that formulating the return to work plan is the most important stage of the VR process and getting the agreement of all parties vital to its success. This needs to be detailed and precise in relation to timings and tasks to be completed by each party (Ross, 2007). Details included in the current study were the date of intended return to work, days and hours to be worked on a weekly basis and changes to role and responsibilities including any supernumerary support or supervision from the line manager and colleagues. For some participants this also involved a discussion, agreement and documentation about the use of annual leave as part of the phased return.

In some cases, participants were encouraged to refer themselves to 'Access to Work', a service provided by the DWP (Gov.uk, 2014), where financial help is available to provide transport to work (e.g. a taxi when the person was not able to drive or manage public transport) and other workplace accommodations (e.g. assessment for adaptations or equipment to enable return to work).

### **3.7.9 Review and monitoring of return to work**

Once the participant had returned to work, the phased return was reviewed on a regular basis (usually this was weekly and then reduced gradually to fortnightly) and modifications to hours, days or duties were made if required. This approach is advocated by Ross (2007). Factors such as fatigue experienced, concentration and stamina levels were taken into account. This review was sometimes completed with the individual alone and self-evaluation was encouraged. For others this entailed liaising and meeting with line managers/ employers and sometimes family members, to review the impact of the work return on the individual, the work place and their family life. This monitoring process was conducted until the individual had resumed their previous hours and duties. For a few individuals, the negotiation of longer term adjustments to accommodate the impact of the stroke was necessary.

### **3.7.10 Maintenance of work return and ongoing support**

After the individual had resumed their pre-stroke hours, roles and responsibilities or had negotiated permanent changes to conditions of work, the therapist maintained contact until both the individual, family members and the employer were satisfied that the situation was stable and work return could be sustained. Contact was either face to face, telephone or email. Participants, family members or employers were told they could contact the therapist by telephone or email if needed. Rubenson et al. (2007), in their qualitative study of eight people with ABI who had returned to work and been there for at least four months, found that support was needed over a long period to achieve a

functional working role and this required a longer term follow-up than is currently offered by rehabilitation services. Longer term follow-up by rehabilitation therapists or a mentor is also advocated by Wolfenden and Grace (2009) based on a literature review and the personal experiences of one of the authors.

### **3.7.11 Gradual withdrawal of the intervention, discharge and evaluation**

Following the maintenance period the frequency of the contact between the therapist, the participant and the employer was gradually reduced until it was withdrawn completely. Discharge took place when all parties were satisfied with the outcome or the maximum time frame for the trial intervention (12 months) had expired. When withdrawing it was important to ensure that adequate ongoing support mechanisms were in place (Ross, 2007). If return to work was not achieved at the point of discharge then liaison with or referrals were made to other services (e.g. Disability Employment Advisers at Job Centre Plus, rehabilitation/ community support services) or the individuals were signposted to appropriate resources and services that they could access independently.

## **3.8 Discussion**

This chapter has described the stages involved in the development of the complex early stroke specific VR intervention recommended by the MRC (2008). The first stage of identifying the evidence exposed a gap in the evidence for effectiveness of VR following stroke (Treger et al., 2007). However, the existing research literature was helpful in



developing a model and providing evidence for some of its components and also in identifying specific gaps in current practice and unmet need from the perspective of people with strokes, family members and professionals working in this field. Existing clinical guidelines (Tyerman & Meehan, 2004) were used as a basis for developing the intervention combined with expert opinion.

The second stage of development was identifying or developing appropriate theory confirmed the acknowledgement of the MRC guidelines (2008) that it is not always clear from the beginning what the theoretical basis for change is and how it will be achieved. Primary qualitative research with key stakeholders helped to identify potential active ingredients of the intervention. This enabled the intervention to be tailored to the local context. Existing literature was also used to identify appropriate theory which underpin mechanisms by which the intervention might be expected to work, for example, goal setting, cognitive rehabilitation and psychological support. However, there are aspects of VR for which mechanisms of change remain unclear, for example, direct involvement of employers, and this highlights an under researched area.

The third stage recommended by the MRC (2008) was modelling the process and outcomes of the intervention. Expert opinion and the case study participant interview highlighted that the intervention was acceptable but the case was limited to a person with a minor stroke, who was self-employed and did not receive any other services.

However, his experience as an employer was valuable in providing insight into the perceived usefulness in liaising with the workplace to promote understanding of the impact of stroke on an individual's ability to do their job. The MRC guidelines (2000) suggest using diagrams or flowcharts as a starting point to identify the relationship between components. Figure 4 was developed, using the findings of the stakeholder interview study (Chapter 2) to demonstrate the way the VR OT would interact with existing services and across different sectors. Figure 5 was developed using a combination of existing literature and the stakeholder interviews to describe the process and nature of intervention to be delivered and evaluated in the trial. The decisions made about choice of outcome measures are described in detail in Chapter 4.

The process of intervention development described above, has been used in previous rehabilitation studies to describe the developmental stages and evaluation of complex OT rehabilitation interventions in nursing and residential settings (Sackley et al., 2004, 2012; Graff, 2006a, 2006b, 2008). There were some similarities with this feasibility study in that the review of relevant literature revealed a paucity of evidence and expert opinion was incorporated by convening a steering group of clinicians, researchers and educators from a variety of backgrounds to make specific recommendations. There was also acknowledgement of the individualisation of intervention within the protocol.

In a study to evaluate the effectiveness of community based OT for people with dementia and their caregivers (Graff, 2008), the intervention development process was described as combining a review of the literature, the use of Kielhofners' theoretical model and a consensus process with a panel of national and international experts in the field. Graff found a lack of evidence for the effectiveness of this type of intervention in the existing research literature and therefore developed theoretical and consensus based guidelines. Graff et al. (2006a) also used case study analysis to model the process of intervention by performing content analysis of one OT patient record. Features such as education, setting feasible goals, adapting the environment and training in compensatory skills which appeared to be successful ingredients in the single case study were later shown to be effective in a randomised controlled trial with 135 patients and their caregivers (Graff et al., 2006b).

A systematic review of 67 studies of complex interventions in stroke care concluded that few had been adequately developed or evaluated (Redfern et al., 2006). The authors suggested this may be a contributory factor in the inability to demonstrate efficacy. It is hoped that by paying sufficient attention to development of the intervention in this feasibility study that this will enable the evaluation of efficacy in a future definitive trial.

Wade (2005), in his paper about describing rehabilitation, uses the ICF (WHO, 2001) as a theoretical foundation of rehabilitation and gives

examples of the way in which activity limitations are addressed to enhance participation. He also discusses a model of the rehabilitation process encompassing assessment, goal setting, intervention, evaluation and discharge (Appendix 7). The cyclical nature of this process is emphasized and the ICF domains of the person and the environment as a focus for intervention are incorporated. It could be argued that the ICF would be a useful basis for assessment and goal setting as well as intervention. This would mean the whole rehabilitation process would be informed by the impact of the individuals' impairment on activity and participation taking into account both personal and environmental contextual factors. This fits with the model in the current feasibility study where the needs of the person within the context of their environment (social, physical and temporal) are assessed and then addressed during intervention with the ultimate goal of returning to work. The relationship with other services has been described in Figure 4 and the process of intervention in Figure 5. The cyclical nature of intervention is evident here in the inclusion of regular review and modification during the third stage of this process in order to sustain work return.

The OT led early stroke specific VR intervention described in this chapter was tested in a feasibility randomised controlled trial (Chapter 4) and evaluated further through content analysis (Chapter 5) and post-trial interviews with trial participants and employers (Chapter 6). The location, mode of delivery, duration and intensity of the intervention are

all described in detail in Chapter 5 as recommended in TIDieR (Hoffman et al., 2014).

### **3.9 Limitations**

One limitation of the process of intervention development described in this chapter is the lack of comprehensive evidence to support the components of VR following stroke. This reiterates the view of Treger et al. (2007) who highlighted lack of evidence for effective assessments and interventions for stroke survivors wishing to return to work.

Although expert feedback following piloting on two case studies participants which ratified what had been provided, both participants had had minor strokes and similar difficulties and were not receiving other rehabilitation services. In addition, one was self-employed and one did not want the OT to directly liaise with her employer. This meant that the potential complexity of feasibility trial participants could not be fully addressed during the development stage.

### **3.10 Conclusion**

It has been possible to develop early stroke specific VR intervention for the feasibility randomised controlled trial using evidence from existing clinical guidelines and research literature, supported by the findings of a qualitative interview study with key stakeholders, VR training, mentorship, case study pilots and the input of an expert panel. The process of development and nature of the intervention have been described and a model of the intervention created.

## **CHAPTER 4 FEASIBILITY RANDOMISED CONTROLLED TRIAL**

### **4.1 Introduction**

To date there has been little research evaluating vocational rehabilitation (VR) interventions for people following stroke (Treger, 2007; Baldwin & Brusco, 2011) and at the time this study commenced there were no randomised controlled trials (RCTs). Without research evidence, it is difficult to justify the provision of specialist services for stroke survivors who wish to return to work and be economically productive and self-sufficient. Preliminary research including qualitative interviews with key stakeholders, case studies and input from an expert panel was used to develop a VR intervention (as described in chapters 2 & 3). The purpose of the intervention was to bridge gaps in existing service provision and support stroke survivors who were working prior to their stroke to resume work with an existing employer (job retention). This intervention was delivered and tested in a feasibility RCT which will be described in detail in this chapter. This will be followed by a discussion of how the findings can inform a definitive multicentre trial.

### **4.2 Research question**

Is it feasible to deliver a stroke specific VR intervention and measure its effects on work, benefits status, work readiness, mood, health-related quality of life, instrumental activities of daily living and participation in a feasibility RCT?

### **4.3 Aims**

The primary aim of this feasibility study was to determine whether it was possible to deliver and measure the effects of stroke specific VR in a feasibility RCT.

Secondary feasibility objectives:

- To assess the willingness of clinicians to identify patients
- To ascertain the number of eligible patients
- To identify the reasons for not recruiting
- To assess the stroke severity and stroke type of people recruited to the trial
- To assess the willingness of participants to be randomised
- To evaluate the suitability of the proposed outcome measures
- To measure acceptability of the intervention
- To evaluate completeness of follow-up and impact of randomisation to the control group on drop out.

### **4.4 Method**

#### **4.4.1 Design**

RCTs are viewed as the gold standard for quality applied research (Robson, 2002). It is an experimental design where participants are randomly assigned to an experimental group receiving the novel intervention or the control group which receives routine care. The

purpose of randomisation is to neutralise the influence of individual variation and isolate the effect of the intervention on outcome (Robson, 2002). The Medical Research Council (2008) recommend that when evaluating complex interventions, such as rehabilitation, development work including feasibility and pilot work is undertaken before a definitive trial takes place. The terms pilot and feasibility have been used interchangeably in some literature.

A feasibility study according to Arain et al. (2010) is undertaken earlier than a pilot and is needed to estimate important parameters that are needed to design the main study, for example, willingness of participants to be randomised, willingness of clinicians to recruit patients, number of eligible patients, characteristics of proposed outcome measures, follow-up rates, response rates to questionnaires and adherence/ compliance rates. In this study a feasibility design was selected in order to assess the above and it is illustrated in Figure 6.

#### **4.4.2 Sampling frame**

As this was a feasibility study and no inferences could be made about effectiveness, a formal sample size calculation was not needed.

However, a pragmatic target of 51 participants was estimated based on personal communication with local clinicians regarding the number of working age people treated on the Royal Derby Hospital stroke rehabilitation ward during 2007-8 (148) and those estimated to have been discharged from the acute stroke ward without significant disability (15). It was estimated that 61 people would meet the study criteria each



year. Allowing 21% for death and non-consent some 51 were estimated to be available for recruitment over a 15 month period.

#### **4.4.3 Recruitment, selection and consent**

Potential participants were identified by a member of the clinical team on the stroke unit (acute stroke ward and stroke rehabilitation ward) at the Royal Derby Hospital or one of the Stroke Research Network (SRN) nurses using the eligibility criteria below. However, the study was not formally adopted by the Clinical Research Network. Approximately 700 people are admitted with suspected stroke to the acute stroke ward at the Royal Derby Hospital per year (Directorate of Finance and Information Royal Derby Hospital, 2011). It was chosen as the single site as people are admitted from a wide range of socioeconomic backgrounds and from a mix of urban and rural locations (Derby city and surrounding towns and villages).

Inclusion criteria: Patients were included if they were

- Aged 16 and over
- Admitted to The Royal Derby Hospital with a diagnosis of stroke
- Living in the Derby city or the southern Derbyshire health community
- Working (paid or voluntary for at least one hour a week) or in education (full time) at the time of their stroke

Exclusion criteria: Patients were excluded if they

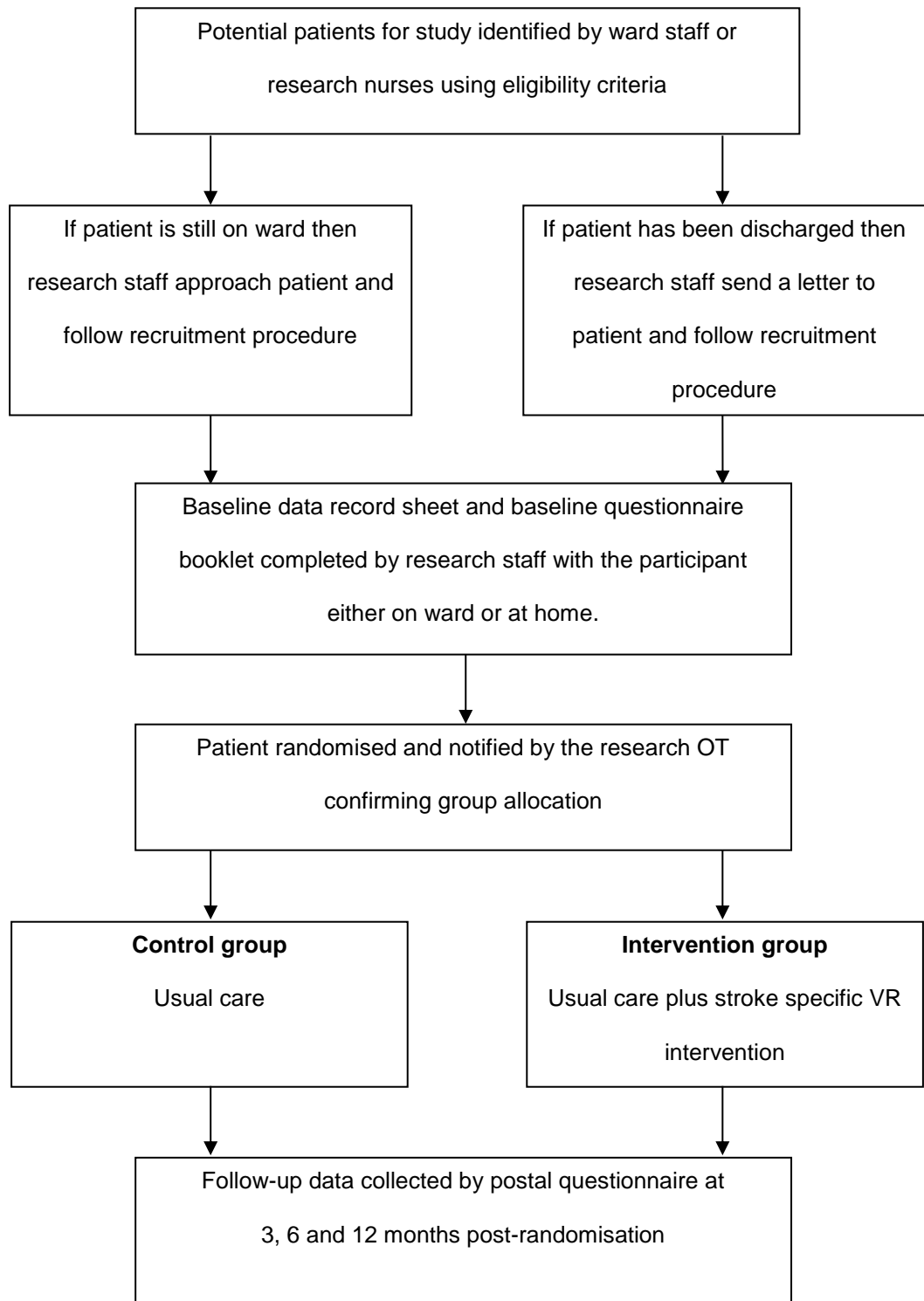
- Refused consent
- Were not considering a return to work
- Had a medical reason precluding return to work (e.g. uncontrolled epilepsy)

People with a language barrier either resulting from stroke (e.g. aphasia) or those for whom English is not their first language were not excluded. To facilitate participation among those with communication difficulties, the help of a speech and language therapist was requested during the recruitment process.

People meeting the inclusion criteria were approached by the research staff (research OT or research associate) who confirmed eligibility, provided a participant information sheet and explained the study. Informed written consent was sought after allowing potential participants 24 hours to consider participation. The research staff went to the stroke unit (acute stroke ward and stroke rehabilitation ward) three times per week on Mondays, Wednesdays and Fridays to maximise recruitment. These days were chosen to minimise people being missed due to discharge immediately preceding or following the weekend. If potential participants had already been discharged an invitation letter was sent with the participant information sheet, consent form and a reply slip on behalf of the stroke consultant. If they did not reply to this letter within two weeks an invitation reminder was sent. If

they still failed to respond to this second invitation, no further contact was made. This procedure was deemed appropriate by the ethics committee.

**Figure 6. Design of the feasibility RCT**



#### **4.4.4 Randomisation**

Randomisation was carried out using a web based randomisation service set up by the Nottingham Clinical Trials Support Unit. The allocation sequence was generated using a function called RALLOC in the statistics package called Stata (StataCorp., 2009). The sequence was a list made up of individual balanced blocks and was devised independent of the study research staff. The size of the blocks is randomly varied, to ensure the next allocation is concealed. This type of randomisation is called simple blocked randomisation.

#### **4.4.5 Blinding**

The research associate was blind to intervention allocation. Therefore, participants were told of their randomisation allocation by the research OT and their general practitioner (GP) was informed by letter. A blinding check was carried out prior to data analysis. The research assistant was asked to guess the allocation for each participant and the percentage which were correct was calculated.

#### **4.4.6 Usual care**

Usual care consisted of any service providing medical care, rehabilitation, advice or support the person usually received. This included hospital admission to the acute stroke unit and some people were then transferred to the care of the early supported discharge team when discharged or transferred to the stroke rehabilitation ward if more intensive rehabilitation was required. Depending on where the person lived, a number of out-patient or community based neurological rehabilitation services were potentially accessible including OT,

physiotherapy and speech and language therapy. The stroke support and coordination service, jointly funded by health and social care, was usually contacted when the person was discharged from hospital and a phone call made by this service within three weeks to offer additional support and information to the stroke survivor and their family members. Once discharged participants were under the care of their GP but usually attended one or two out-patient appointments with a stroke physician or rehabilitation consultant. This was the standard six week follow-up initiated by the National Stroke Strategy (2007). They may also have received support from Department of Work and Pensions services, for example, Disability Employment Advisor or Access to Work. This may have been recommended by out-patient department OT staff. Data was collected on services received at three, six and 12 month follow-ups.

#### **4.4.7 OT led stroke specific VR**

The OT led early stroke specific VR developed for this study is described in detail in Chapter 3. It was developed using the findings of a stakeholder interview study, existing clinical guidelines, research literature and the experience and training of the research OT. Once the participant had been notified of allocation to the intervention arm of the trial, the OT made arrangements for the intervention to commence. The OT used a case-coordination model of intervention (Fadyl & McPherson, 2009), working alongside usual care but also referring to services or utilising community resources to enhance participants' ability to return to work.

A summary of intervention components is outlined in Table 6 below.

**Table 6. Summary of intervention components**

<b>Intervention component</b>	<b>Description</b>
Assessment of individual	Initial interview, standardised measures, observation of mood, function, cognition, stroke impact, work, participation and self efficacy regarding work return.
Job analysis and worksite assessment	Analysis of job and workplace demands, roles and responsibilities.
Provision of information	Tailored verbal and written information including leaflets, booklets, websites provided for individual, family members, employers, managers and colleagues.
Provision of psychological support	Psychological support provided for participants, family members, managers and employers.
Liaison with other services and agencies	Liaison including face to face meetings, telephone calls, emails and letters with other services and professionals.
Goal setting and intervention planning	Realistic short and long terms goals identified, discussed and agreed with participant and where appropriate employer/ manager.  Goals regularly reviewed and modified in conjunction with feedback on progress, self-evaluation and workplace monitoring.
Intervention sessions and homework tasks	Focus on education or regaining specific skills and abilities required for individual's job e.g. fatigue management, increasing strength, stamina, concentration, verbal and written communication.  Homework tasks provided e.g. planning activities, exercise, computer activities, using public transport, social networking.
Work preparation	Simulated work tasks in the home environment or community settings, work samples from employer/ line manager where

Intervention component	Description
	<p>possible.</p> <p>Building up general activity levels and re-establishing routines to prepare for work return.</p>
Planning return to work	<p>Discussing work options with participants e.g. when to return to work, hours and days and tasks they felt they would be able to manage.</p> <p>Structured planning of a phased return to work in liaison with workplace, occupational health and human resources (where appropriate).</p> <p>Return to work plan developed, negotiated and agreed with individual and employer including transitional arrangements, reasonable adjustments and work place accommodations during phased return.</p>
Review and monitoring of return to work	<p>Regular review and modification to hours, days, duties with individual and line manager/ employer where appropriate.</p> <p>Monitoring until individual resumed previous hours and duties where possible, negotiation of longer term adjustments where needed.</p>
Maintenance of work return and ongoing support	<p>Contact maintained after individual resumed pre-stroke hours, roles and responsibilities or longer term adjustments agreed until all parties satisfied situation was stable and sustainable. Contact sometimes face to face but telephone and email also used.</p>
Gradual withdrawal of intervention, discharge and evaluation	<p>Frequency of contact gradually reduced during maintenance period until withdrawn completely.</p> <p>Discharge when all parties satisfied with the outcome or maximum time frame for trial intervention expired (12 months).</p> <p>Referral and signposting to other resources and services if return to work had not been achieved.</p>



The intensity (frequency and duration) of intervention are reported in Chapter 5 where content of intervention during the trial is also analysed.

#### **4.4.8 Data collection**

##### **4.4.8.1 Baseline data collection**

Baseline data collection was completed by the research OT or the research associate, as a face to face interview with the participant prior to randomisation. At baseline data gathered included date of birth, gender, ethnicity, marital status, date of stroke, date of hospital admission and discharge, previous medical history, occupational and benefits status, job title, hours worked, annual income and ability to drive. Further data collected at baseline is shown in Table 7. See baseline questionnaire booklet in Appendix 8.

##### **4.4.8.2 Follow-up data collection**

Follow-up data was collected by post at three, six and 12 months after recruitment. These time points were selected using evidence from a previous research study by Lindstrom et al. (2009) who conducted a national survey in Sweden of factors influencing return to work after stroke. They found that 86% of the population returned to work within one week to 12 months after stroke and that half returned within three months and the other half between three and 12 months.

Follow-up data collected were changes to demographic data including changes in marital status, ability to drive, return to work plans, occupational and benefits status, annual income, hours worked, reasons for returning to work and workplace adjustments. Further data

collected at follow-up is shown in Table 7. If questionnaires were not returned then efforts were made to obtain primary outcome data via email, phone calls and other means.

#### **4.4.8.3 Primary outcomes**

The primary outcomes chosen for this feasibility study were occupational (working or not) and benefit status as work status is the most commonly used outcome measure in return to work after stroke studies (Baldwin & Brusco, 2011). Due to the sudden onset of stroke, it is usual to be off sick for a period of time and then return when recovered. This is different to other neurological conditions (e.g. multiple sclerosis), more common musculoskeletal health conditions (e.g. arthritis, low back pain) and mental illnesses (e.g. bipolar disorder) where there is a tendency towards relapse and remission and measuring sickness absence may be considered more useful (Waddell & Burton, 2004).

In this feasibility study work is defined as being in paid or voluntary work for at least one hour per week or full time education. This definition of work originated from the Brain Injury Community Rehabilitation Outcome Scales (Powell et al., 1998) and was used in a previous study in the locality on vocational rehabilitation following traumatic brain injury (Radford et al., 2013b). Occupational status was measured by asking whether the participant was in work or not at the given time point and then by asking for more detailed information about the number of hours worked per week and whether these had changed since the stroke and whether in full or part time work.

#### 4.4.8.4 Secondary outcomes

The secondary outcome measures are those included at follow-up listed in Table 7.

**Table 7. Baseline and follow-up outcome measures**

Variable	Measure	Baseline	3 month follow-up	6 month follow-up	12 month follow-up
Stroke Type	Bamford Classification	X	-	-	-
Stroke severity	NIH Stroke Severity Scale (NIHSS)	X	-	-	-
Disability	Stroke Impact Scale (V 3.0)	X	-	-	-
Cognition	MS Cognitive Screen	X	-	-	-
Mood	Hospital Anxiety and Depression Scale (HADS)	X	X	X	X
Function - instrumental activities of daily living	Nottingham Extended Activities of Daily Living (NEADL)	X	X	X	X
Quality of life	EuroQol – EQ-5D	X	X	X	X
Work	Work Limitations Questionnaire (WLQ25)	X	X	X	X
	Work Productivity and Activity Impairment Instrument V2 (WPAI)	X	X	X	X
Participation	Sydney Psychosocial Reintegration	X	X	X	X

Variable	Measure	Baseline	3 month follow-up	6 month follow-up	12 month follow-up
	Scale (SPRS 2)				
Work self-efficacy	Confidence questions from the Condition Management Programme Evaluation Study	X	X	X	X

#### **4.4.8.4 Justification for inclusion of standardised measures used in feasibility RCT**

##### **4.4.8.4.1 Mood – Hospital Anxiety and Depression Scale (HADS)**

Mood was measured using the HADS which consists of seven items for depression and seven for anxiety and participants choose one of four responses to indicate how they have been feeling in the last week (Bennett & Lincoln, 2006). It was designed to identify clinical anxiety and depression in people in the setting of a hospital medical out-patient clinic (Zigmond & Snaith, 1983) but it is also deemed suitable for use in the community (Bennett & Lincoln, 2006). Scores of 8-10 indicate a possible clinical disorder and 11-21 a probable one (Bennett & Lincoln, 2006). It has been validated for use following stroke (Aben et al., 2002; Johnston et al., 2000). D'Alisa et al. (2005) found that mood disorders detected using the HADS score contributed to restricted social reintegration post-stroke.

##### **4.4.8.4.2 Instrumental Activities of Daily Living - The Nottingham Extended Activities of Daily Living Scale**

The Nottingham Extended Activities of Daily Living Scale (NEADL) was included as a measure of function/ performance in instrumental

activities of daily living (IADL). The NEADL consists of 22 items. Each item is scored on a four point Likert-scale ranging from 0 (unable) to 3 (able without assistance). It was specifically developed for use following stroke (Nouri & Bennett, 1987) and was therefore chosen in the current study as an appropriate measure of function. It has well established reliability and validity (Gladman et al., 1993; Wu et al., 2011), and has shown sensitivity to change in stroke rehabilitation trials (Walker et al., 2004; Gilbertson et al., 2000; Logan et al., 1997; Walker et al., 1999; Corr & Bayer, 1995). The individual patient data meta-analysis of RCTs of community OT (Walker et al., 2004) showed that this intervention was associated with higher NEADL scores reflecting ability to perform higher levels of activities which endorsed the results of a previous systematic review (Steultjens et al., 2003).

#### **4.4.8.4.3 EQ-5D**

The EQ-5D was chosen as a measure of health-related quality of life. It is a standardised, non-disease specific instrument for describing and valuing health states, widely used in economic evaluation (Szende et al., 2007). It is suitable for use in postal surveys and face to face interviews. Respondents tick whether they have 'no problems', 'some problems' or 'severe problems' on a given day, in five domains: 'mobility', 'self-care', 'usual activities', 'pain/discomfort' and 'anxiety/depression'. Part two enables participants to mark their current health state on a visual analogue scale (VAS) where 0 is the worst state imaginable and 100 the best. The EQ-5D is the health related quality of life and cost utility tool recommended by the National Institute for Health

and Clinical Excellence (NICE) and used in decisions regarding which treatments represent the best quality care and offer the best value for money for the NHS (Wailoo et al., 2010). It has been validated for use following stroke (Dorman et al., 1997).

#### **4.4.8.4.4 Work – Work Limitations Questionnaire (WLQ25)**

In the absence of a stroke specific work measure, this 25 item reliable and valid questionnaire, designed to assess on the ‘on the job’ impact of a health condition and/ or treatment was selected (Lerner et al., 2001). It covers four dimensions, limitations handling time, physical, mental-interpersonal and output demands and a two week reporting period. Despite not being tested on people following stroke, it was chosen as it is holistic and looks in detail at both the physical and psychosocial demands of a job. It was tested on people with both physical and mental health conditions (Lerner et al., 2001) and this is relevant for stroke which can have a physical, cognitive and psychological impact. It has been used to evaluate the impact of a work-focused intervention on productivity for employees with depression (Lerner et al., 2012). It was also shown to be the most comprehensive of five work productivity measures for people with arthritis (Tang et al., 2013).

#### **4.4.8.4.5 Work - Work Productivity and Activity Impairment Instrument (WPAI)**

In contrast to the detailed and holistic WLQ described above, the WPAI, another generic work tool, was chosen as a quick and easy measure of work productivity which only takes a few minutes to complete. It has six

items which ask about whether someone is currently working, hours missed from work in the previous seven days due to a specific health problem (stroke), hours missed for other reasons (holiday etc.) and hours actually worked. It then asks the person to rate their work productivity over the previous seven days using a Likert Scale of 0-10 (0=stroke had no effect on my work, 10= stroke completely prevented me from working). A similar Likert Scale is also included to measure impact of stroke on activities outside work (e.g. shopping, housework, childcare etc.). Reproducibility and construct validity were tested on 106 employed individuals affected by a health problem using self-administration and interviewer administration (Reilly et al., 1993). The self-administered questionnaire was shown to have adequate reproducibility but less construct validity than the interviewer administration. It has been validated for use with a range of health conditions including allergic rhinitis, asthma, Crohn's Disease, ankylosing spondylitis (Reilly et al., 2010) and rheumatoid arthritis (Bansback et al., 2012) in the measurement of work productivity.

#### **4.4.8.4.6 Participation – Sydney Psychosocial Reintegration Scale (SPRS-2)**

This measure was developed for use with people following traumatic brain injury (Tate et al., 1999) but further studies have been conducted using the measure with people with acquired brain injury (Ownsworth & Flemming 2005; Turner et al., 2009) and with spinal injury and brain tumour (Tate et al., 2012). It was chosen because it is a measure of participation, a construct increasingly used following the introduction of the International Classification of Functioning Disability and Health (ICF)

(World Health Organisation, 2001), which refers to 'involvement in a life situation'. There is evidence to demonstrate reliability and validity and there are no significant floor or ceiling effects (Tate et al., 2012). SRPS-2 Form A -self is a questionnaire with three domains; work and leisure, relationships and living skills each of which have four items that the person can fill in themselves. A five point rating scale (not at all, a little, moderately, a lot and extreme) is used to identify the extent to which things have changed because of the health condition. There is also a 15 item background questionnaire with qualitative questions to collect factual information about work/ studies, leisure, relationships and living situation which is completed prior to above quantitative questionnaire. It was also chosen to assess the level of broader psychosocial reintegration (including work) and because it was specifically designed for people with a neurological condition and has been used following stroke (Ownsworth & Flemming, 2005; Ownsworth & Shum, 2008).

#### **4.4.8.4.7 Cognition - Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ)**

This measure was selected as a brief self-report screening tool for cognitive impairment at baseline in the absence of a stroke specific measure of this kind. It is a 15 item questionnaire with a five point Likert Scale (4=very often, 3=quite often, 2=occasionally, 1=very rarely, 0=never or does not occur) and participants are required to base their ratings on how they have been over the previous three months. It is a sensitive and reliable screening test which predicts neuropsychological impairment in multiple sclerosis (Benedict et al., 2003). It is important to measure cognitive impairment at baseline as it is one of the factors that



has been shown to reduce the probability of work return following stroke (Vestling et al., 2003).

#### **4.4.8.4.8 Disability – Stroke Impact Scale (SIS) Version 2.0**

The SIS was chosen to measure the level of disability caused by the stroke. Duncan et al. (1999) document the psychometric properties of the SIS Version 2.0. This 64 item reliable and valid self-report stroke specific measure assesses eight domains (strength, hand function, ADL/IADL, mobility, communication, emotion, memory and thinking, and participation) using five point Likert Scales. It was chosen to assess the impact of the stroke on participants at baseline. It was also used as an alternative way of measuring stroke severity in the absence of a NIHSS score. It has been validated for use in a UK setting (Jenkinson et al., 2013) and high levels of internal consistency were found. It was reviewed as one of the most frequently used measures of participation following stroke (Tse et al., 2013) who pointed out that it was not possible to identify the domains in this measure which met the test-retest criterion and that only the domains of strength, hand function, mobility, ADL and emotion met the criterion for construct validity.

#### **4.4.8.4.9 Stroke Severity - National Institutes of Health Stroke Scale (NIHSS)**

This is a 15 item neurological examination stroke scale, for measuring the severity of cerebral infarction, it has been found to have high inter-rater reliability, high test-retest reliability and acceptable examination and scale validity (Brott et al., 1989). It is a strong predictor of the patient's post-acute care disposition (Kasner, 2006).

The NIHSS (Table 8) has been found to be highly associated with ADL outcome (Barthel Index at 6 months post-stroke) (Kwakkel et al., 2010) and correlates significantly with disability (FIM scores) in those with ischaemic and haemorrhagic strokes (Roth et al., 1998). It was chosen in the current study to examine the relationship between stroke severity and vocational outcomes of trial participants.

**Table 8. NIHSS scoring system**

<b>Score</b>	<b>Stroke Severity</b>
0	No stroke symptoms
1-4	Minor stroke
5-15	Moderate stroke
16-20	Moderate to severe stroke
21-42	Severe stroke

**4.4.8.4.10 Stroke Type - Bamford Classification**

The Bamford Classification (Bamford et al., 1991) was chosen to categorise the type of stroke experienced by participants. Bamford et al. (1991) described the incidence and natural history of four clinically identifiable subgroups of cerebral infarction in a community based study of 675 patients with first ever stroke. These relate to the location of the infarction and are total anterior circulation infarct (TACI), posterior partial anterior circulation infarct (PACI), lacunar infarct (LACI) and posterior circulation infarct (POCI). The TACI group had a minimal chance of a good functional outcome and a high mortality rate. The PACI group were more likely to have an early recurrent stroke than other groups. The LACI group remained substantially disabled. The POCI group had the best chance of a good functional outcome but were

at greater risk of a recurrent stroke later in first year after the stroke. This system of classification is also known as the Oxfordshire Community Stroke Project (OCSP) classification (Amarenco et al., 2009). Classification is usually completed by the medical team who look for the presence or absence of the four main features of a stroke (hemiparesis, higher cortical dysfunction including language problems, hemianopia and brainstem signs).

**Table 9. Bamford Classification**

<b>Stroke Type</b>	<b>Lacunar (LACS)</b>	<b>Partial anterior circulation (PACS)</b>	<b>Total anterior circulation (TACS)</b>	<b>Posterior circulation (POCS)</b>
<b>Signs</b>	Motor or sensory deficit only	2 of the following: motor or sensory deficit; higher cortical dysfunction; hemianopia	All of: motor or sensory; cortical; hemianopia	Isolated hemianopia; brain stem signs; cerebellar ataxia

In cases where the Bamford classification was not recorded by the hospital, a researcher and stroke medicine consultant, affiliated with the university and working at a different hospital, determined the likely Bamford classification based on the descriptions of the patients' symptoms recovered from the medical notes. However, the stroke medicine consultant disagreed with the classifications made by the hospital in a number of cases. It was decided to take the consultant's opinion over the diagnosis made by the ward staff in an attempt to increase consistency. However, this has the limitation of not being

completed face to face with the patient through clinical examination as the system intended.

#### **4.4.8.4.11 Measurement of confidence about return to work**

When Condition Management Pilot Programmes underwent evaluation by the Department of Health, a set of questions focusing on confidence about returning to work were used as a measure of work readiness by case managers and results returned to Job Centre Plus by providers (Ford & Plowright, 2009). This enabled the level of participants' confidence about returning to work, finding work, managing their health condition in a work environment and that working would not make the condition worse to be measured. Ford and Plowright (2009) found that work readiness scores were significantly related to improved depression outcome scores with the greatest work readiness in the recovered group of participants with a HAD score of less than eight. They also found that paid employment at 12 months was only significantly associated with the question about confidence to find work. It was felt this would be a useful measure to include in the current study, so that even for people who did not return within the time frame of the study, their confidence about their ability to do so in the future and work readiness could be ascertained.

#### **4.4.9 Piloting the questionnaire**

The baseline and three/ six/ 12 month questionnaires were piloted on six people including two OTs working on research projects about VR at the university and an OT seconded to the project one day a week from the NHS. Two patients of a clinical colleague were also invited to

complete the questionnaire and provide feedback on the clarity of instructions and practical difficulties, problem questions and emotional load and time taken to complete the questionnaire. A stroke survivor on the expert panel was also asked to complete the questionnaire and provide feedback. A number of changes were made based on the feedback received. These included:

Baseline data record sheet:

- ethnicity categories were expanded
- additional previous health problems were added (diabetes, heart disease and high blood pressure)
- marital status choices were expanded.

Baseline and three/ six and 12 month follow-up questionnaire booklets:

- more information was requested about the respondents' current work situation
- 'Employment and Support Allowance' was added to the question about benefits
- the order of other services was changed to reflect those more likely to be used being placed at the top
- the wording and layout of some of the items on the non-standardised questions was also improved to give greater clarity

- names of the standardised questionnaires were removed as they were felt to be unnecessary.

General feedback from OTs and patients was that the questionnaire was too long. However, because it was a feasibility trial and considered important to test a number of work measures in order to identify one for use in a definitive trial, it was not shortened. However, it was acknowledged that this may impact on the completeness of data collection. The baseline questionnaire booklet was longer than the follow-up ones because it contained a measure of cognition and demographic questions. It was conducted as an interview and could be spaced over a number of sessions if needed. The follow-up questionnaire booklet was sent out by post but with an aphasia friendly front cover sheet offering assistance with completion if needed was included.

#### **4.4.10 Follow-up data collection procedure**

Questionnaire booklets were sent out two weeks ahead of review date. If participants did not return postal questionnaires two weeks after the due date then they were telephoned by the research associate and assistance with completing the questionnaires over the phone or face to face was offered. Duplicate questionnaires were sent out when no contact made by telephone. At the end of the study it was necessary to send some questionnaires out approximately six weeks ahead of the due date to ensure adequate time for data entry and analysis.

#### **4.4.11 Data analysis**

As this was a feasibility study, the trial enabled measurement of demographics of the study population, eligible numbers, recruitment rate, the spectrum of disease among recruits, reasons for not recruiting, acceptability of VR to the intervention group and with usual care in controls and the completeness of follow up of the primary endpoint. It also determined whether participants could be randomised to the intervention and the effect on drop out of randomisation to the control group.

Ten percent of data was randomly selected and checked by the research associate for accuracy of data input. Following this, descriptive analysis was performed and this was retrospective, exploring measures used (including floor and ceiling effects of more than 15% (Terwee et al., 2007) and differences between intervention and control groups. This was conducted using SPSS Version 21 and Stata SE Version 14.

### **4.5 Results**

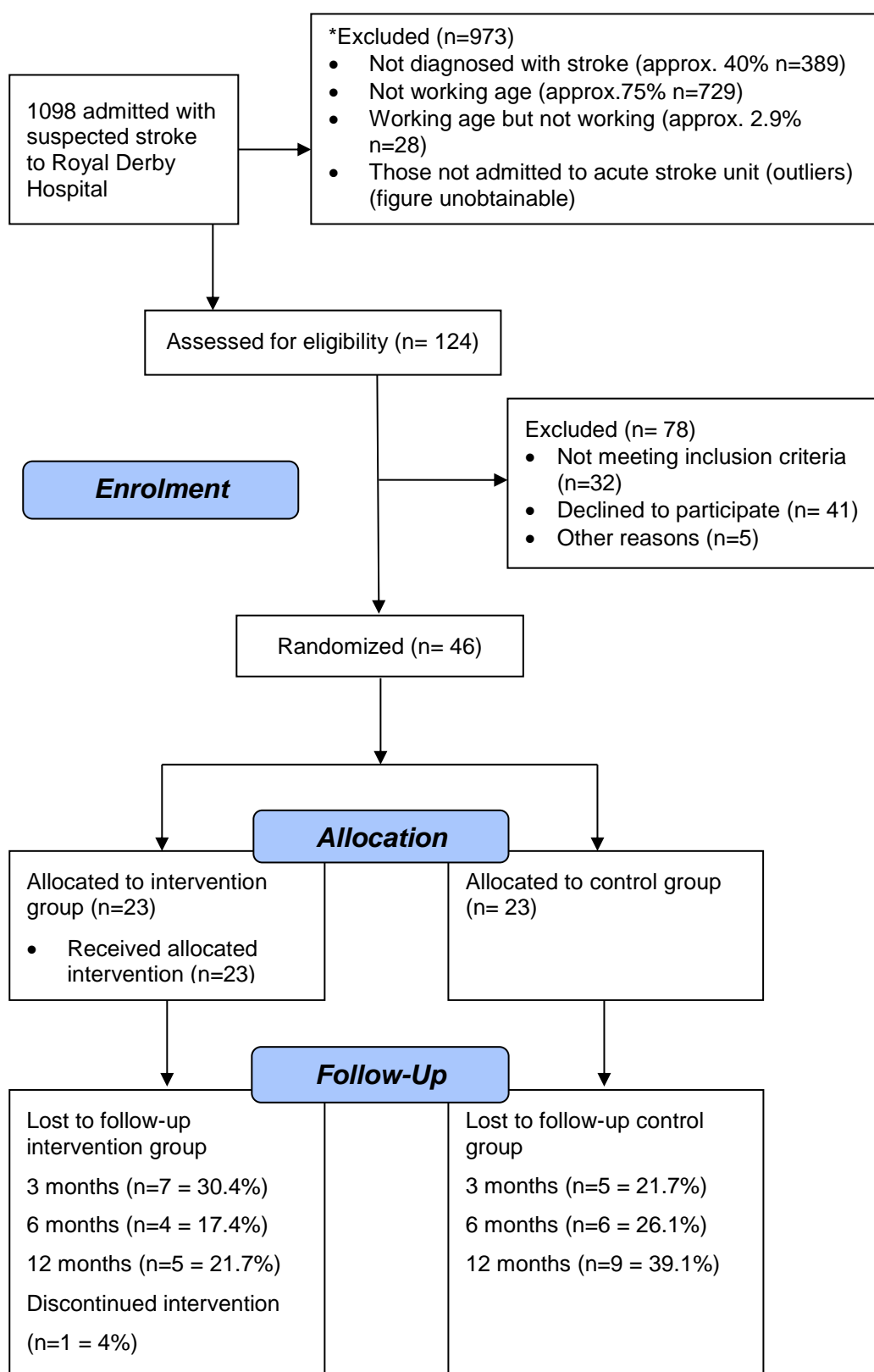
#### **4.5.1 Recruitment of participants**

Recruitment and randomisation took place between September 2010 and December 2011. The flow of participants through the study is summarised in Figure 7. Of the 124 identified by staff on the stroke unit, 32 did not meet the criteria and 41 declined to participate. Five were excluded for other reasons (described in section 4.5.3 Feasibility of recruitment) and the remaining participants were randomised. Of these 23 were allocated to the intervention group and 23 to the control group. All members of the intervention group received the intervention and only

one withdrew. Numbers lost to follow-up at the three time points are shown in Figure 7.



**Figure 7. CONSORT flow diagram**



\* These figures were estimated using evidence from a previous study and local demographic data as they were not recorded during this study (there is some overlap between those not diagnosed with stroke and those of working age).

## 4.5.2 Characteristics of the sample

### 4.5.2.1 Demographic characteristics

The groups were well balanced for demographic characteristics at baseline apart from education levels (Table 10). The mean age was 58 in the intervention group and 54 in the control group. There were 17 males in the intervention group and 19 in the control group. The majority of participants in both groups were married and of white British ethnic origin. A greater proportion of the intervention group received higher education and more people in the control group received further education. A higher number of people in the intervention group were driving before the stroke.

**Table 10. Demographic characteristics**

<b>Demographic characteristics</b>	<b>Intervention</b>	<b>Control</b>	<b>Total sample</b>
<b>Age at recruitment</b>			
Mean	58.3	53.8	56.0
(SD)	(12.7)	(12.6)	(12.7)
Range	24-78	18-77	18-78
<b>Gender</b>			
Males	17 (73.9%)	19 (82.6%)	36 (78.3%)
Females	6 (26.1%)	4 (17.4%)	10 (21.7%)
<b>Ethnicity</b>			
White British	23 (100.0%)	22 (95.7%)	45 (97.8%)
Caribbean	0 (0.0%)	1 (4.3%)	1 (2.2%)
<b>Marital Status</b>			
Single	4 (17.4%)	5 (21.7%)	9 (19.6%)
Married	15 (65.2%)	13 (56.5%)	28 (60.9%)
Separated	0 (0.0%)	1 (4.3%)	1 (2.2%)
Divorced	2 (8.7%)	0 (0.0%)	2 (4.3%)
Widowed	0 (0.0%)	1 (4.3%)	1 (2.2%)
Living with a partner	2 (8.7%)	2 (8.7%)	4 (8.7%)
Partner, living apart	0 (0.0%)	1 (4.3%)	1 (2.2%)

<b>Demographic characteristics</b>	<b>Intervention</b>	<b>Control</b>	<b>Total sample</b>
<b>Highest Educational Level</b>			
Secondary school (no GCSE)	4 (17.4%)	3 (13.0%)	7 (15.2%)
Secondary school (GCSE)	7 (30.4%)	6 (26.1%)	13 (28.3%)
Further education	2 (8.7%)	11 (47.8%)	13 (28.3%)
Higher education	10 (43.5%)	3 (13.0%)	13 (28.3%)
<b>Driving before stroke</b>			
Yes	19 (82.6%)	14 (60.9%)	33 (71.7%)
No	4 (17.4%)	9 (39.1%)	13 (28.3%)

#### 4.5.2.2 Occupational characteristics

The groups were well balanced at baseline with regard to most occupational characteristics (Table 11). The number of weeks with current employer, pre-stroke weekly working hours and annual income prior to the stroke were similar in both groups. But a higher proportion of people in the intervention group were in professional/ managerial and skilled jobs and more in the control group had unskilled or semi-skilled level jobs at baseline.

**Table 11. Occupational characteristics**

<b>Occupational characteristics</b>	<b>Intervention</b>	<b>Control</b>	<b>Total Sample</b>
<b>Weeks employed with current employer</b>			
Mean	699.5	779.8	742.4
(SD)	(657.9)	(695.3)	(671.3)
Range	1 - 2288	54 - 2160	1 - 2288
<b>Pre-stroke Working Hours</b>			
Mean	32.2	35.9	34.1
(SD)	(15.8)	(13.2)	(14.5)
Range	3 - 55	7.5 - 55	3 - 55

<b>Occupational characteristics</b>	<b>Intervention</b>	<b>Control</b>	<b>Total Sample</b>
<b>Annual Income</b>			
Mean (SD)	£20,081 (£12,983)	£21,262 (£12,435)	£20,688.23 (£12,529.58)
Range	£4,200-£45,182	£2,400-£50,000	£2,400-£50,000
<b>SOC Skill Level* n (%)</b>			
Level 1 (unskilled)	2 (8.7%)	3 (13%)	5 (10.9%)
Level 2 (semi-skilled)	2 (8.7%)	9 (39.1%)	11 (23.9%)
Level 3 (professional)	9 (39.1%)	7 (30.4%)	16 (34.8%)
Level 4 (managerial/ professional)	10 (43.5%)	4 (17.4%)	14 (30.4%)

\* Using the Standard Occupational Classification (Office of National Statistics, 2010)

#### **4.5.2.3 Health and stroke characteristics**

Health and stroke characteristics at baseline are shown in Table 12.

Previous health problems were fairly balanced between groups. A few more people had a history of transient ischaemic attack and mental health problems in the intervention group. The length of stay in hospital was longer for the control group, a mean of 27 days compared with 19. There was some variation in the type of stroke (Bamford classification) as more people in the intervention groups had lacunar (LACS) strokes and more in the control group had total anterior circulation (TACS) and posterior circulation (POCS) strokes. Stroke severity, speech and visual effects were balanced across the groups. Stroke impact as measured by the Stroke Impact Scale was balanced between the groups. Four more people in the intervention group had cognitive impairment,

measured by the Multiple Sclerosis Neuropsychological Screening Questionnaire.

**Table 12. Health and stroke characteristics**

<b>Health and stroke characteristics</b>	<b>Intervention</b>	<b>Control</b>	<b>Total population</b>
<b>Previous Health Problems n (%)</b>			
TIA	5 (21.7%)	2 (8.7%)	7 (15.2%)
Stroke	1 (4.3%)	2 (8.7%)	3 (6.5%)
Heart Disease	3 (13.0%)	3 (13.0%)	6 (13.0%)
Diabetes	2 (8.7%)	2 (8.7%)	4 (8.7%)
High Blood Pressure	9 (39.1%)	7 (30.4%)	16 (34.8%)
Brain Injury	0 (0.0%)	0 (0.0%)	0 (0.0%)
Neurological Condition	0 (0.0%)	0 (0.0%)	0 (0.0%)
Mental Health Problem	5 (21.7%)	2 (8.7%)	7 (15.2%)
Drug Problem	0 (0.0%)	0 (0.0%)	0 (0.0%)
Alcohol Problem	1 (4.3%)	0 (0.0%)	1 (4.3%)
Other	4 (17.4%)	4 (17.4%)	8 (17.4%)
<b>Length of stay in hospital (days)</b>			
Mean	19.6	27.1	23.4
(SD)	(21.6)	(26.9)	(24.39)
Range	0-82	1-100	0-100
<b>Stroke Severity (NIHSS) n (%)</b>			
Minor (1-4)	8 (34.8%)	8 (34.8%)	16 (34.8%)
Moderate (5-15)	7 (30.4%)	6 (26.1%)	13 (28.3%)
Moderate/Severe (16-20)	2 (8.7%)	2 (8.7%)	4 (8.7%)
Severe (21-42)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Missing**	6 (26.1%)	7 (30.4%)	13 (28.3%)
<b>Bamford Classification n (%)</b>			
LACS	5 (21.7%)	2 (8.7%)	7 (15.2%)
PACS	7 (30.4%)	5 (21.7%)	12 (26.1%)
TACS	3 (13.0%)	6 (26.1%)	9 (19.6%)
POCS	5 (21.7%)	8 (34.8%)	13 (28.3%)
Missing**	3 (13.0%)	2 (8.7%)	5 (10.9%)
<b>Stroke Impact Scale (SIS)</b>			
Median scaled score	76.1	67.9	74.2

Health and stroke characteristics	Intervention	Control	Total population
<b>Speech Affected n (%)</b>			
Not affected	8 (34.8%)	10 (43.5%)	18 (40.0%)
Aphasia	4 (17.4%)	3 (13%)	7 (15.2%)
Dysarthria	7 (30.4%)	8 (34.8%)	15 (32.6%)
Dysarthria and aphasia	4 (17.4%)	1 (4.3%)	5 (10.9%)
Missing**	0 (0.0%)	1 (4.3%)	1 (2.2%)
<b>Vision Affected* n</b>			
Not affected	14	9	23
Hemianopia	6	3	9
Blurred Vision	1	2	3
Nystagmus	0	3	3
Quadrantanopia	1	2	3
Other	1	4	5
<b>Cognitive Impairment (MSNQ) n (%)</b>			
Non-impaired	18 (78.2%)	22 (95.7%)	40 (86.9%)
Impaired (27+)	5 (21.8%)	1 (4.3)	6 (13.1%)

\*visual impairments are not given percentages because some participants reported multiple visual defects, therefore the frequencies of reported impairments are shown above

\*\* missing data – not available from medical records

### 4.5.3 Feasibility of recruitment

46 participants were recruited over the 16 month period falling just five patients short of the target required. However, the number of people admitted to the hospital during the recruitment period with a stroke was 1098 (Directorate of Finance and Information Royal Derby Hospital, 2013). This indicates that the target population was larger than originally estimated. The eligible numbers were influenced by mortality, proportion with a confirmed stroke diagnosis and levels of unemployment in the locality. The numbers excluded and screened out by staff identifying potential recruits is estimated in the Consort diagram based on findings of a previous study indicating up to 40% of people admitted to hospital with a suspected stroke are not diagnosed with

stroke (Harbison et al., 2003) and local demographic data on unemployment rates in the area during the recruitment period (Derbyshire City Council, 2014) (Figure 7).

Reasons for failure to fit with inclusion criteria are listed in Table 13.

Reasons for declining are listed in Table 14. Medical reasons included the presence of another condition preventing participation (terminal cancer diagnosis and other medical condition). Other reasons for non-participation included death (n=1) and being advised not to approach patients by ward staff due to severity of stroke (n=1), severe speech and language difficulties (n=1) and very low mood (n=1). These were staff from different disciplines including nurses, OTs and speech and language therapists who felt approaching these patients to participate in research would not be appropriate given the difficulties they were experiencing at the time. One patient did not speak English, was not registered with a GP and although hospital visitors translated an explanation of the study, the person declined to participate (n=1).

**Table 13. Reasons for failure to fit inclusion criteria**

<b>Reason for failure to fit inclusion criteria</b>	<b>Number</b>
Not diagnosed with a stroke (migraine, TIA or other diagnosis)	9
Not working at time of stroke	9
Decided to retire due to stroke	9
Medical reasons	2
Retired at time of stroke	2
Decided not to return to work due to stroke	1

**Table 14. Reasons for declining to participate in return to work study**

<b>Reasons for declining</b>	<b>Number</b>
Missed on ward and did not reply to invitation letters	11
Approached on ward but then did not reply to phone calls or letters	3
Felt able to return to work without assistance (mild strokes)	8
Severe stroke – patient felt it was too early to discuss work	2
Significant speech and language difficulties – unable to consent or family declined	4
Declined to participate (cognitive difficulties)	3
Depressed/ low mood and not able to think about work	2
Severe learning difficulties (prior to stroke) – family did not feel it was appropriate to participate	1
Felt overwhelmed – could not think about work	1
Wanted to be guaranteed intervention	1
Did not wish to participate in research – no reason given	5

#### **4.5.4 Spectrum of disease amongst participants**

Participants were recruited with stroke of varying severity and types (Table 12). However, there were a greater proportion overall with minor or moderate strokes.

#### **4.5.5 Feasibility of randomisation**

Only one person declined to participate because they wanted to be guaranteed to be in the intervention arm of the trial i.e. did not want to be randomised. Therefore, it is feasible to randomise participants. However, it should be noted that there was a higher rate of loss to follow-up at the six and 12 month time points in the control group.



#### **4.5.6 Feasibility of blinding**

It was intended that the research associate would be blind to intervention allocation. The research OT took responsibility for entering data into the computerised randomisation system and then notified participants which arm of the trial they had been allocated to. There were a number of incidents when the research associate became unblinded due to a participant telling her that they had seen the research OT when follow-up questionnaires were being pursued, or when participants named the research OT on their follow-up questionnaire when asked about services received. However, a blinding check was carried out prior to data analysis which demonstrated that the research associate could not accurately identify those people allocated to intervention by their research number as only 22 out of 46 (48%) were guessed correctly thereby no greater than chance.

#### **4.5.7 Compliance with intervention**

Only one participant withdrew from intervention. The reasons for this withdrawal were not clarified despite efforts to ascertain this. Therefore, compliance with the intervention was very high and indicates that delivery of the intervention is feasible. The content of intervention delivered in the trial along with details of the intensity and duration are described in Chapter 5. The mean number of sessions was ten for trial participants (range 1-25) and the mean number of hours spent with each individual in face to face contact was 9.75.

#### **4.5.8 Services received by intervention and control group participants**

Both intervention and control group participants reported receiving health and social care services (Table 15). A higher proportion of the intervention group saw a consultant, especially at 12 months, whereas a similar number saw their GP, although this also dropped in the control group at 12 months. A higher proportion of the intervention group saw an OT but fewer saw a physiotherapist. Very few participants in either group saw a psychologist, speech and language therapist or social worker.

Similar numbers in each group received benefits advice. Very few participants saw a Disability Employment Advisor, solicitor or attended a self-help group. The most common source of additional help came from family and friends.

**Table 15. Services received by intervention and control group participants – number, percentage and range**

Services	Intervention Group Months			Control Group Months		
	3 (n=16)	6 (n=19)	12 (n=18)	3 (n=18)	6 (n=17)	12 (n=14)
<b>Consultant</b>						
n	12	15	11	12	11	8
%	75.0	78.9	61.1	66.7	64.7	42.8
Range	0-4	0-3	0-8	0-2	0-3	0-4
<b>GP</b>						
n	14	17	15	16	14	10
%	87.5	89.5	83.3	88.9	82.4	71.4
Range	0-4	0-7	0-10	0-10	0-6	0-12
<b>Psychologist</b>						
n	3	3	1	3	4	1
%	18.8	15.8	5.6	16.7	23.5	7.1
Range	0-1	0-2	0-2	0-1	0-3	0-1
<b>OT</b>						
n	12	8	10	8	8	5
%	75.0	42.1	55.6	44.4	47.1	35.7
Range	0-15	0-17	0-35	0-8	0-24	0-27
<b>Physiotherapist</b>						
n	6	7	5	10	9	4
%	37.5	36.8	27.8	55.6	52.9	28.6
Range	0-10	0-25	0-54	0-15	0-33	0-40
<b>Speech and Language Therapist</b>						
n	4	4	3	3	1	0
%	25.0	21.1	16.7	16.7	5.9	0.0
Range	0-5	0-11	0-6	0-8	0-12	0
<b>Social worker</b>						
n	1	1	2	3	1	1
%	6.25	5.3	11.1	16.7	5.9	14.3
Range	0-1	0-1	0-12	0-1	0-1	0-2
<b>Other health related services<sup>1</sup></b>						
n	6	3	5	6	2	1
%	37.5	15.8	27.8	33.3	11.8	7.2
Range	0-5	0-10	0-6	0-3	0-24	0-8
<b>Benefits advisor</b>						
n	4	1	3	5	4	3
%	25.0	52.6	16.7	27.8	23.5	21.4
Range	0-2	0-4	0-3	0-1	0-3	0-1

Services	Intervention Group Months			Control Group Months		
	3 (n=16)	6 (n=19)	12 (n=18)	3 (n=18)	6 (n=17)	12 (n=14)
<b>Disability Employment Advisor</b>						
n	0	1	1	1	1	1
%	0.0	5.3	5.6	5.0	5.9	14.3
Range	-	0-1	0-4	0-1	0-1	0-1
<b>Solicitor</b>						
n	2	0	2	0	1	0
%	12.5	0.0	11.1	0.0	5.9	0.0
Range	0-2	-	5-10	-	0-2	-
<b>Self-help group<sup>2</sup></b>						
n	1	0	1	0	1	1
%	12.5	0.0	5.6	0.0	5.9	7.2
Range	0-1	-	0-1	-	0 -*	0-1
<b>Other help received<sup>3</sup></b>						
n	2	4	1	0	4	2
%	12.5	11.1	5.6	0.0	23.5	14.3
Range	0-1	0-1	0-1	-	0-1	0-1

1 Stroke support service, Intermediate care service, Council for housing adaptations, nurses, private physio

2 Stroke club, Headway, Computer Course, Yoga

3 Family, friends and neighbours, Citizens Advice, Self-Management Group, Disability Direct Bowling Club, Online forum

\* unknown

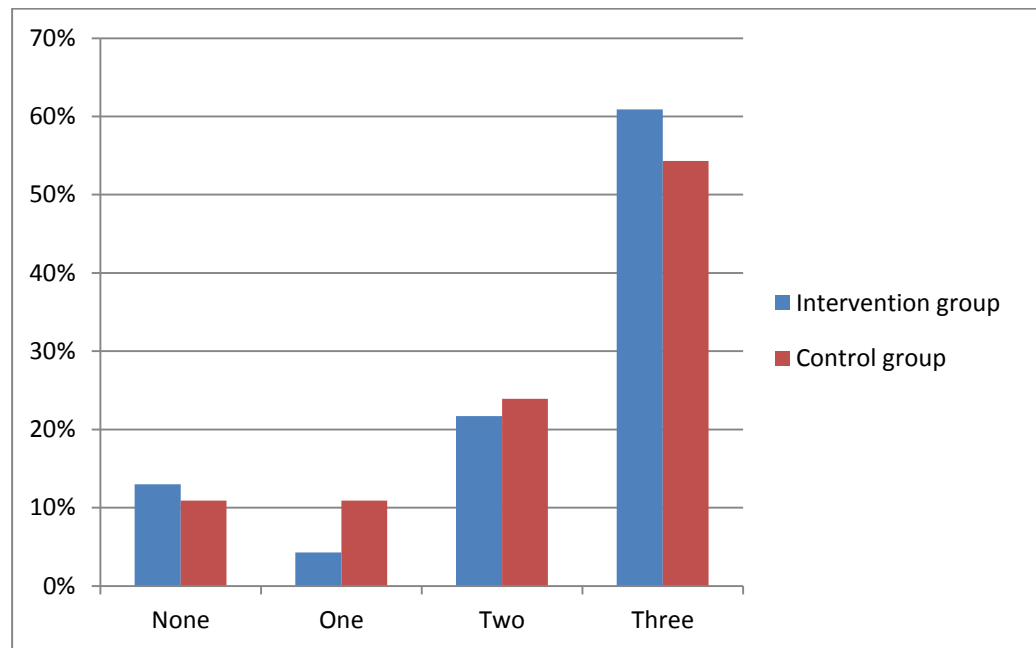
n=number of people who received service, %= percentage of group, Range=range in number of visits

## 4.5.9 Feasibility of data collection

### 4.5.9.1 Questionnaire Completion

The number of questionnaires each participant returned (ranging from none to three which would be a full data set) is presented in Figure 8.

**Figure 8. Number of questionnaires returned per participant**



The number of questionnaires returned at each time point by people in the intervention and control groups are shown in Table 16 below. More people in the intervention group responded at six and 12 months and there was less loss to follow-up. The average response rate across all three time points and for both groups was 73.9%.

**Table 16. Number of questionnaires returned at each time point**

	<b>Intervention group</b>	<b>Control group</b>	<b>Total</b>
<b>3 months</b>			
Received	16 (69.6%)	18 (78.3%)	34 (73.9%)
Non-response	7 (30.4%)	5 (21.7%)	12 (26.0%)
<b>6 months</b>			
Received	19 (82.6%)	17 (73.9%)	36 (78.3%)
Non- response	4 (17.4%)	6 (26.1%)	10 (21.7%)
<b>12 months</b>			
Received	18 (78.3%)	14 (60.9%)	32 (69.6%)
Non- response	5 (21.7%)	9 (39.1%)	14 (30.4%)
<b>Overall</b>			
Received	53 (76.8%)	49 (71.1%)	102 (73.9%)
Non-response	16 (23.2%)	20 (28.9%)	36 (26.0%)

#### **4.5.9.2 Completion of standardised measures**

This section reports on the completeness of each questionnaire, i.e. the proportion of questions completed and left unanswered (Tables 17-22).

Completeness was analysed using intention to treat, therefore participants who were lost to follow up automatically scored 0% for completeness of their assessments.

**Table 17. Hospital Anxiety and Depression Scale completion rates**

<b>HADS</b>	<b>Intervention (%)</b>	<b>Control (%)</b>	<b>Mean across groups (%)</b>
<b>3 months</b>			
Mean	69.25	78.26	73.76
(SD)	(46.86)	(42.17)	(44.32)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	82.30	73.60	77.95
(SD)	(38.64)	(44.73)	(41.56)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	78.86	60.87	69.87
(SD)	(42.17)	(49.90)	(46.52)
Range	0-100	0-100	0-100

**Table 18. EQ-5D completion rates**

<b>EQ-5D</b>	<b>Intervention (%)</b>	<b>Control (%)</b>	<b>Mean across groups (%)</b>
<b>3 months</b>			
Mean	68.84	76.81	72.83
(SD)	(46.68)	(41.97)	(44.17)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	81.88	69.57	75.73
(SD)	(38.57)	(47.05)	(42.99)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	78.26	60.87	69.57
(SD)	(42.17)	(49.90)	(46.52)
Range	0-100	0-100	0-100

**Table 19. NEADL completion rates**

<b>NEADL</b>	<b>Intervention (%)</b>	<b>Control (%)</b>	<b>Mean across groups (%)</b>
<b>3 months</b>			
Mean	67.79	70.75	69.27
(SD)	(45.99)	(43.40)	(44.24)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	76.88	73.52	75.20
(SD)	(41.54)	(44.68)	(42.69)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	76.28	58.89	67.59
(SD)	(41.36)	(48.54)	(45.45)
Range	0-100	0-100	0-100

**Table 20. Work Productivity and Activity Impairment Instrument completion rates**

<b>WPAI</b>	<b>Intervention (%)</b>	<b>Control (%)</b>	<b>Mean across groups (%)</b>
<b>3 months</b>			
Mean	55.88	60.71	58.29
(SD)	(49.63)	(48.74)	(48.47)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	71.66	70.00	70.83
(SD)	(45.18)	(47.01)	(45.57)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	68.75	35.00	51.87
(SD)	(47.87)	(47.99)	(50.14)
Range	0-100	0-100	0-100



**Table 21. Sydney Psychosocial Reintegration Scale completion rates**

<b>SPRS</b>	<b>Intervention (%)</b>	<b>Control (%)</b>	<b>Mean across groups (%)</b>
<b>Qualitative questions</b>			
<b>3 months</b>			
Mean	63.88	68.56	66.22
(SD)	(44.28)	(43.39)	(43.41)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	71.57	51.51	61.54
(SD)	(40.33)	(44.88)	(43.40)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	71.57	51.17	61.37
(SD)	(40.80)	(45.07)	(43.74)
Range	0-100	0-100	0-100
<b>Work and Leisure questions</b>			
<b>3 months</b>			
Mean	59.78	69.57	64.68
(SD)	(46.92)	(43.27)	(44.91)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	70.65	66.30	68.48
(SD)	(44.37)	(45.61)	(44.55)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	65.22	53.26	59.24
(SD)	(43.13)	(48.44)	(45.75)
Range	0-100	0-100	0-100
<b>Relationships questions</b>			
<b>3 months</b>			
Mean	63.04	71.74	67.39
(SD)	(48.19)	(42.17)	(44.99)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	73.91	68.48	71.20
(SD)	(40.93)	(46.60)	(43.45)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	74.78	55.65	65.22
(SD)	(41.44)	(50.08)	(46.46)
Range	0-100	0-100	0-100

<b>SPRS</b>	<b>Intervention (%)</b>	<b>Control (%)</b>	<b>Mean across groups (%)</b>
<b>Living skills questions</b>			
<b>3 months</b>			
Mean	64.13	75.00	69.57
(SD)	(48.16)	(43.30)	(45.62)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	82.61	69.57	76.09
(SD)	(38.76)	(47.05)	(43.13)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	77.17	56.52	66.85
(SD)	(41.91)	(50.69)	(47.15)
Range	0-100	0-100	0-100
<b>Total questions</b>			
<b>3 months</b>			
Mean	63.13	70.26	66.70
(SD)	(44.08)	(41.72)	(42.59)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	73.57	59.48	67.00
(SD)	(38.04)	(41.26)	(39.88)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	72.19	54.15	63.17
(SD)	(40.35)	(47.40)	(44.47)
Range	0-100	0-100	0-100

**Table 22. Work Limitations Questionnaire completion rates**

<b>WLQ – Time demands</b>	<b>Intervention (%)</b>	<b>Control (%)</b>	<b>Mean across groups (%)</b>
<b>3 months</b>			
Mean	35.65	26.96	31.31
(SD)	(46.30)	(44.56)	(45.15)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	46.96	56.52	51.74
(SD)	(50.31)	(50.69)	(50.17)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	43.48	25.22	34.35
(SD)	(48.11)	(43.58)	(46.32)
Range	0-100	0-100	0-100
<b>WLQ – Physical demands</b>			
<b>3 months</b>			
Mean	31.16	35.51	33.34
(SD)	(44.18)	(45.87)	(44.58)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	51.45	55.80	53.63
(SD)	(48.44)	(50.15)	(48.80)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	50.00	26.09	38.05
(SD)	(50.00)	(44.90)	(48.52)
Range	0-100	0-100	0-100
<b>WLQ – Mental demands</b>			
<b>3 months</b>			
Mean	37.20	32.85	35.03
(SD)	(47.92)	(44.76)	(45.90)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	49.76	54.59	52.18
(SD)	(49.11)	(49.23)	(48.68)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	47.83	21.74	34.79
(SD)	(48.71)	(42.17)	(46.94)
Range	0-100	0-100	0-100

<b>WLQ – Time demands</b>	<b>Intervention (%)</b>	<b>Control (%)</b>	<b>Mean across groups (%)</b>
<b>WLQ – Output demands</b>			
<b>3 months</b>			
Mean	33.91	33.04	33.48
(SD)	(46.49)	(46.56)	(46.01)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	49.57	49.57	49.57
(SD)	(48.94)	(48.19)	(48.03)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	47.83	26.09	36.96
(SD)	(49.63)	(44.90)	(48.06)
Range	0-100	0-100	0-100
<b>WLQ – Total</b>			
<b>3 months</b>			
Mean	34.78	32.3	33.56
(SD)	(45.23)	(43.17)	(43.97)
Range	0-100	0-100	0-100
<b>6 months</b>			
Mean	49.57	54.26	51.92
(SD)	(47.11)	(48.88)	(47.53)
Range	0-100	0-100	0-100
<b>12 months</b>			
Mean	47.48	24.35	35.92
(SD)	(48.71)	(42.47)	(46.67)
Range	0-100	0-100	0-100

On most measures and domains the highest rates of completion were at six months with lowest rates at three and 12 months. This is more marked on the WPAI and the WLQ with completion rates the lowest on the WLQ.

#### **4.5.9.3 Missing baseline data - Bamford Classification and NIHSS**

As Bamford and NIHSS scores were routinely recorded on admission to the acute stroke ward, a decision was made to use this data. However, measures were poorly completed by ward staff. Also speech and

language and visual impairments following stroke were poorly recorded, which meant it was difficult to accurately classify problems.

#### 4.5.10 Outcome measurement

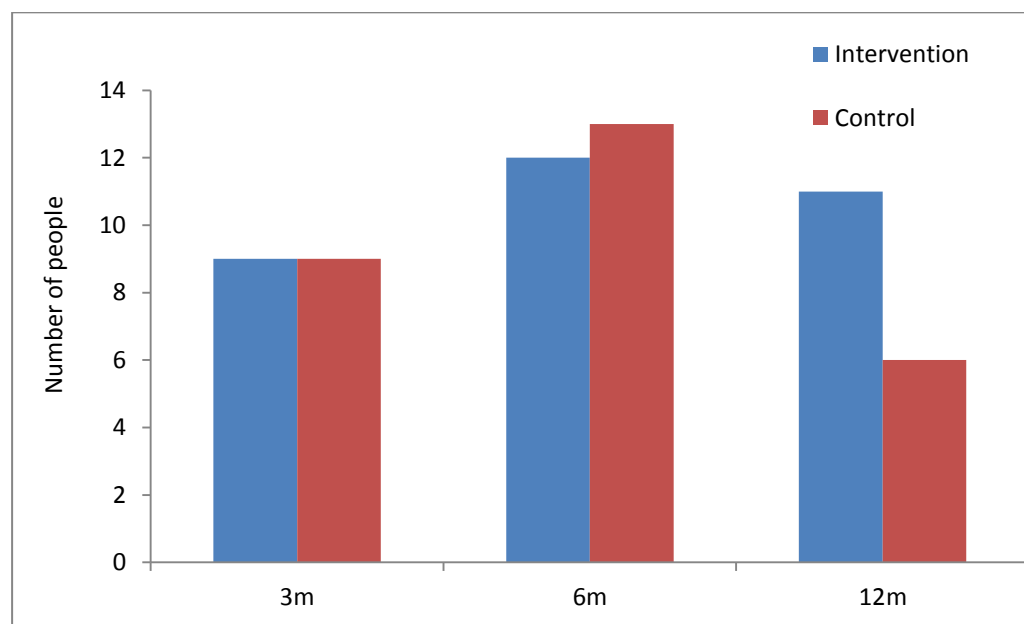
##### 4.5.10.1 Primary outcome

The primary outcome was whether the participant had returned to work at three, six and 12 months post stroke (the term ‘work’ is used to refer to paid, voluntary and educational roles). Table 23 and Figure 9 detail the numbers of participants who reported that they had returned at each time point.

**Table 23. Numbers of participants in intervention and control groups in work at all time points (self-reported)**

	Intervention	Control	Total
<b>3 months</b>	9	9	18
<b>6 months</b>	12	13	25
<b>12 months</b>	11	6	17

**Figure 9. Numbers of participants in intervention and control groups in work at all time points (self-reported)**



Despite efforts to obtain full data sets, there were some participants who were lost to follow up and therefore the primary outcome of work return was unknown.

For participants with missing data at three months, return to work dates reported in a later questionnaire were used to determine three month work outcomes. At three months, seven participants in the intervention group and five control participants had missing questionnaires. Work outcomes were imputed for four intervention and two control participants using data from their 6 and 12 month responses.

One intervention participant was not in work (and did not return to work throughout the course of the project) two were working when their three month follow up was due and one was not.

One of the missing control participants was in work at the three month follow up point and one was not. For the remaining three, one participant failed to record their return to work date and two participants failed to return any questionnaires.

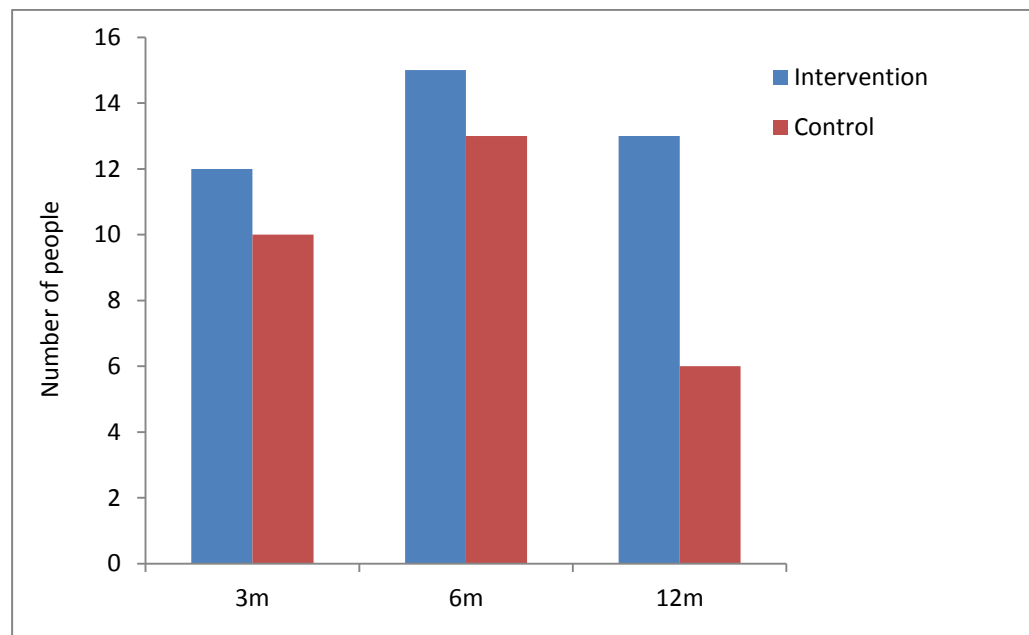
This increased the number of participants recorded as being 'in work at three time points' therefore it is likely that the number of participants in work is underrepresented due to loss to follow up.

If a participant returned their three month questionnaire and reported that they were not working, but then failed to return their six or 12 month questionnaire, it was not possible to determine whether they returned to work. However, to classify them as 'not in work at any time point' would be misleading, therefore they were classed as 'unable to determine'.

In addition, the knowledge the research OT had about three participants in the intervention group was utilised to determine the primary outcome. However, this method of collecting data could possibly bias the results towards the intervention group as more is known about their vocational status than the control group. Furthermore, one participant who did not return their three, six or 12 month questionnaire responded to an email requesting their return to work date and primary outcome.

The primary outcomes obtained from the full and partial data combined are presented in Figure 10 and Table 24.

**Figure 10. Primary outcome – full and partial data combined (number of participants from intervention and control groups in work at each time point)**



**Table 24. Primary outcome – full and partial data combined (number of participants from intervention and control groups in work at each time point)**

	<b>Intervention</b>	<b>Control</b>	<b>Total</b>
<b>3 months</b>	12	10	22
<b>6 months</b>	15	13	28
<b>12 months</b>	13	6	19

#### **4.5.10.2 Secondary outcome measures**

Descriptive analysis of standardised outcome measure scores at all the time points are shown in Tables 25-30 and Figures 7-12.

##### **4.5.10.2.1 HADS**

The total depression median score was higher in the control group at six months. The confidence interval for this score does not contain a zero which indicates there is likely to be an effect. There were floor effects of over 15% for anxiety scores at six and 12 months.

**Table 25. HADS total anxiety scores**

<b>HADS Total Anxiety Scores</b>	<b>Intervention</b>	<b>Control</b>	<b>95% Confidence Interval (CI) for difference in medians between groups</b>
<b>Baseline</b>			
Number	23	23	
Median (SD)	4.00 (4.11)	5.00 (3.82)	-3.63, 1.63
Range	1-15	0-14	
IQR	3-8	2-8	
<b>3 months</b>			
Number	16	18	
Median (SD)	6.50 (3.75)	5.00 (4.68)	-3.56, 6.56
Range	0-12	0-13	
IQR	2-9	1-10	



<b>HADS Total Anxiety Scores</b>	<b>Intervention</b>	<b>Control</b>	<b>95% Confidence Interval (CI) for difference in medians between groups</b>
<b>6 months</b>			
Number	19	17	
Median (SD)	5.00 (3.73)	5.00 (3.25)	-3.63, 3.63
Range	0-11	0-13	
IQR	0-8	2-7	
<b>12 months</b>			
Number	18	14	
Median (SD)	4.50 (4.45)	4.00 (3.70)	-3.29, 4.29
Range	0-16	0-14	
IQR	1-8	1-5	

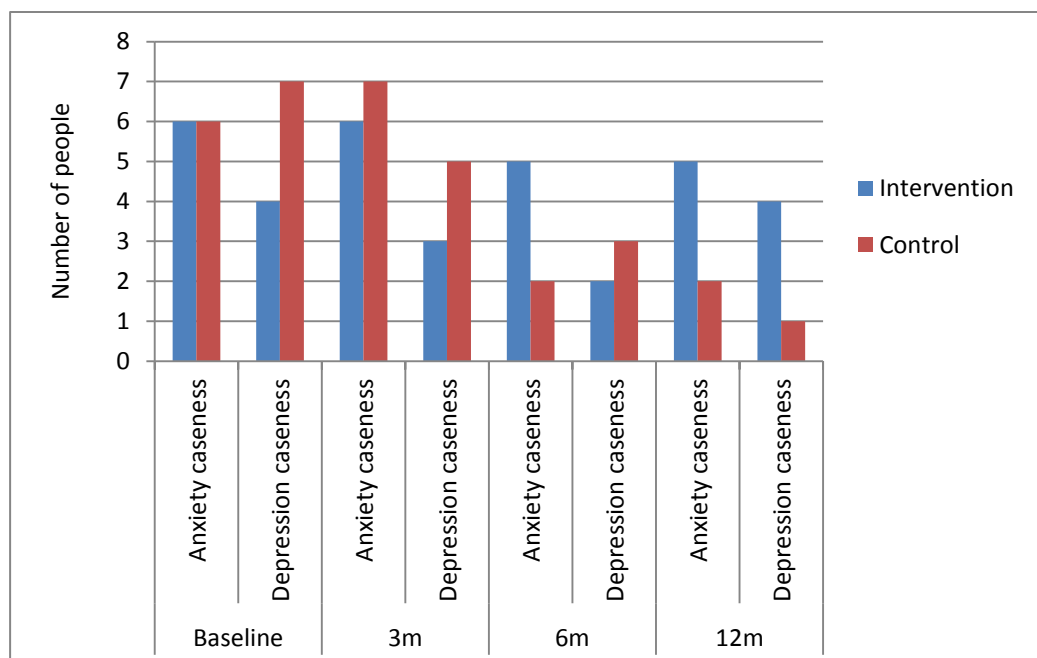
**Table 26. HADS total depression scores**

<b>HADS Total Depression Scores</b>	<b>Intervention</b>	<b>Control</b>	<b>95% CI difference in median values between groups</b>
<b>Baseline</b>			
Number	23	23	
Median (SD)	5.00 (5.16)	5.00 (3.14)	-3.96, 3.96
Range	0-17	0-12	
IQR	2-11	2-6	
<b>3 months</b>			
Number	16	18	
Median (SD)	3.50 (3.36)	4.00 (5.18)	-4.71, 3.71
Range	0-12	0-16	
IQR	2-5.5	1-9	
<b>6 months</b>			
Number	19	17	
Median (SD)	2.00 (3.23)	5.00 (3.82)	-5.34, -0.66
Range	0-11	0-15	
IQR	1-6	3-5	
<b>12 months</b>			
Number	18	14	
Median (SD)	3.00 (3.19)	4.00 (3.48)	-4.18, 2.18
Range	0-9	0-13	
IQR	1-6	2-6	

### HADS – anxiety and depression caseness

Analysis appears to show higher levels of caseness (scores eight or above which indicate a possible clinical disorder, Zigmond & Snaith,1983) in the control group at baseline and at three month follow-up. This changed towards there being a higher incidence for both anxiety and depression in the intervention group at both six and 12 month follow-up (Figure 11).

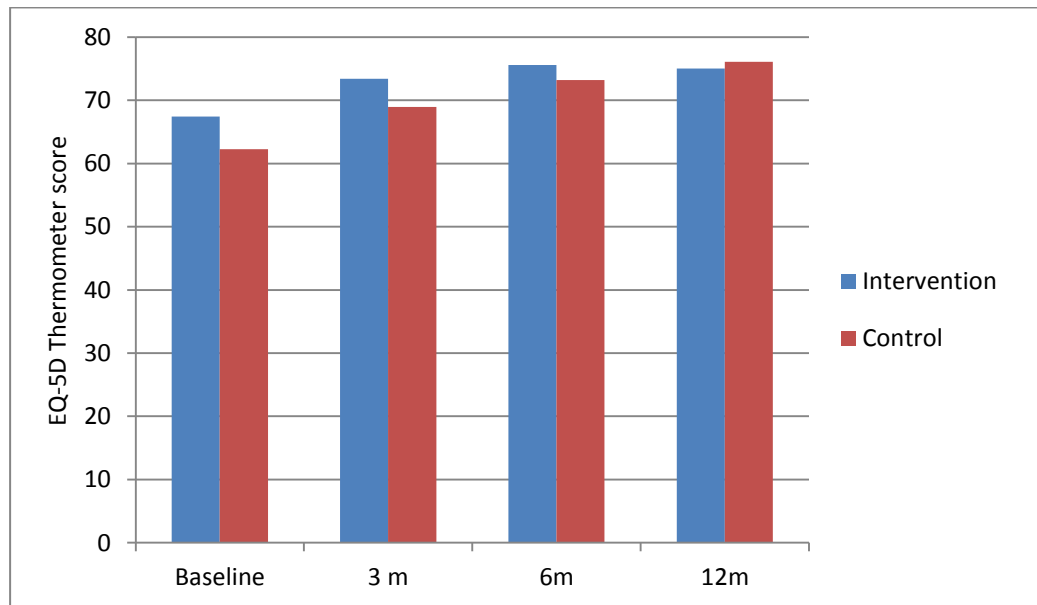
**Figure 11. HADS anxiety and depression caseness**



#### 4.5.10.2.2 EQ-5D

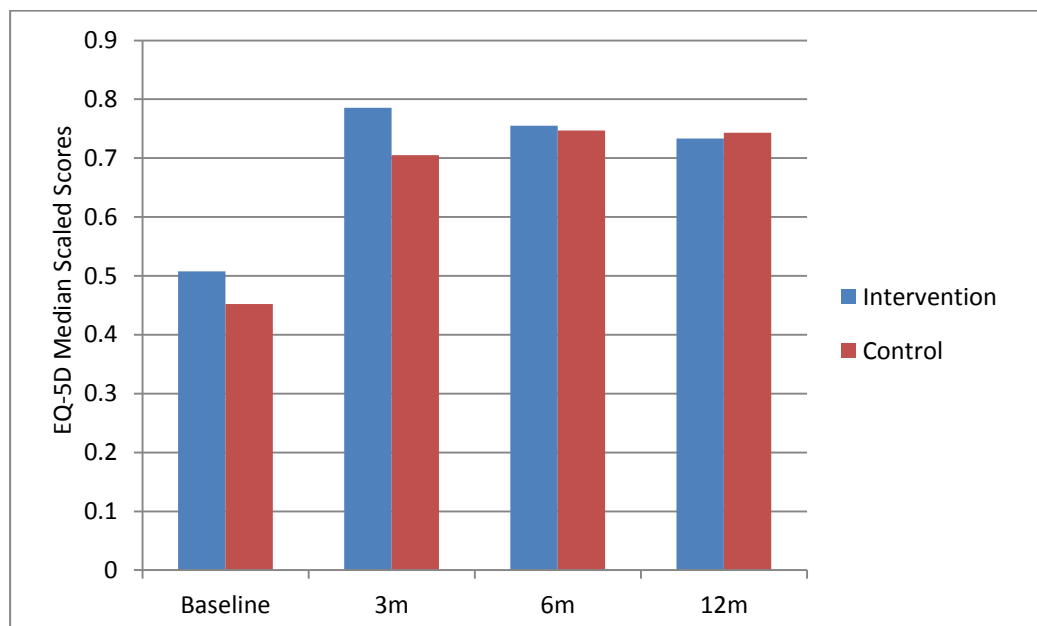
Overall participants rated themselves to be in fairly good health, using the EQ-5D thermometer (in both intervention and control groups, slightly higher in intervention group) even at baseline (Figure 12). This gradually increased as individuals recovered from the stroke over time. There were no floor or ceiling effects on thermometer scores.

**Figure 12. EQ-5D thermometer self-report measure of health status (median scores)**



The EQ-5D median scaled scores (Figure 13) plateaued after three months which suggests that most recovery occurred within the first three months in both the intervention and control groups. There were ceiling effects of over 15% on scaled scores at three, six and 12 months.

**Figure 13. EQ-5D median scaled scores**



#### 4.5.10.2.3 NEADL

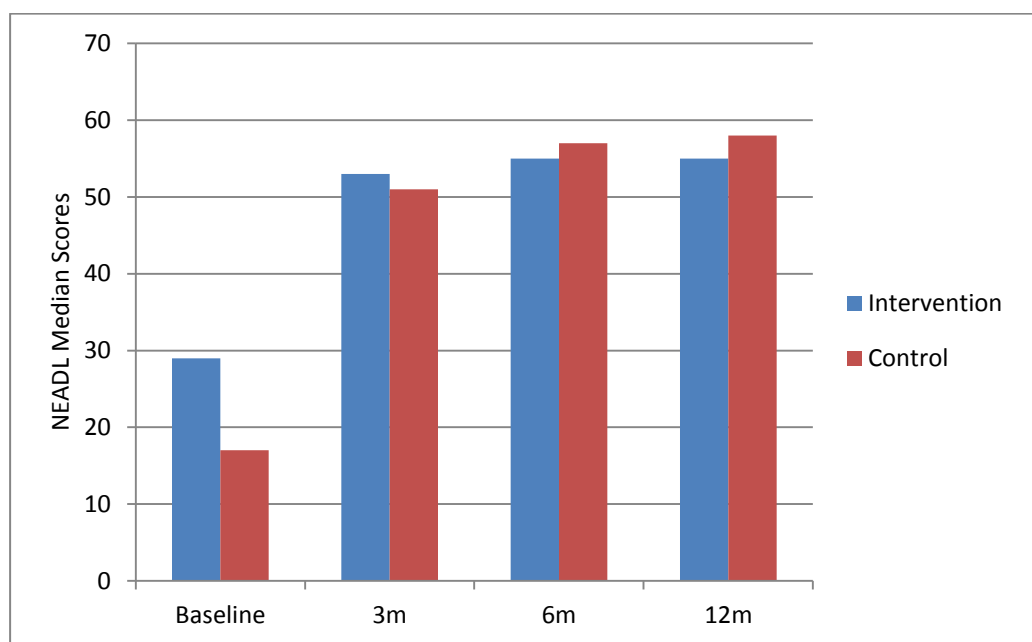
NEADL scores reported in Table 27 and Figure 14 demonstrate improvement of performance of instrumental activities of daily living after three months which then plateaued in both intervention and control groups. There were ceiling effects in over 15% of participants at 12 months.

**Table 27. NEADL scores**

<b>NEADL Scores</b>	<b>Intervention</b>	<b>Control</b>	<b>95% CI for differences in medians between groups</b>
<b>Baseline</b>			
Number	20*	22*	
Median	29	17	-10.72, 34.72
Range	4-63	4-59	
IQR	11-46	12-47	
<b>3 months</b>			
Number	16	17*	
Median	53.00	51.00	-18.63, 22.63
Range	7-66	5-61	
IQR	36-58	27-63	
<b>6 months</b>			
Number	18*	17	
Median	55.50	57.00	-15.10, 12.10
Range	12-66	17-66	
IQR	42-61	42-63	
<b>12 months</b>			
Number	18	14	
Median	55.00	58.50	-15.29, 8.29
Range	15-66	17-66	
IQR	44-60	45-63	

\*Missing data as NEADL not completed or not fully completed

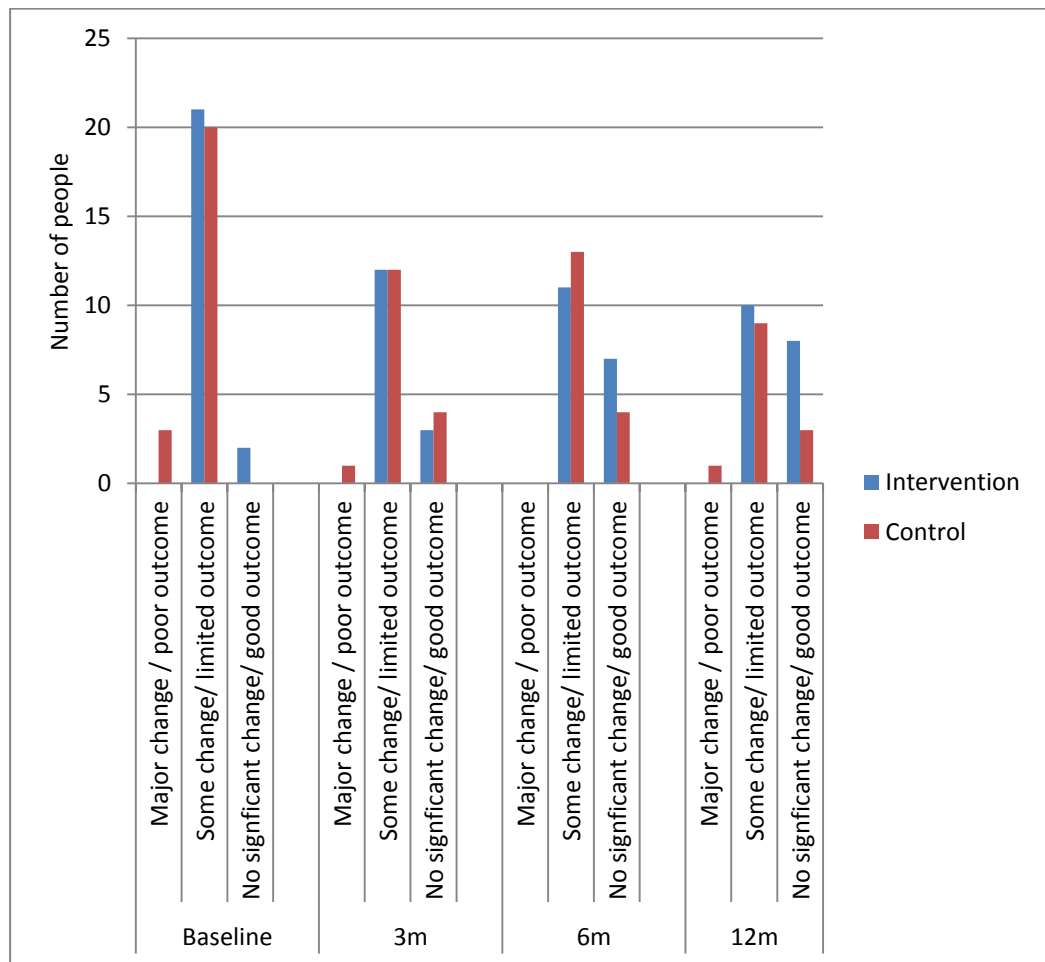
**Figure 14. NEADL median scores**



#### **4.5.10.2.4 SPRS**

The overall SPRS classification (Lammi et al., 2005) at baseline, three, six and 12 months are shown in Figure 15 and Table 28. Questions in this measure (Form A) ask about how much things have changed, in relation to participation, because of the stroke. The number of people in the intervention group who perceived there to be some change/ limited outcome decreased and the number who perceived no significant change/ good outcome increased over time but this pattern was not replicated in the control group. There were also no floor or ceiling effects using Form A at any time points.

**Figure 15. SPRS overall classification**



**Table 28. SPRS overall classification**

<b>SPRS Overall Classification</b>	<b>Intervention</b>	<b>Control</b>
<b>Baseline</b>		
Number	23	23
Major change	0	3
Some change	21	20
No significant change	2	0
<b>3 months</b>		
Number	15*	17*
Major change	0	1
Some change	12	12
No significant change	3	4
<b>6 months</b>		
Number	18*	17
Major change	0	0
Some change	11	13
No significant change	7	4
<b>12 months</b>		
Number	18	13*
Major change	0	1
Some change	10	9
No significant change	8	3

\*Missing data as SPRS not completed or not fully completed

#### **4.5.10.2.5 WPAI**

WPAI scores, reported in Table 29 demonstrate that overall work impairment percentages decrease dramatically after three months and people in the intervention group are less impaired at work than those in the control group at six and 12 month follow-up points. There were floor and ceiling effects of over 15% for overall work impairment scores at all time points except for no floor effects at baseline.

**Table 29. WPAI scores - overall work impairment percentage**

<b>WPAI Overall Work Impairment Percentage Scores</b>	<b>Intervention</b>	<b>Control</b>	<b>95% CI for difference in median between groups</b>
<b>Baseline</b>			
Number	20*	21*	
Mean	99.37	93.41	
Median	100	100	0, 0
Range	90-100	90-100	
IQR	100-100	100-100	
<b>3 months</b>			
Number	16	8*	
Mean	46.52	44.47	
Median	30.00	55.90	-58.72, 55.90
Range	0-100	0-100	
IQR	10-50	0-96.46	
<b>6 months</b>			
Number	14	19	
Mean	47.32	62.52	
Median	56.36	100	-117.46, 30.18
Range	0-100	0-100	
IQR	0-100	0-100	
<b>12 months</b>			
Number	1	14	
Mean	8	40.00	
Median	33.33	0	-70.79, 70.79
Range	0	0-100	
IQR	0-100	0-100	

\*Missing data as WPAI not completed or not fully completed

#### **4.5.10.2.6 WLQ**

A scaled score was calculated for each subscale of the WLQ. An index score was then calculated based on the weighted sum of the scaled scores of the four subtests. This was then used to create a productivity loss percentage by using the exponential function of the negative index score and this is subtracted by one and multiplied by 100 to create a percentage loss of health-related productivity (Table 30 and Figure 16). Percentage productivity loss in the control group was higher than in the



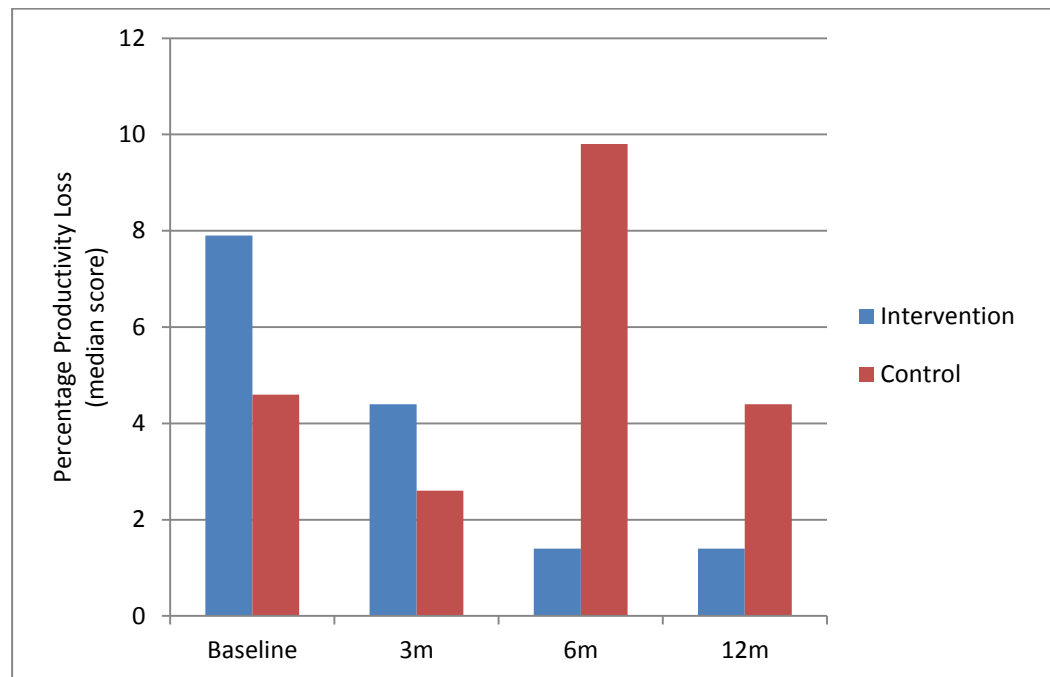
intervention group at six and 12 months. This is notably so at six months where the confidence interval does not include a zero indicating a likely effect. There were no floor or ceiling effects of greater than 15% in productivity loss scores except for a floor effect at 12 months.

**Table 30. WLQ productivity loss percentage scores**

<b>WLQ Productivity Loss Percentage Scores</b>	<b>Intervention</b>	<b>Control</b>	<b>95% CI for difference in median between groups</b>
<b>Baseline</b>			
Number	4*	2*	
Median	7.89	4.56	-12.43, 19.10
Range	1.68-15.06	0-9.12	
IQR	1.68-11.89	0-9.11	
<b>3 months</b>			
Number	7*	6*	-2.42, 6.92
Median	4.41	2.16	
Range	0-6.53	0-8.46	
IQR	0.27 – 5.61	0-3.91	
<b>6 months</b>			
Number	12*	13*	
Median	1.36	9.79	-13.74, - 3.12
Range	0-9.60	0-14.70	
IQR	0.71-2.46	1.75-12.95	
<b>12 months</b>			
Number	10*	6*	
Median	1.38	4.37	-10.22, 4.26
Range	0-10.01	0-14.62	
IQR	0.24-5.95	0-13.71	

\*Missing data as WLQ not completed or not fully completed

**Figure 16. WLQ percentage productivity loss (median scores)**

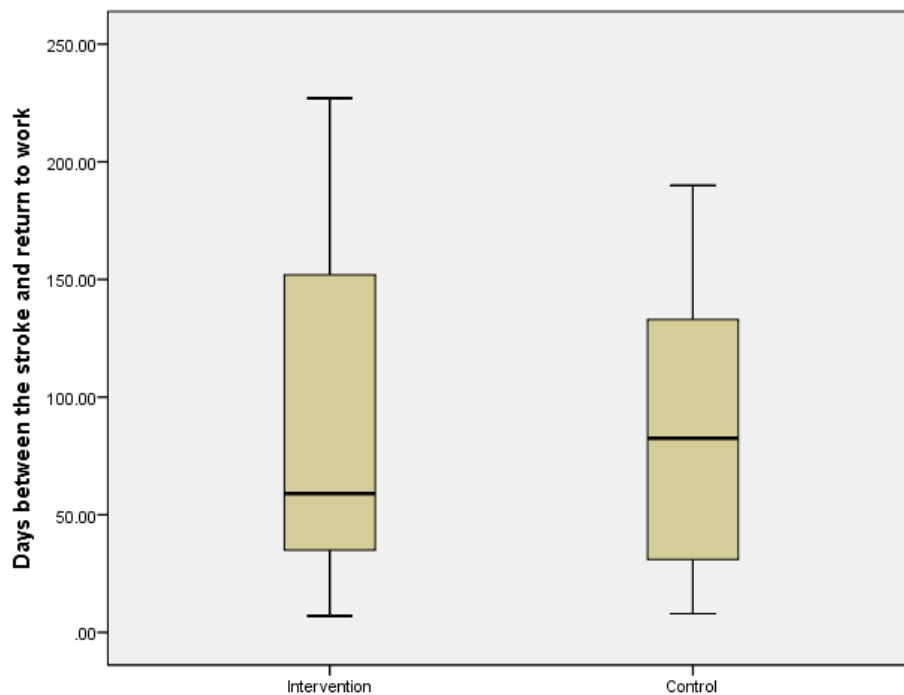


#### **4.5.10.3 Non-standardised question outcomes**

##### **4.5.10.3.1 Time taken to return to work**

The number of days between the date of stroke and the date of work return is displayed in Figure 17. This includes all participants who returned to work at some point throughout the trial (even if they did not maintain this work return) and those who had a recorded return to work date (either they reported their return to work date, or it was recorded by the research OT).

**Figure 17. Time taken to return to work (days)**



Fourteen participants in the intervention group reported a return to work date. An additional three dates were supplied by the research OT for participants in this group who were either lost to follow up or did not give a return date. One participant in the control group had a missing return to work date so this was estimated based using the first of the month of the recorded follow-up.

The time taken to return to work for the 17 participants in the intervention group was compared to 14 participants in the control group (Table 31). The mean time taken to return to work was longer in the intervention group.

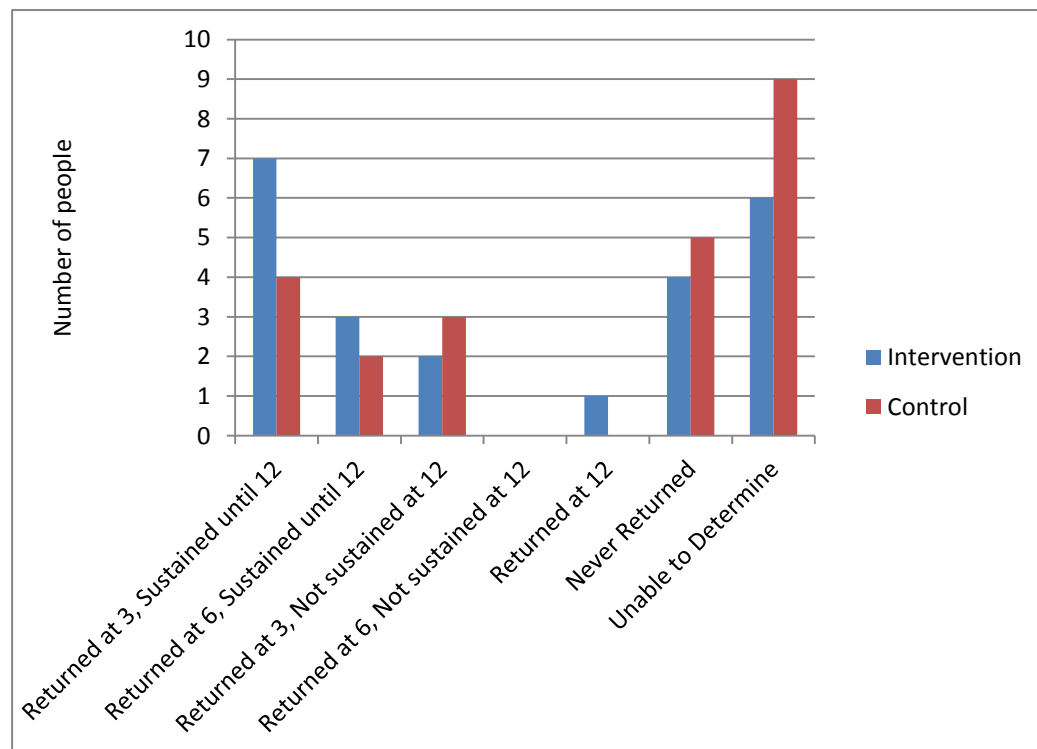
**Table 31. Time to return to work (days)**

Days to return to work	Number	Mean	Median	Range	SD
<b>Intervention group</b>	17	94.88	59.00	7 - 227	77.41
<b>Control group</b>	14	85.57	82.50	8 - 190	62.12

**4.5.10.3.2 Sustainability of Work Return**

The sustainability of work return has been examined using the added information obtained from the follow-up questionnaires and results are displayed in Figure 18. It suggests that the ability to sustain a return to work was greater in the intervention group.

**Figure 18. Sustainability of return to work**



Two participants in the intervention group reported being in work at three months but not in work at 12 months. One of these participants was in work at three months but was unable to continue her voluntary role due to fatigue and other issues relating to her stroke. The participant was of retirement age and already receiving a pension. The second participant who did not sustain their work return reported that he was planning to retire in the near future when he joined the project as he was past retirement age. He was self-employed and ran his own business. He reported being in work at three and six months, but had ceased running the business at the 12 month follow-up.

All three participants who were classed as 'returned at three, not sustained at 12' in the control group were in work at three and six months but reported this was no longer the case at 12 months. One participant reported he was unable to continue his work return due to physical demands of the job and found he was no longer able to cope with this. Another participant was required to take a leave of absence due to health issues unrelated to his stroke and was receiving medical treatment, but he hoped to return when he recovered. The third reported that they were not in work at 12 months, however no reasons were given.

One participant in the intervention group did not return until the 12 month follow-up, it is not known whether this person sustained work in the longer term.

#### **4.5.10.3.3 Feasibility of determining sustained return to work**

Due to loss to follow up, it was not possible to determine whether work return was sustained for six participants in the intervention group and nine participants in the control group. This was because 14 participants failed to return their 12 month follow up, thus it is not known if work return was sustained beyond the six month follow up point, or if those who had not returned by six months, achieved this by 12 months. Table 32 demonstrates the pattern of work status per participant throughout the trial.

**Table 32. Work status pattern per participant**

	3 months	6 months	12 months		3 months	6 months	12 months
Intervention Group				Control Group			
RTW01	1	1	1	RTW02	0	1	1
RTW03	1	1	1	RTW04	0	0	0
RTW05	0	0	0	RTW06			
RTW08	0	1	1	RTW07	0	0	0
RTW09	1	1	0	RTW10	0		
RTW12	0	0	0	RTW11	1	1	1
RTW14	1	1	1	RTW13	0	0	0
RTW18	1	1	1	RTW15	0	1	1
RTW19	1	1	1	RTW16	1	1	
RTW20	1	1	1	RTW17		1	
RTW22	1	1	1	RTW21	1	1	1
RTW23	1	0	0	RTW24	1	1	
RTW25	0	1	1	RTW28	1	1	1
RTW26	0	0	1	RTW29	1		
RTW27	0	0	0	RTW30	0		
RTW32	0	1	1	RTW31	1	1	0
RTW35				RTW33	1	1	1
RTW36	1	1		RTW34	0	0	0
RTW38	0	0		RTW37			
RTW40	0	0	0	RTW39	1	1	0
RTW42	0	1	1	RTW41	1	1	0
RTW43	1	1	1	RTW44	0	0	0
RTW46	1	1	1	RTW45	0	1	

Key:

1 = the participant is in work

0 = participant not in work



loss to follow up



participants lost to follow up but vocational status determined using return to work dates



information that has been recovered from the research OT

#### **4.6.8.3.4 Hours of work returned to post-stroke**

Working hours were assessed in a variety of ways. Participants stated their exact weekly working hours, although this was an item on the questionnaire which was poorly completed. Participants also reported whether they were working the 'same' hours as prior to their stroke, if not, they had the option to tick that they were working 'less' or 'more' hours now. Due to poor completion of questions on exact weekly working hours it was deemed more meaningful to look at whether they were working the same/ more or fewer hours at the three time points.

##### *Baseline*

Prior to their stroke, participants in the intervention group were working an average of 32.2 hours per week (range 3-55, SD 15.80) whereas participants in the control group were working an average of 35.98 hours per week (range 7.5-55, SD 13.25).

##### *Three months*

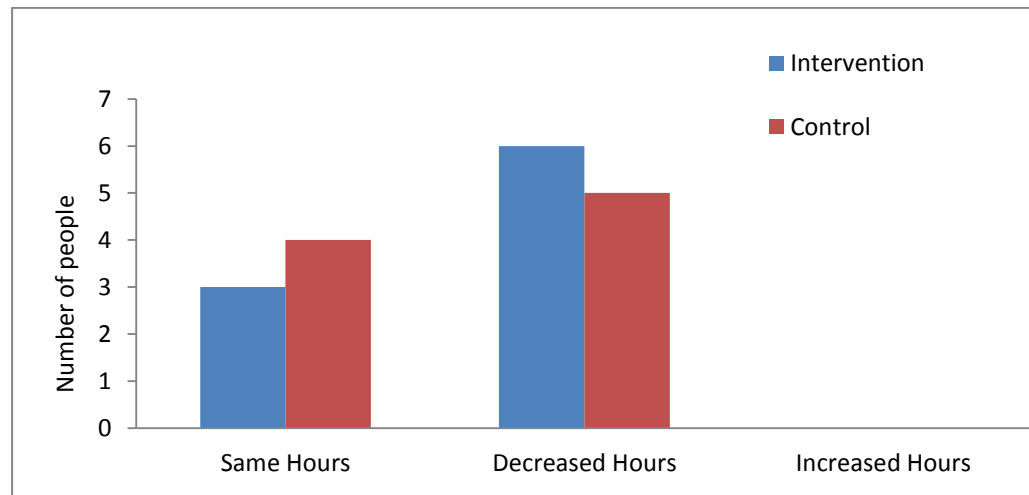
Of the participants who had returned their questionnaires, nine participants in each group had returned to work at three months. Three participants in the intervention group and four participants in the control group were working the same hours as they had prior to their stroke (Figure 19).

Of the remaining six participants in the intervention group, all six described themselves as working fewer hours than they had prior to their stroke. Of the five remaining participants in the control group, all



five were working fewer hours than they had prior to their stroke. No participants reported an increase in their working hours.

**Figure 19. Hours worked 3 months post-baseline**

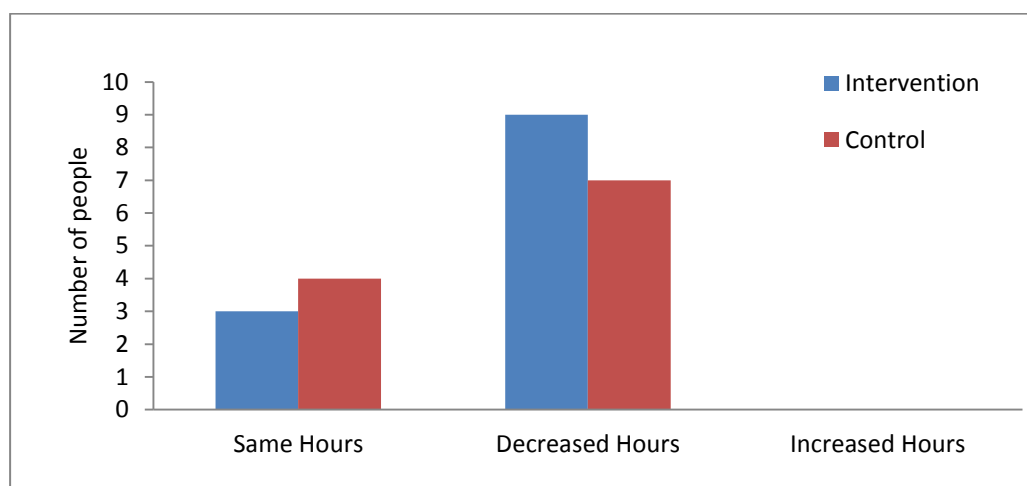


### *Six months*

At the six month follow up period, 12 participants in the intervention group had returned to work and 13 participants in the control group had returned to work.

Nine participants in the control group were working fewer hours than they were prior to their stroke, whereas seven participants in the control group were working fewer hours than they were prior to their stroke. No participants in either group reported working more hours than prior to their stroke (Figure 20).

**Figure 20. Hours worked 6 months post-baseline**

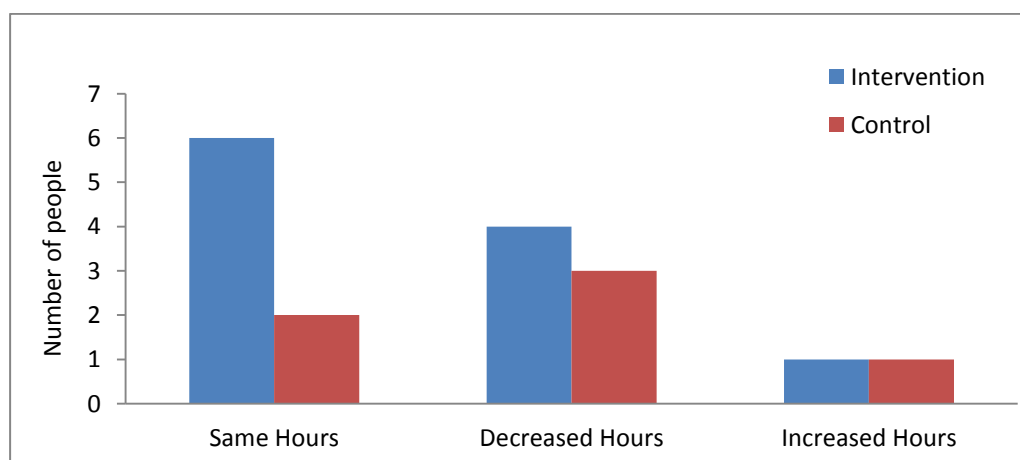


*Twelve months*

At the 12 month follow up period, 11 participants in the intervention group and six participants in the control group were in work.

Four participants in the intervention group and three participants in the control group were working fewer hours than they were prior to their stroke. One participant in each group reported working more hours than prior to their stroke (Figure 21).

**Figure 21. Hours worked 12 months post-baseline**



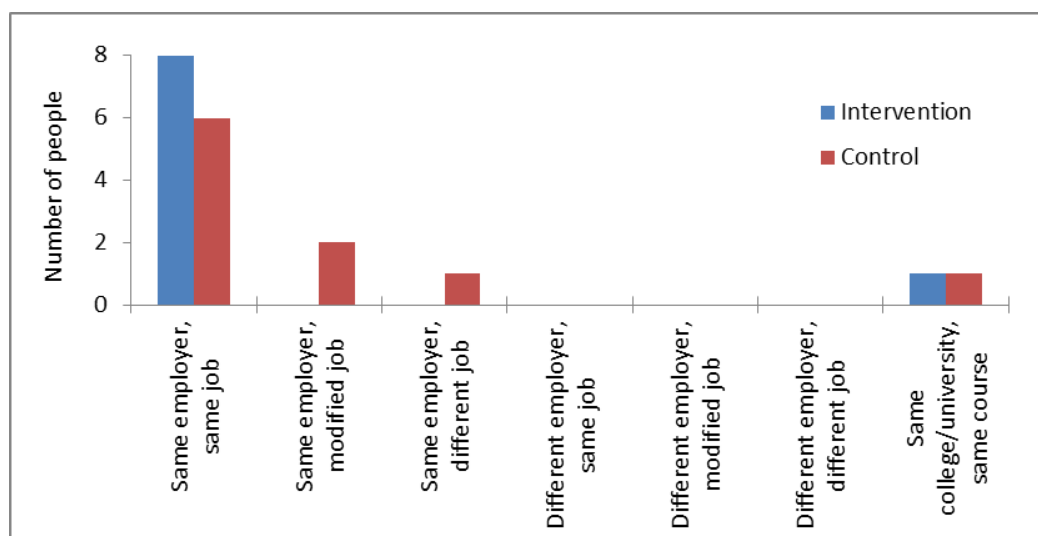
There were difficulties in assessing working hours using the terms 'full time' and 'part time'. There was some variation between participants in self-reported 'full' and 'part time' work. For example, some people who classified themselves as working full time were working hours ranging from 37-100. Similarly, people working part time ranged from 3.5 to 36 hours per week. Also, for voluntary workers the term 'part time' seemed insufficient to explain their patterns of working which could vary considerably week to week and sometimes were fewer than two hours per week.

#### **4.5.10.3.5 Roles and Responsibilities**

##### *Three months*

Of those who had returned to work at three months, 17/18 returned to work with the same employer. Eight participants in the intervention group and six in the control group resumed work with the same employer doing the same job (and one participant from each group returned to the same educational course). Two participants in the control group were with the same employer, but doing a modified job, and the last returnee in the control group was with the same employer but doing a different job (Figure 22).

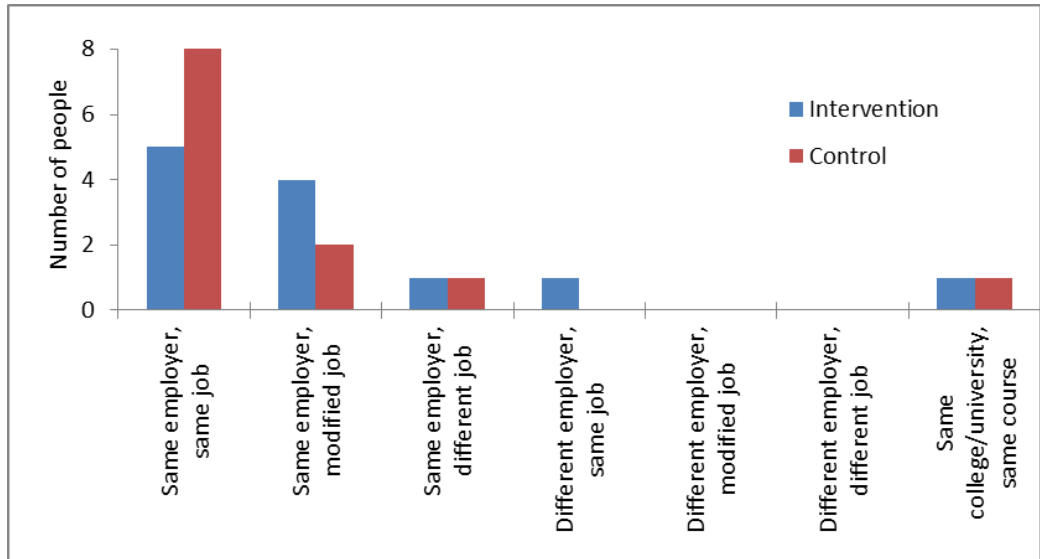
**Figure 22. Roles and responsibilities at 3 months post-baseline**



*Six months*

At six months post stroke, 12 participants in the intervention group had returned to work and seven had not returned (four cases missing), in comparison in the control group 13 had returned whereas four participants had not returned (six cases missing). Of those who had returned, five participants in the intervention group were with the same employer doing the same job (one answer was left blank). Four participants were with the same employer but doing a modified job, one participant was with the same employer but doing a different job and one was with a different employer doing the same job. In comparison, in the control group, eight participants were with the same employer doing the same job and one participant was at the same college doing the same course), two were with the same employer but doing a modified job, one was with the same employer doing a different job and data was missing in one case (Figure 23).

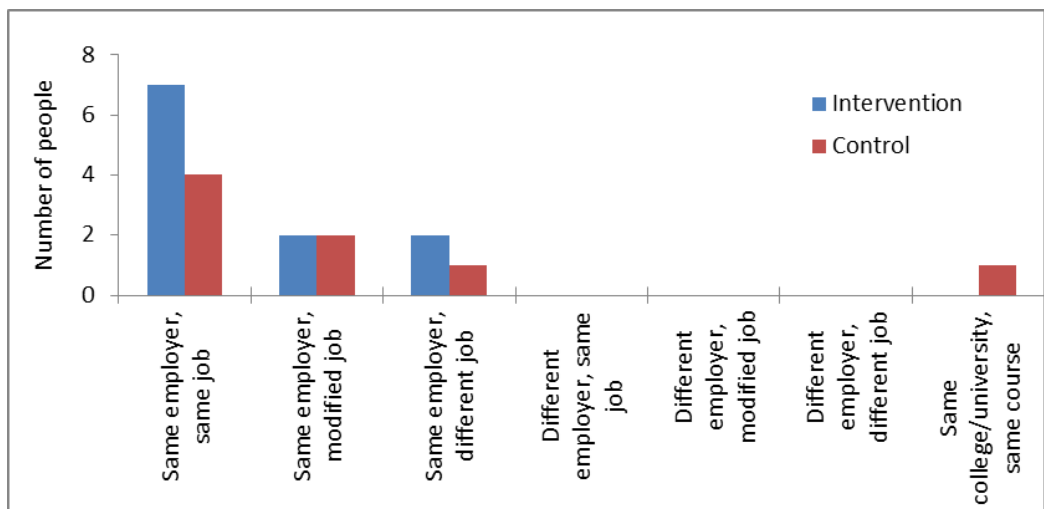
**Figure 23. Roles and responsibilities 6 months post-baseline**



*Twelve months*

At twelve months post-baseline, 11 participants in the intervention group were in work (six were not, six were lost to follow up) and six participants in the control group were in work (eight were not, and nine were lost to follow up) (Figure 24).

**Figure 24. Roles and responsibilities at 12 months post-baseline**



#### **4.5.10.3.6 Workplace accommodations made by employer**

The frequency of workplace accommodations made by the employer (for example, reduced responsibilities and workload, more breaks and supervision) is shown in Figure 25. This indicates that more people reported that accommodations were made in the intervention group and these were still in place at 12 months.

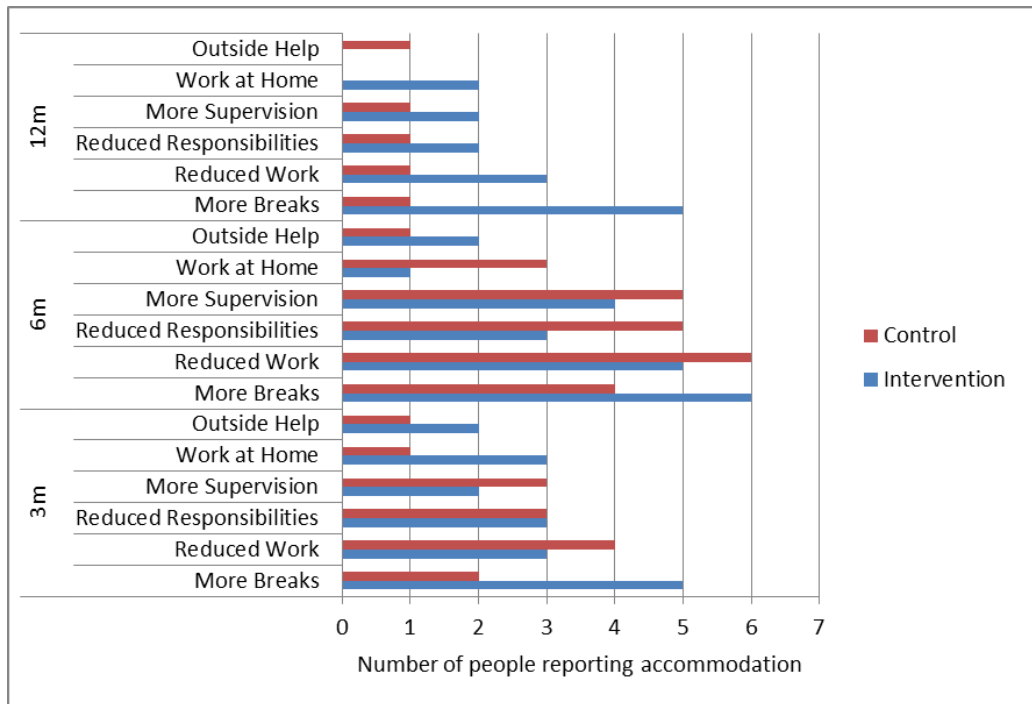
**Figure 25. Frequency of accommodations made by employer**



#### **4.5.10.3.7 Type of Work place accommodations made by employer**

The types of accommodations made by employers are shown in Figure 26. Outside help, when specified, usually referred to use of occupational health services.

**Figure 26. Type of accommodations made by employer**



**4.5.10.3.8 Receipt of benefits post-stroke**

The proportion of people claiming benefits at some point during the trial for both groups is shown in Figure 27. This indicates that more people in the control group were on benefits.

**Figure 27. Proportion of people claiming benefits at some point during trial (%)**

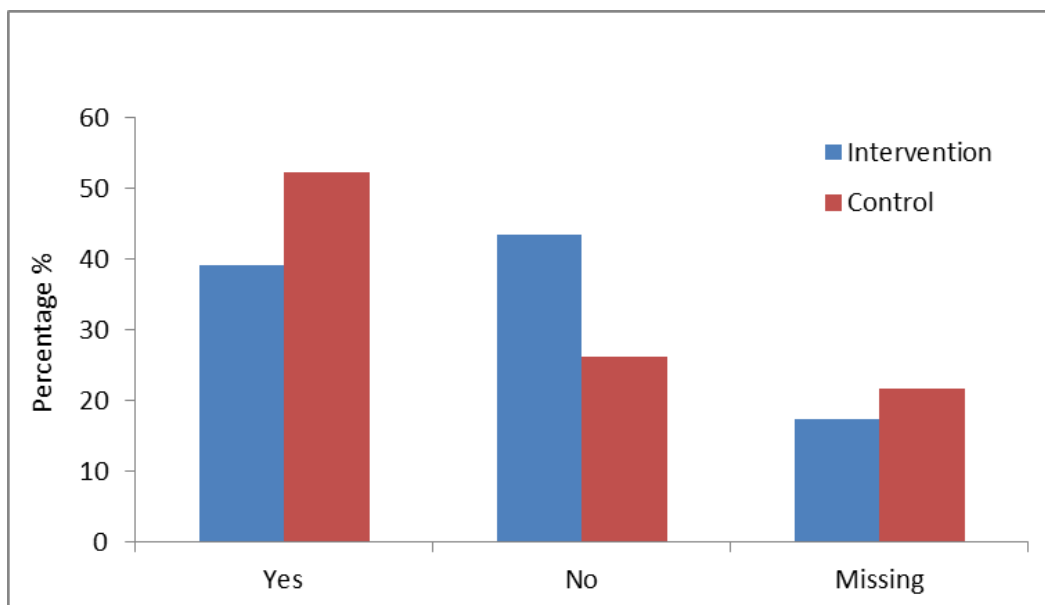
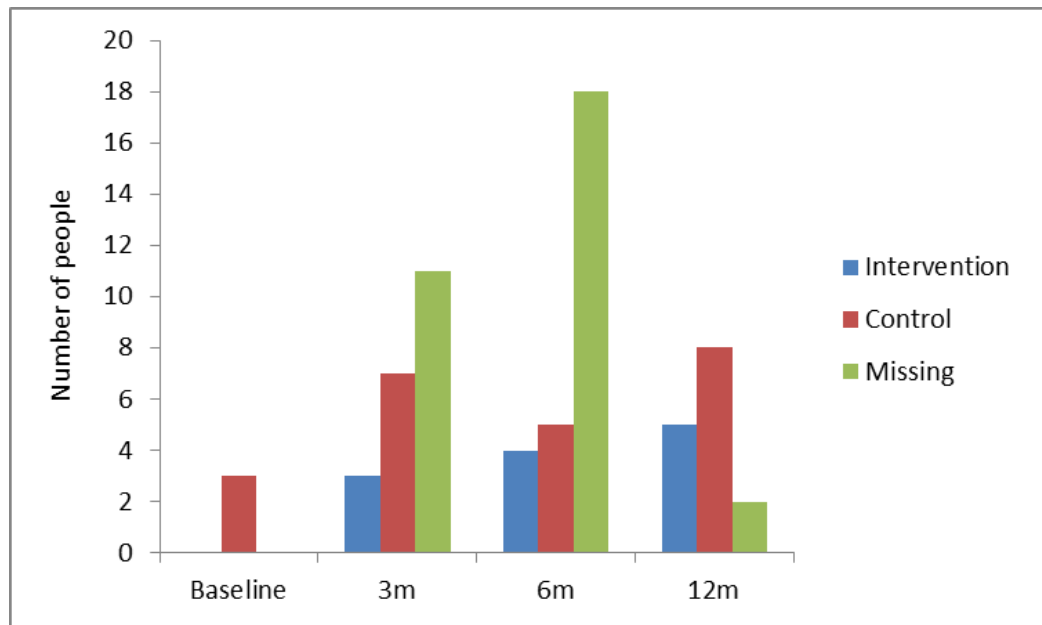


Figure 28 illustrates the number of people claiming benefits at all the time points and number where this data was missing from questionnaires returned. It indicates that more people were claiming benefits, at all time points, in the control group than the intervention group. It is difficult to interpret findings on specific benefits claimed due to large amount of missing data and uncertainty around the accuracy of the response due to a change in named benefits during the course of the study. Therefore, these results are not reported.

**Figure 28. Frequency of participants claiming at benefits**



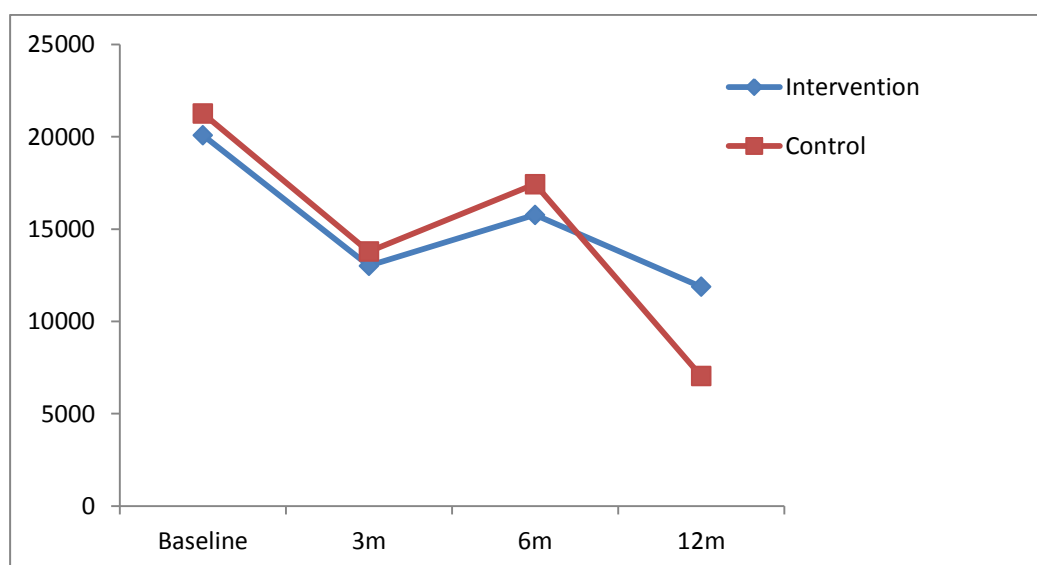
The data indicates that four people in control group and three in the intervention group appear to be living solely on benefits at 12 months. This was evident from the type of benefits they were claiming (e.g. Employment and Support Allowance and Disability Living Allowance) and their work status (i.e. not working and not receiving an income).



#### 4.5.10.3.9 Income before and after stroke

Average annual income for both groups at all the time points is shown in Table 33 and Figure 29. This indicates that impact on income was more detrimental in the control group but there was a downward trend in both groups over time.

**Figure 29. Average annual income (£)**



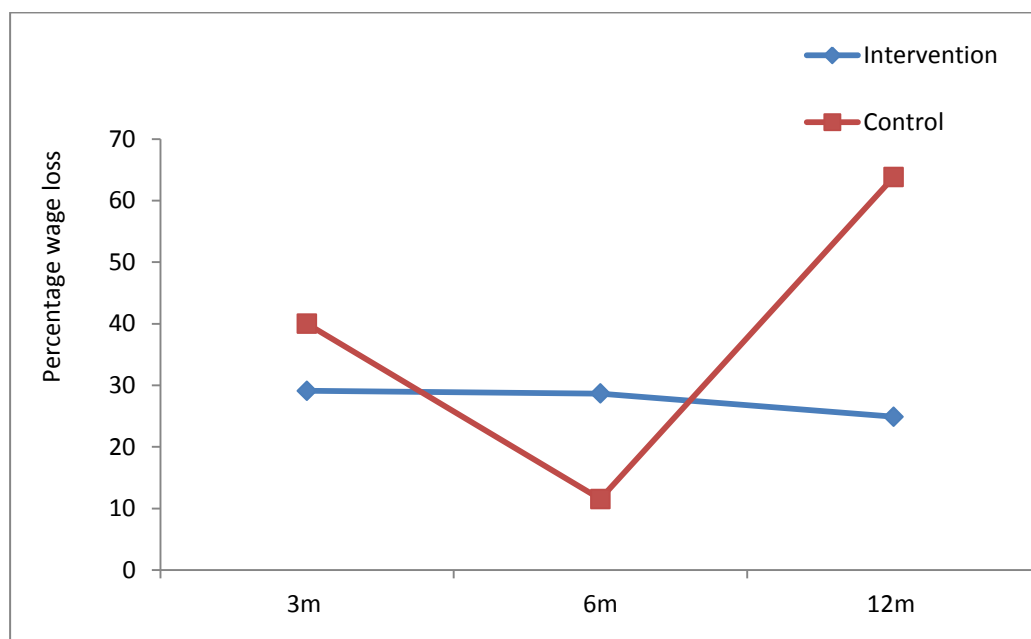
**Table 33. Average Annual Income (£)**

<b>Average annual income</b>	<b>Intervention</b>	<b>Control</b>
<b>Baseline</b>		
Number	17*	18*
Mean (SD)	20080.94 (12983.14)	21261.78 (12434.51)
<b>3 months</b>		
Number	13*	15*
Mean (SD)	13014.08 (15744.12)	13778.53 (16311.16)
<b>6 months</b>		
Number	7*	12*
Mean (SD)	15766.86 (16334.99)	17433.25 (13573.97)
<b>12 months</b>		
Number	14*	9*
Mean (SD)	11873.6 (14858.91)	7044.44 (12207.28)

\*Missing data

The percentage wage loss post stroke at all the time points is shown in Figure 30. It shows substantial wage loss at 12 months in the control group.

**Figure 30. Percentage wage loss post-stroke between intervention and control groups at all time points**



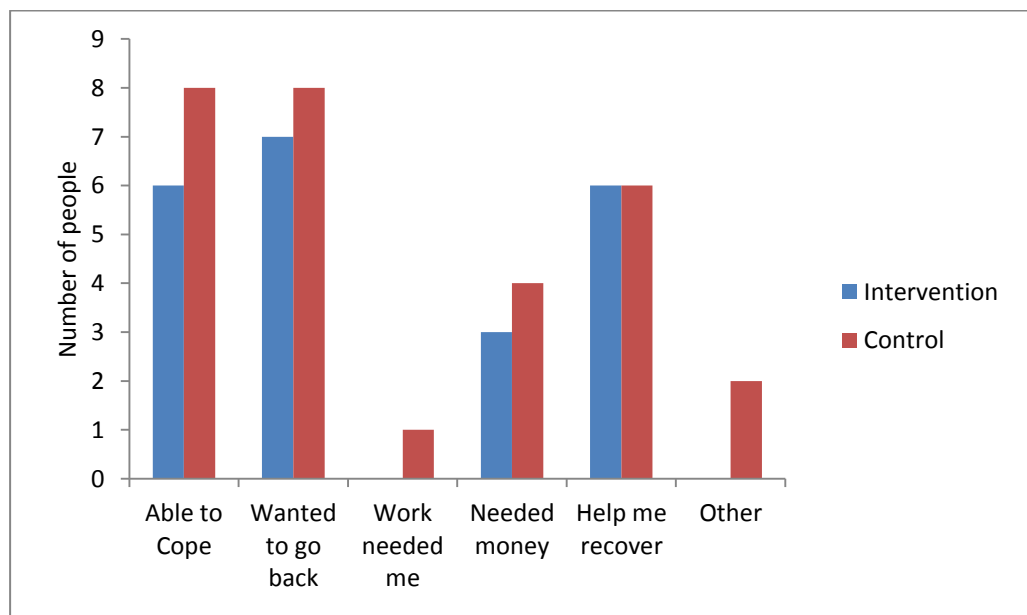
**Table 34. Percentage wage loss post-stroke between intervention and control groups at all time points**

Percentage Wage Loss	Intervention	Control
<b>3 months</b>		
Number	9	12
Mean (SD)	29.09 (42.32)	39.99 (50.37)
<b>6 months</b>		
Number	7	10
Mean (SD)	28.65 (49.33)	11.53 (29.03)
<b>12 months</b>		
Number	12	6
Mean (SD)	24.89 (65.09)	63.82 (50.24)

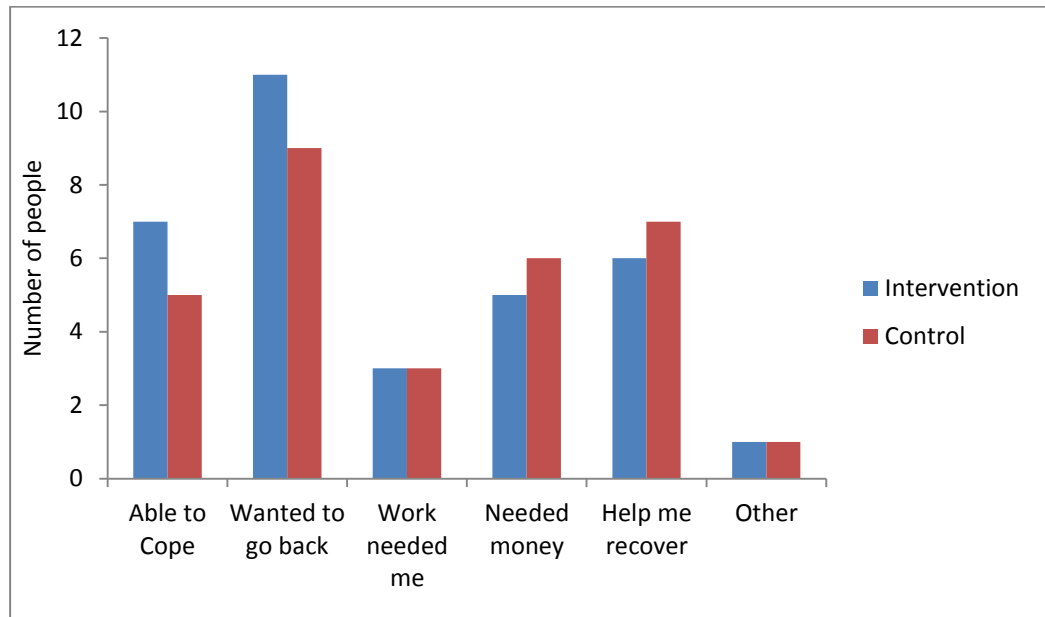
#### 4.5.10.3.10 Reasons for returning to work

Participants answered a question looking at reasons why they had returned to work. The options consisted of the following: felt able to cope, wanted to go back, felt work needed them, needed the money, thought work would help them recover, and 'other' where the participant had the option to add any other reasons. The two other reasons specified were benefits being stopped and needing to work to keep mind active. The frequencies of participants who ticked each option are displayed in the Figures 31, 32 and 33 below. The most frequent reasons for returning, in both groups, were that participants felt able to cope and wanted to go back followed by thinking returning would help them recover. The proportions reporting that they felt able to cope or wanted to return were greater in the control group at three months but the patterns reversed over time.

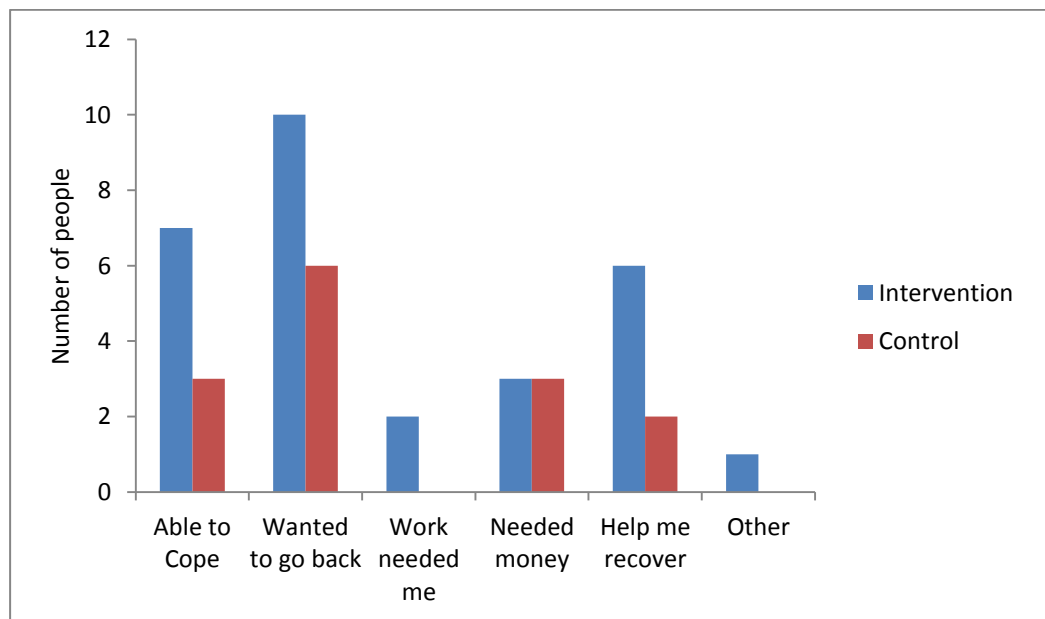
**Figure 31. Reasons for returning to work at 3 months**



**Figure 32. Reasons why people returned to work at 6 months**



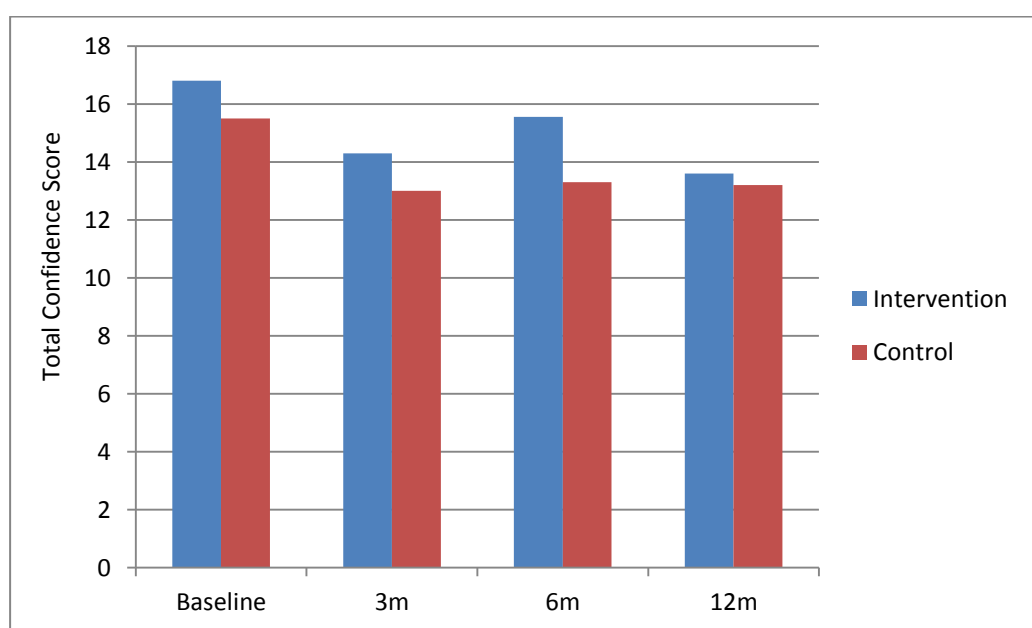
**Figure 33. Reasons why people returned to work at 12 months**



#### 4.5.10.3.11 Measuring confidence about work return

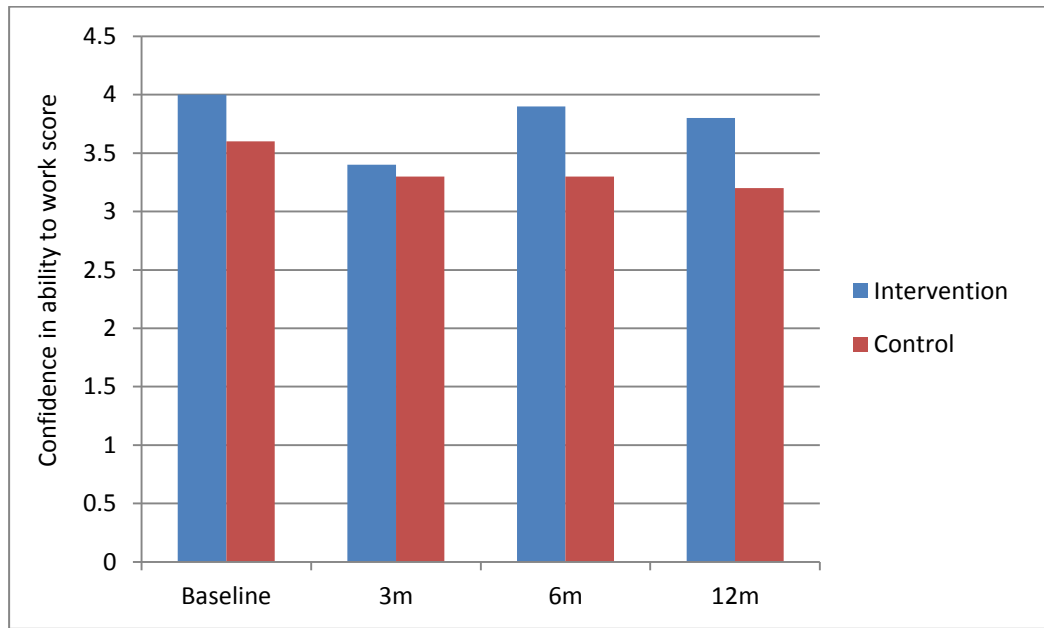
Total scores for confidence in ones' ability to return to work and find work were calculated and median scores at all time points for both groups are shown in Figure 34. Overall confidence about work return was quite high (maximum score possible is 20) although it does appear to decrease slightly over time.

**Figure 34. Confidence measure – overall total (median scores)**

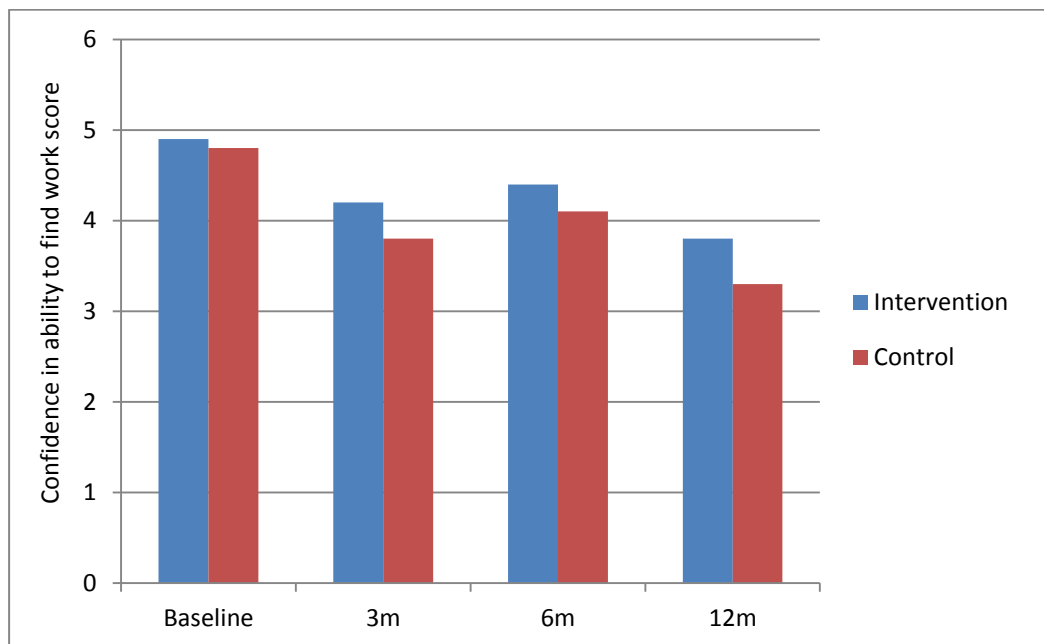


Each confidence question was analysed independently by calculating median scores at each time point. Results are shown in Figures 35-38. Those in the intervention group demonstrate the same or higher levels of confidence than those in the control group in response to these questions.

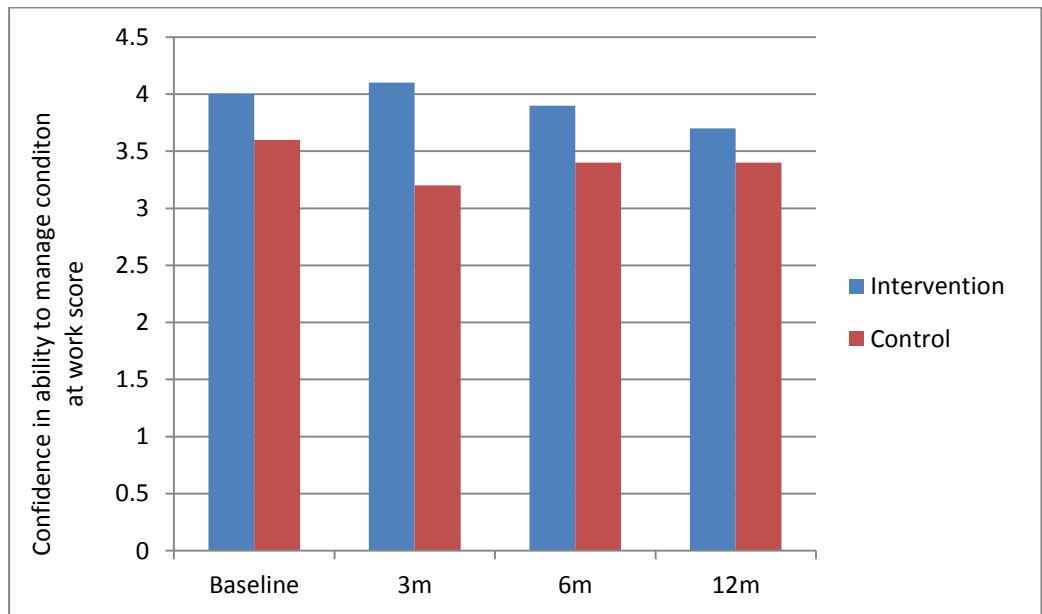
**Figure 35. Confidence in ability to work (median scores)**



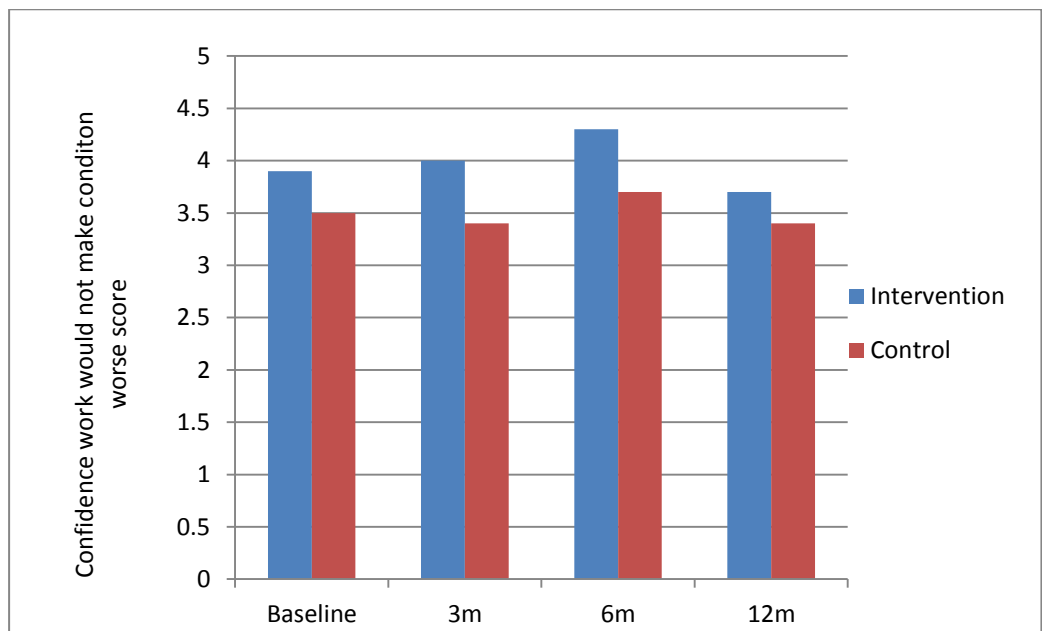
**Figure 36. Confidence in ability to find work (median scores)**



**Figure 37. Confidence in ability to manage condition (stroke) in a work environment**



**Figure 38. Confidence that working would not make condition (stroke) worse**





#### **4.6 Feasibility of estimating effect size in order to power a definitive trial**

The size of the sample needed in a definitive trial can be calculated using data from the feasibility trial. It is vital to ensure the trial is designed so that it has a good chance of detecting significant differences if they exist. The statistical method for determining the sample size is called a power calculation. Statistical power is the measure of how likely the study is to provide a statistically significant result for the difference between groups of a given magnitude. The probability that a test will produce a significant difference at a given level of significance (usually 0.05) is the power of the test which should be greater than 0.8 (Bowling, 1997).

Information about the likely difference between groups can be taken from the feasibility study and a decision made about the smallest observed difference between groups which would be of interest. The size of the minimum difference to be detected, the significance level and the power can be entered into a computer package with a statistical formula for calculating sample size based on the power (Bowling, 1997). In this study it was decided that the effect size from the feasibility trial would be used in preference to an estimated minimal clinically important difference because the latter is often arbitrary and not evidence based. Instead it depends on the potentially diverse opinions of clinicians and researchers according to their individual experience (van Walraven et al., 1999). Also Feeley et al. (2009) state that it is a very useful option when there is an absence of literature on which to

base effect size estimates and the design and outcome measures are going to be similar in the full scale trial.

A power calculation has been performed using G\*Power software (Faul et al., 2009). In this feasibility study, 48% of the intervention group and 26% of the control group returned to work and remained there at 12 months. The difference between these two figures (the effect size) was used in the power calculation. With an assumed power of 80% and a significance level of 0.05, 150 participants would be needed (75 in each arm) at 12 months to demonstrate this effect size. However, as there was a dropout rate of 26% in the feasibility trial, the number needed would be 202. The calculation for this is  $150/0.74$  which inflates the sample size in the light of the anticipated drop out. It could be argued that the effect size in the feasibility study was magnified due to being a one centre study with a considerable amount of time invested in recruitment and chasing follow-up postal questionnaires. If the feasibility study had been conducted in more than one centre it would have been possible to multiply the figure of 202 by the intra-class correlation coefficient to estimate the numbers needed in a multicentre study. It is likely this would increase the number of participants needed.

## **4.7 Discussion**

The purpose of this feasibility study was to estimate important parameters that are needed to design the main study (Arain et al., 2010). These include feasibility of recruitment, randomisation, delivery of intervention, usual care as control, blinding, primary outcomes,

characteristics of proposed secondary standardised outcome measures, non-standardised questions, dealing with missing data, overall response and follow-up rates of questionnaires which will now be discussed in this order.

#### **4.7.1 Feasibility of recruitment**

This study has demonstrated that recruitment was feasible. 46 people were recruited over a 16 month period which was five short of the target recruitment figure of 51. However, it appears that this target may have been conservative in light of the actual numbers of people admitted to hospital with a suspected stroke during the recruitment period. Possible reasons for this will now be discussed.

Recruitment took place on the acute stroke ward and the stroke rehabilitation ward of Royal Derby Hospital. The aim was to recruit people in the very early stages following stroke. One of the reasons for this was evidence from a cohort study by Vestling et al. (2003) which showed that 21.6% of people in the cohort had tried to return to work but not succeeded, 64% of whom had impaired cognitive ability. This may have been because they were 'walking and talking' following their stroke and therefore discharged without rehabilitation. It is possible that subtle cognitive difficulties only became apparent at the time when they returned to work. Other qualitative and survey studies also indicated unmet need with respect to return to work support (Lock et al., 2005; Stroke Association & Different Strokes 2006; Medin et al., 2006; McKeivitt et al., 2011).

There were challenges in recruiting in the acute phase following stroke and in trying to ensure that people were not missed. People can be discharged within 24 hours of admission to the acute stroke unit and study staff only visited the wards three times a week (Monday, Wednesday and Friday) thereby missing recruitment opportunities. The research OT and research associate were reliant on ward staff (nursing, rehabilitation and research) identifying patients who met the study criteria. A prospective cohort study of depressive symptoms after stroke by Hill et al. (2009) highlighted difficulties of recruiting soon after acute stroke. They attributed this to 30% mortality and about half of the patients who survived being significantly disabled and therefore not suitable for a return to work study. They recruited 592 out of 6000 stroke or query stroke admissions screened for eligibility (just under 10%). Also Pickering et al. (2010), who examined recruitment in three observational follow-up studies of stroke patients focusing on reasons for non-participation, stated that between 10-50% of those screened were recruited during hospital admission for stroke. They explored the potential factors influencing recruitment rates and concluded that recruitment was particularly difficult when it was being carried out at the same time as discharge from hospital. They also said it was limited by the inability to get informed consent particularly amongst those with severe strokes. This was evident in this feasibility study where most of the participants recruited had minor or moderate strokes. One of the reasons patients declined to participate was being unable to consider work return in the acute phase due to the severity of their stroke. Often

this was due to severe speech and language difficulties, cognitive impairment and/ or low mood. Family members and ward staff had an understandable tendency to be protective towards these patients therefore not actively promoting the issue of work return. This contributed to a potential recruitment bias towards those with mild to moderate stroke and those with less severe communication or cognitive difficulties. However, as this was a study about early intervention to support people back into work, it may be that those with severe strokes need help with this at a later stage in the stroke pathway when they have recovered sufficiently to be able to focus on work return.

Another reason why people declined to participate was that they did not feel they needed assistance with return to work and this was in relation to having had a mild stroke. There is a risk that the full impact of the stroke would not be realised until after discharge home and return to work had been attempted. Potential recruits were always advised that if they changed their minds during the six month recruitment window they could contact the research team and join the study at a later date but this never happened.

Another potential source of recruitment bias was the occupational skill level. A greater proportion of those recruited were in professional and managerial jobs identified using SOC codes (Office of National Statistics, 2010) and had attended further or higher education. There is evidence to suggest that people with higher socioeconomic status are more likely to participate in research studies (Galea & Tracy, 2007).

Also with respect to recruitment, the sample was almost exclusively white British with only one person from an ethnic minority taking part. This did not reflect the demographic of Derbyshire where in 2006 the Black and Ethnic Minority population was recorded at 4.6%. This group includes non-British white races as well as those from Asian and African-Caribbean descent. One possible reason is that unemployment levels are 30% higher in the latter group in Derbyshire (Derbyshire County Council, 2009). However, the incidence of stroke in the black population was shown to be higher in a prospective study using a South London Stroke Register (Stewart et al., 1999). The proportion of people of Asian and African-Caribbean descent is different to that in Derbyshire with the latter having a higher proportion of Asians (Census Report, 2011). The other factor is that ethnic minority groups are under-represented in clinical trials (Hussain-Gambles et al., 2004). This UK narrative review of mainly US literature found that people who participate in trials are predominantly white, educated men from middle class backgrounds. One of the potential reasons for low recruitment of people from ethnic minority groups cited in the review is fear and mistrust of the medical profession. Strategies proposed to overcome this issue include education and training of healthcare professionals and the use of advocacy or community link workers who can help provide a bridge to the building of trust.

One of the challenges of recruitment on the acute stroke ward was that not all those admitted with clinical diagnosis of stroke were confirmed as strokes following medical tests and scans. Some people were

subsequently diagnosed with a transient ischaemic attack, migraine or other conditions. A study by Harbison et al., (2003) examined the diagnostic accuracy of stroke referrals from primary care, emergency room physicians and ambulance staff using the Face Arm Speech Test and found that 13% were later confirmed as transient ischaemic attacks and 27% had non-stroke diagnoses including seizures, infections, tumours and migraines. Overall, approximately 40% of people admitted with suspected stroke did not have this diagnosis confirmed. This needs to be taken into account when screening for potential recruits in future studies.

It is not known, what proportion of working age people admitted with a stroke to the Royal Derby Hospital, were actually employed. A bulletin produced by Derbyshire County Council (2014) shows that unemployment in Derbyshire stood at 2.9% in December 2012.

However, the figures for Derby city and Southern Derbyshire District (areas covered by recruitment in feasibility study) were 4.8% and 2.1% respectively. Also people recruited in this study were aged 16 and above and included those in paid employment, students and volunteers (who were retired) so it would be difficult to estimate what proportion of the local population this included. Decisions would need to be made in a future definitive trial as to whether it would be more appropriate to only recruit those in paid employment or education and exclude those in voluntary work. From an economic perspective this may be preferable.

The number of people admitted to the Royal Derby Hospital during the recruitment period indicates that not all potentially eligible participants were identified by ward staff and stroke research network (SRN) nurses. This impacted negatively on the study recruitment rate. The reasons for this could be that due to the busy acute ward environment, some potential recruits were missed. During the lifetime of the study, there were a number of staff changes both in the research team (three research associates) and at the hospital (two research nurses). This left gaps between when a member of staff left and new staff were recruited and able to commence work. During this time the research OT continued to recruit and her working hours were increased but she was also delivering intervention to those already recruited so capacity was significantly reduced. This study was also not adopted by the SRN and therefore any assistance offered by the research nurses working for this network was a gesture of good will as the NHS Trust was not receiving any financial payment for recruitment as they would in SRN adopted trials. However, this may have impacted on the rigour of the screening process and ability to identify all those who were eligible.

This feasibility trial has provided an opportunity to learn lessons about recruitment that could be utilised in the recruitment strategy for a future definitive multi-centre trial. Time needs to be built in for research study staff to go to research sites regularly and to build relationships with staff on site to maximise recruitment. Future studies must be adopted with full Clinical Research Network (CRN) recruitment staff involvement working to a clear and tight protocol. This need to build a research



community was recommended by Newington and Metcalfe (2014a) following their thematic meta-synthesis of 18 papers examining the views of researchers and clinicians in 10 clinical specialities. It was also one of the findings in a report on recruitment issues in the MAESTRO (mirror therapy) trial (Tyson, 2012) which recommended regular and structured liaison with the whole stroke multidisciplinary team when recruiting to rehabilitation trials. When educating staff about the eligibility criteria, the importance of language being used also needs to be stressed. This was highlighted in a study of recruitment issues in RCTs by Paramasivan et al. (2011) and training sessions were recommended. In a future definitive trial it would be important to explain to potential recruits that they only have to be 'considering' going back to work and not to have definitely decided to return in order not to exclude people who are unsure whether it will be possible. Data from this study also indicate that people will also be considering early retirement due to their age and their stroke but there may be a period of time where they are uncertain about whether this is the best course of action is for them. Donovan et al. (2014) interviewed 72 people including 32 doctors, 40 nurses and other health professionals involved in recruiting people to six RCTs and found that nurses were anxious about approaching participants and experienced a conflict between the research and their clinical responsibilities and said the latter took precedence. This is why CRN adoption is critical. There is evidence of this in the current stroke study where clinicians advised against approaching a small number of potential participants due to the severity of their stroke and low mood.

Newington and Metcalfe (2014b), in another interview study with 11 individuals from clinical research teams, concluded that new and diverse strategies were needed to ensure that all eligible patients are invited to participate including establishing integrated academic and clinical teams.

To increase the participation rate of those with communication difficulties, the help of a speech and language therapist was requested during the recruitment process. Additional time and support from research staff was also needed when completing baseline and follow-up questionnaires. This resource issue has to be taken into consideration when planning a larger definitive trial.

#### **4.7.2 Randomisation**

It was feasible to randomise participants. Only one person declined to participate because they wanted to be guaranteed intervention. Ward staff did not appear to have any difficulties with the knowledge people would be randomised to the intervention although some needed to be reminded that intervention was not guaranteed so that they would continue to refer patients as usual to out-patient rehabilitation services. Feeley et al. (2009) differentiate between feasibility and acceptability and explain that the former relates to ease or convenience of execution of the study intervention, design and procedures whereas the latter refers to suitability or favourability of the reception by the clinical population of interest, intervention providers or health professionals who care for the population of interest. It appears randomisation was both feasible and acceptable in this study. However it should be noted that

there was a higher rate of loss to follow-up at the six and 12 month time points in the control group so there was an effect of being randomised to this group

Randomisation led to an intervention group and a control group whose characteristics were well balanced despite the small numbers. The only two variables which were different were the job type and highest educational level achieved. More people in the intervention group had skilled, professional and managerial jobs and had attended higher education. These factors have been found to influence outcomes in previous return to work studies. Being in a managerial job, working as a gardener, being self-employed and a university education were all shown to increase the probability of returning to work in a national survey in Sweden (Lindstrom et al., 2009). The SOC codes used in the current study to calculate the skill level, classifies jobs such as an electric meter fitter and a gardener as skilled jobs (Level 3) (Office for National Statistics, 2010) and it may be considered a crude measure of socioeconomic status. Another Swedish cohort study (Trygged et al., 2011) found that a university education was a significant independent predictor of return to work following stroke. In a definitive trial, if there was an imbalance in characteristics of the intervention and control groups then this would need to be adjusted for during data analysis or alternatively stratification on job type and education could be used at randomisation stage.

### **4.7.3 Delivery of intervention**

Feeley et al., (2009) stated that it is important to assess the feasibility and acceptability of the intervention. It was feasible to deliver the intervention in the trial as only one participant, allocated to the intervention arm, withdrew from intervention during the study. The reason for this is not known as the OT was unable to contact the participant after disengagement from intervention took place. The intensity and duration of the intervention was highly variable as it was designed to be individualised and tailored to the needs of each participant. However, it would be important in a definitive trial to provide training to the therapists delivering the intervention at different sites to ensure a consistent approach and the fidelity of the intervention. Further description and analysis of intervention delivery is included in Chapter 4. Perceived acceptability and usefulness of the intervention from the perspective of trial participants and employers who received it is described in Chapter 6 in a qualitative post-trial interview study.

### **4.7.4 Usual care as a control**

There were challenges inherent in using usual care as a control and the specific nature of intervention being delivered in this feasibility trial. Due to the stakeholder interview study (Chapter 2), the research OT, who conducted most of the interviews, became aware of services available in the city and county to support people back into work following a stroke. As the intervention was delivered alongside usual care, it was inevitable that liaison took place between the research OT and other professionals and services that were involved (a model illustrating this

is included in Chapter 3). It was also possible for the research OT to refer to some of these services (e.g. clinical neuropsychology) and to enable participants to access additional support from the third sector. This may be seen as a contamination risk. In a multi-centre trial, there may be considerable variability in services available and how aware the research OTs are of these services and other potential resources. Therefore, what constitutes usual care may be highly variable across centres in a definitive multi-centre trial. It will be important to record services being received by participants during the definitive trial and to clearly differentiate between trial intervention and usual care especially in relation to OT.

#### **4.7.5 Feasibility of blinding**

It was feasible to blind a research associate to intervention allocation and this would be an important feature of a definitive trial. Future considerations to secure blinding include a note in bold capital letters on the follow-up questionnaire telling the participant to only include services other than the research OT. At the beginning of telephone calls when chasing follow-up questionnaires, the research associate could explain to the participant that they are not to know whether the person is receiving the intervention or not. Also therapist providing intervention in the trial needs to coach patients not to divulge this information at follow-up.

#### **4.7.6 Primary Outcome**

##### **4.7.6.1 Occupational Status**

The key finding was that twice as many participants returned to work in the intervention group as in the control group. As this was a feasibility trial with a small sample in a single centre there may be many reasons for these results. More people with skilled, managerial and professional jobs were recruited into the trial and despite randomisation, more of this group were randomised to the intervention arm. However, income at baseline was comparable in the two groups. In a very large nationwide prospective cohort study in Denmark on gainful occupation after stroke Hannerz et al. (2011) found the odds of returning to work were higher in those with skilled, technical or professional jobs. They related this to the educational requirements of the job. In relation to socioeconomic factors, another Swedish study using data from a national in-patient care register, demonstrated that education and income were independent predictors of returning to work after stroke (Trygged et al., 2011). They showed that individuals with a university education were 13 percent more likely to return to work than those who had only completed compulsory education and those in the highest income quartile were about twice as likely to return as those in the lowest. When moving to a definitive trial it is hoped that randomisation will lead to a balanced sample in terms of occupational status. However, it may be advisable to stratify according to job type and education level to ensure this balance occurs across groups. It may also be advantageous to explore some of these contextual social and employment factors

further in a qualitative study to find out what aspects of job type influence work return and how these can be taken into consideration when delivering vocational rehabilitation. For example, whether people in higher level positions are provided with greater flexibility and more accommodations when they return to work and how this might be negotiated for those in less autonomous work roles.

The results of the feasibility trial, in relation to primary outcome, have been used to do a sample size calculation. This has enabled estimation of the numbers needed in a larger scale definitive trial and planning for screening and recruitment.

#### **4.7.6.2 Income status**

Average annual income was affected in a more detrimental way in the control group than the intervention group but it decreased over time in both groups. However, percentage wage loss was substantially higher in the control group at 12 months which must be linked with occupational status. In a three year prospective cohort study of 414 younger stroke survivors in Australia (the POISE study), Essue et al., (2012) found that higher pre-stroke income did not buffer against financial hardship after stroke. Very few previous studies on returning to work after a stroke have collected data on income but it is important to do so in a definitive trial so that economic analysis can be performed and cost effectiveness of VR intervention can be calculated (Treger et al., 2007; Radford & Walker 2008; Baldwin & Brusco, 2011).

#### **4.7.6.3 Benefits status**

A higher proportion of the control group were claiming benefits at all time points during the trial however there was an issue with missing data on benefits being claimed. The data indicates that four people in control group and three in the intervention group appeared to be living solely off benefits at 12 months. Due to the small numbers involved, it is difficult to interpret these results. The POISE study in Australia found two thirds of the cohort reported economic hardship at 12 months after stroke despite government social security systems being in place (Essue et al., 2012).

#### **4.7.6.4 Characteristics and suitability of standardised secondary outcome measures used**

The characteristics of the standardised measures used will now be examined in relation to feasibility and acceptability of use in this study.

##### **4.7.6.4.1 Stroke Impact Scale**

This measure was only used at baseline and was useful in assessing stroke severity when NIHSS scores were missing. However, there was overlap between this and other measures on domains such as cognition (MS Cognitive Screen), mood (HADS), activities of daily living (NEADL), work and leisure (WLQ, WPAI and SPRS) and therefore to shorten the questionnaire in future this measure could be omitted.

##### **4.7.6.4.2 Cognitive screening**

The MS cognitive screening tool has the potential to identify pre-stroke cognitive difficulties and those caused by the stroke as question asks about difficulties in previous three months. It is a measure designed for



those with multiple sclerosis and it has not been tested or previously used on a stroke population. However, it was useful in calculating the proportion of the population that are cognitively impaired at baseline and whether there were any differences between the intervention and control group. This would be important in a definitive trial as cognitive impairment is a factor which can influence return to work probability. Vestling et al. (2003) found that those with preserved cognitive ability are 2.64 times more likely to return to work after a stroke although the paper does not specify how this was measured. It is possible that participants may be unaware of cognitive difficulties at baseline and only develop insight at a later date when returning to work and faced with more complex tasks. However, this could be measured in a work scale such as the Work Limitations Questionnaire which includes questions on concentration and ability to think clearly at work. The Montreal Cognitive Assessment (MoCA) has recently been shown to be more sensitive than the Mini-mental State Examination following acute stroke (MMSE) (Dong et al., 2010) but it is still a global screening tool for cognitive decline and not a stroke specific measure.

#### **4.7.6.4.3 Euro Qol: EQ-5D**

This measure was useful in determining health-related quality of life which is an important outcome in a return to work study. Completion rates were high in this measure which make it a feasible outcome measure. The results show that participants generally viewed themselves in fairly good health in both the intervention and control groups, slightly more so in the intervention group. The scores on the

thermometer gradually increased over time whereas the scaled scores appeared to plateau from three months onwards which could be due to the ceiling effects of over 15% on scaled scores at three, six and 12 months and no ceiling or floor effects in the scores on the thermometer. It also suggests most recovery took place in the first three months which is consistent with the NEADL scores.

For the above reasons and to be a valuable part of the economic analysis performed in a definitive trial as recommended by NICE (Wailoo et al., 2010) this measure should be retained.

#### **4.7.6.4.4 Hospital Anxiety and Depression Scale (HADS)**

Completion rates for the HADS were high demonstrating feasibility. Study results appear to show that scores which may indicate clinical levels of anxiety were more prevalent in the control group in at baseline and at three month follow-up and higher in the intervention group in the six and 12 month follow-ups. This could be explained in part by a greater loss to follow-up in the control group. It may also indicate a greater degree of insight into the long term impact of the stroke and resulting impairment in those in the intervention group or it may be that returning to work can generally increases anxiety levels.

#### **4.7.6.4.5 Nottingham Extended Activities of Daily Living Scale (NEADL)**

Completion rates were high for this measure demonstrating feasibility however there were ceiling effects of over 15% at 12 months. Study results show minimal differences in function between the intervention and control groups and a plateauing effect after 3 months.

When completing the NEADL at baseline many participants were still in hospital which meant that the ability to do many of the activities in the scale was restricted. It is important for researchers to be consistent when completing this and only record activities actually done in previous week and not what they could hypothetically do if not in hospital. This should be part of training needed to ensure consistent completion this standardised measure. It is a useful measure of functional ability following stroke and should be included in a definitive trial.

#### **4.7.6.4.6 Sydney Psychosocial Reintegration Scale – 2 (SPRS-2)**

Completion rates for this measure were between 63% and 67%. There were also no floor or ceiling effects at any time points for this measure. However, there is some overlap in domains with other measures, for example, community travel in the NEADL and communication in the WLQ. However, when measuring changes to relationships (with partner, family, friends and colleagues) the SPRS joins the latter two groups together when in a return to work study it may be helpful for them to be measured separately. The WLQ only covers workplace relationships. Participation in leisure is not covered in other measures in this study but this is not a key outcome for this study and so the measure could be omitted in a future trial.

#### **4.7.6.4.7 Work Limitations Questionnaire (WLQ)**

Completion rates for the WLQ were low, especially at three and 12 months. This is because it was only possible for this questionnaire to be completed if the respondent had returned to work for a minimum of the

previous two weeks as it is a measure of work productivity. Percentage productivity loss in the control group was much higher than the intervention group at six and 12 months and this difference was marked at 6 months. There were no floor or ceiling effects of greater than 15% in productivity loss scores except for a floor effect at 12 months. There were some difficulties with the questionnaire in that some questions concern the amount of time difficulty was experienced whereas others concern the amount of time the person was able to handle certain parts of their job without difficulty. This reversal could be confusing for the participant. However, it is an holistic measure of work productivity that takes account of physical health and emotional difficulties and the physical, cognitive and psychosocial demands of the job.

#### **4.7.6.4.8 *Work Productivity and Activity Impairment Instrument (WPAI)***

Completion rates for the WPAI were high at 6 months but were 58% and 51% at three and six months respectively. This was a simple and quick questionnaire to complete which looks at impairment of work productivity and activities other than work over previous seven days. The wording had to be changed to include 'while you were working (paid or voluntary)/ studying' to ensure that it wasn't limited to those in paid work. It is a fairly blunt instrument as it uses a ten point likert scale to measure how productivity at work has been affected. It's main weakness is the floor and ceiling effects which are evident at all time points except for no floor effects at baseline. However this was because people were either working or not.

#### **4.7.6.4.9 Comparison of work measures (WPAI and WLQ)**

If overall work impairment found in the WPAI is compared with the productivity loss measured by the WLQ, it can be seen there is a similar but not identical pattern over time. In a prospective study of productivity loss due to presenteeism among people with arthritis, Zhang et al. (2010) found that estimates of productivity loss varied widely according to the instruments chosen. The WPAI and WLQ were two of the measures compared and they found the calculation of hours lost due to presenteeism was potentially overestimated with respect to the WPAI as a result of using the ten point Likert Scale as the basis for this calculation. For the purposes of a definitive trial, the WPAI is a fairly blunt instrument whereas the WLQ provides more detail about productivity in relation to various aspects of a job and it is more sophisticated. However, the completion rates for the WLQ are lower than the WPAI. But this is almost certainly because participants can complete the WPAI even if they have not returned to work, whereas the WLQ can only be completed if someone is back at work. However if you are only interested in workplace productivity then the WLQ would be the tool of choice. There were floor and ceiling effects at all time points for the WPAI whereas only floor effects were present at 12 months for the WLQ. Based on the findings of this feasibility study, and if only one work measure was to be included in the definitive trial, the WLQ would be the best one to choose.

#### **4.7.6.5 Dealing with missing data**

Considerable time was spent chasing up missing data, especially NIHSS scores and Bamford classifications as this information was often missing from the medical notes. In a definitive trial, research staff should seek advice from medical staff while the participant is still on the ward. If the participant has been discharged from hospital at the time of recruitment this is more challenging but medical notes can be requested and advice sought from medical staff where possible. A recommendation for a future definitive trial would be to not rely on ward based data.

#### **4.7.6.6 Feasibility and acceptability of non-standardised questions**

##### ***4.7.6.6.1 Questions with poor completion rates***

A number of questions in the booklet had poor completion rates. Data on annual income was missing as some participants were not willing to disclose this information. There may have been an issue of mistrust in that participants were not sure how the information would be used. The same issue arose for questions about benefits. At the time of the study, welfare reforms were being implemented and the names of certain benefits were changed (i.e. Incapacity Benefit became Employment and Support Allowance). It is possible that participants were confused about names of benefits and also statutory sick pay was included in this section of the questionnaire and some people may not have been aware whether this was being claimed by their employer while they were off sick. For these reasons the data collected on types of benefits claimed was incomplete and unreliable in this study and improved ways

of collecting accurate data on benefits need to be devised. One possibility is to provide a more thorough explanation of why this data is collected and how it will be used and providing assurance regarding anonymity and confidentiality.

Another problem was the definition of full and part time work. There was variation in the number of hours this constituted for different individuals. Part time work for some participants was three hours a week and for others 30 hours, full time work could range from 36 hours to 80 hours a week. Also patterns of work varied as some worked intensively for short periods of time and others had more regular hours. The definition of full or part time work would need to be more clearly defined in a definitive trial.

Determining the exact hours participants were working at the follow-up points was also problematic. Poor completion of this question could be attributed, in part, to the layout of the questionnaire as it was not together with a question entitled 'Hours of work' but was part of a table where tick responses were required for the other questions. It may also have been difficult for some to specify weekly working hours due to changing patterns of work as discussed above. This kind of detail and a clear definition of what is meant by return to work is also missing from previous studies (Baldwin & Brusco, 2011). It appears that asking participants whether they are working the same or different hours since stroke and if different then asking them whether they are working more or fewer, appeared to be best way of evaluating this outcome in the

current study. However, a better way of obtaining accurate data about exact hours worked and the proportion of pre-working hours people return to would need to be devised in a definitive trial as a measure of return to work success.

#### **4.7.6.6.2 Sustaining work return**

The data on sustaining work return indicates that a number of people returned at three months but this was not sustained at six or 12 months. There were a number of reasons for this. They included fatigue, not being able to cope with physical demands of job, planned retirement and ill health (other than stroke).

Andersen et al. (2011) suggested that fatigue appears to be an independent determinant of not being able to resume paid work following stroke. This association was independent of physical disability or cognitive deficits which were controlled for in the multivariate analysis. Functional outcome was good but less than half of the 83 Danish patients studied were able to return to work after two years without continuous adjustments being made. Alaszewski et al. (2007), in their qualitative interview study of 43 stroke survivors found that 80% reported fatigue which impacted on their return to work. Fatigue was found to be a major source of frustration for people returning to work in a qualitative interview study of 12 people who had returned to work after a stroke which resulted in feelings of not being in control (Vestling et al., 2013). The role of fatigue in the inability to sustain return to work is not clear in existing literature. It is possible that the person who said they



could no longer cope with the physical demands of the job in this feasibility study may also have been experiencing fatigue.

Planned retirement is an issue related to the age of the participants. Hillman & Chapparo (2001) interviewed 13 retired men following stroke and found that some continued to actively engage in roles that were directly linked with their past worker role as they still wished to be productive as this was central to their self-identity. However, others felt they had earned the right not to work and chose to focus on leisure instead. It was evident that some trial participants decided to retire during the intervention and follow up periods. This may have been for a number of reasons including planned retirement. However, it could also have been because they did not realise the recovery they were hoping for and felt unable to return to work or sustain the work return.

Some participants may have chosen to discontinue working, irrespective of their age, as the stroke changed their perception of work and quality of life. This was evident in the study by Alaszewski et al. (2007) where interviewees explained that stroke had changed the meaning of work for them because they felt stress had been a contributory factor in their stroke. Another qualitative interview study (Rubenson et al., 2007) found that some participants really valued work and the social status and personal satisfaction it provided but others acknowledged the risks of going back too early for financial reasons.

With increasing age, it is also possible that other illnesses impact on the ability to work as it did for one participant who had a comorbid medical

condition. Due to changes in legislation it is now possible to work beyond 65 years and people were recruited to the feasibility trial who were working (paid or voluntary) with no age restrictions. However, this issue may need to be reconsidered in a definitive trial.

#### **4.7.6.6.3 Workplace accommodations**

The higher number of workplace accommodations made for participants in the intervention group persisted to the 12 month follow-up, which was also reported in a cohort comparison study of VR following traumatic brain injury (Radford et al., 2013b). There may be a number of reasons for this. It is possible that more adjustments were negotiated and a longer time frame allowed for adjustments when the OT was involved. This may have directly influenced the success, speed and sustainability of the work return as people in the intervention group took slightly longer to return but a higher proportion returned and this was sustained. It may also have been due to the higher number of people in professional and managerial jobs in the intervention group which could have provided more flexibility due to greater autonomy, the nature of their work and their higher status within the organisation. In contrast those in the control group may have had shorter phased returns which could have been restricted to the standard length recommended by company/ organisational policy rather than this being extended in the light of education from the therapist about stroke being more complex than other health conditions. A research report from the HSE (Thomson et al., 2003) cites six weeks as the typical period of time offered for a phased return after ill health from one city council but gives a case

example of how this could be extended to twelve weeks for people returning after absence due to work-related stress.

It is possible that self-employed people and those engaged in voluntary work made adjustments to their work but these were not recorded as the question about workplace accommodations asks about adjustments made by the employer. This wording would need to change in a definitive trial to capture this information.

The most common workplace accommodations were the provision of extra breaks, reduced responsibilities and workload and more supervision. Extra breaks was the adjustment most frequently still in place at 12 months. The impact of workplace adjustments on productivity, if long term or permanent, requires further investigation as it has economic consequences.

#### **4.7.6.6.4 Confidence about return to work**

Overall confidence about return to work appears to be quite high in the participants of this feasibility study although it does appear to decrease slightly over time. This may be due to those who have not returned to work feeling less confident over time and maybe gaining insight into the severity of their stroke and its impact on their ability to return to work.

Levels of confidence in ability to return to work would have been influenced by eligibility criteria as those joining the study were hoping to return to work and therefore higher confidence levels would be expected compared to those who declined or were lost to follow-up because they no longer felt they would be able to return to work.

When each confidence question was analysed independently those in the intervention group demonstrated the same or higher levels of confidence than the control group. This may be due to the education and information provided by the OT increasing their belief in their ability to return, manage their condition at work and confidence that work would not make their condition worse.

These confidence questions were used in the condition management evaluation (Ford & Plowright, 2009) to assess work readiness in the event that a return was not achieved and this was the only indicator of success in the evaluation. This makes the assumption that because you are confident that you are more likely to return to work at some point in the future. However, this will depend on many different factors including the level of insight into your condition (not always present with complex neurological conditions) and the job market where you live.

There were some difficulties with the confidence questions themselves, the first question asks about confidence in ability to work. This is a very general question which may or may not relate to the person's actual job. The second question about the ability to find work could be perceived as hypothetical and irrelevant if the participant has a job but is currently on sick leave. For those who have lost their jobs, confidence can relate to the local jobs market and the current economic climate as much as their own ability to find work. Confidence in the ability to manage their health condition at work may relate to flexibility of workplace/ employer

and accommodations made and likewise the confidence that in general working would not make the condition worse.

In this study, it was shown that it is feasible to measure effectiveness using the primary outcome of work status and other secondary outcome measures. However, participants' confidence in their ability to return to work could be critical to its success. Therefore it would be advisable to retain some measure of confidence in a larger study.

#### **4.7.6.6.5 *Reasons for returning to work***

The most frequent reasons for going back to work, in both the intervention and control groups were that participants felt able to cope and wanted to go back, followed by thinking that returning would help them recover. More people in the control group felt able to cope and wanted to go back at three months whereas at six and 12 months this pattern was reversed. It is possible this was linked with higher levels of confidence and a more realistic sense of work readiness augmented by the intervention.

#### **4.7.7 Overall questionnaire response rates and loss to follow-up**

The average overall response rates for the questionnaires at all three time points was 73.9%. Two previous stroke rehabilitation research studies achieved postal questionnaire response rates of 85% in a six month follow-up (Parker & Dewey, 2000) and 84% in a one off survey (Murray et al., 2013). These rates were considered to be high by the authors and were achieved with extensive telephone follow-up in the Parker and Dewey (2000) study where 60% were received after initial

posting and before reminders were sent out. A previous stroke study reported a 69% response rate for a postal questionnaire about unmet need three and six months after stroke and included those with communication and/ or cognitive difficulties as was the case in the current study (LoTS care LUNS study team, 2013). However the length of the questionnaire in these three studies appeared to be shorter and less complex than the one used in the current study and so the response rate is considered feasible. However, to achieve this, a considerable amount of time was spent chasing up follow-up questionnaires and missing data and would need to be factored in when planning a definitive trial. Loss to follow-up was higher in the control group at six and 12 month time points (see Figure 7).

For three standardised measures (SPRS – Work and Leisure questions, WPAI and WLQ) the completion rates were notably higher at six months than at three and 12 months. This may be explained in part by the number of people in work being at its highest at six months. Participants may have left questions blank on assessments which they perceive as not applicable to them, for example the ‘work and leisure’ section of the SPRS. WPAI and WLQ have lowest completion rates as both relate to ability to work/ productivity at work but WLQ is lowest of the two. This is likely to be due to numbers in work as the WPAI can still be completed even if not in work as it has question related to ‘activity’ impairment in addition to work impairment whereas you have to have been working in previous two weeks to complete WLQ.

Questionnaire fatigue could also cause lower completion rates, for example, the WLQ comes straight after SPRS and it is the penultimate questionnaire. To complete WLQ you have to have been in work for the previous two weeks whereas the SPRS is a more global measure of participation with only one of three domains directly related to work.

Some participants voluntarily provided feedback that they felt the questionnaire was too long and repetitive. There was duplication due to some questions appearing in slightly different formats in a number of standardised measures. It would be difficult for participants to understand that standardised measures cannot be changed to avoid this repetition. The question of whether the burden of participation and demands placed on participants are acceptable is discussed by Feeley et al. (2009). They point out that people are dealing with a health crisis and ways of reducing the burden by shortening the questionnaires or shortening data collection sessions should be considered. It is possible that for those who did not return to work, the completion of the questionnaire confronts this issue and may be difficult for respondents.

It is clear from the data collected that the questionnaire booklet would need to be shortened and in the light of the findings of this feasibility study, it is recommended that the SIS, SPRS and WPAI be excluded.

#### **4.8 Limitations of feasibility RCT**

This was a single centre trial with a small sample. The over ambitious collation of a series of questionnaires to evaluate outcomes with the purpose of testing out a range of measures, especially of work and

participation, meant the burden placed on participants was too great and this may have influenced loss of follow-up, especially in the control group. It is important to streamline outcome measures and be realistic about what participants are willing and able to complete in the definitive trial.

It is acknowledged that, RCT studies for complex interventions are challenging and it is important to describe and understand the context as well as the intervention itself. Wells et al. (2012) completed multiple qualitative case studies of RCTs for complex interventions and found that contextual factors including personal, organisational and trial specific can influence trial delivery. For example, the delivery of the intervention will depend on the motivation and skill of the therapist and her relationship with trial participants. Recruitment may be influenced by the enthusiasm of clinical staff for the intervention and a perception that the research is focused on a clinically relevant question. Good communication skills are needed by the researchers to engage clinical staff and potential recruits in the trial. Even the adoption by research networks can present its' own challenges in terms of staff who may not have experience of rehabilitation explaining a complex intervention to potential recruits.

The intervention itself, being individualised, adaptable and variable, is difficult to standardise and in a definitive trial, a process evaluation would be needed (Moore et al., 2015). This would ensure a realistic account of the trial and relevant contextual factors are reported and



potentially influential components examined in relation to effectiveness outcomes. The analysis of the content and context of intervention is covered in Chapter 5.

#### **4.9 Conclusion and recommendations for definitive trial/ future research**

In conclusion it would be feasible to conduct a definitive trial of early specialist stroke specific VR. However, the following changes should be considered:

- Reduction of the length of the questionnaire booklet by the removal of the Stroke Impact Scale, Sydney Psychosocial Reintegration Scale and Work Productivity and Activity Impairment Instrument
- A more accurate way of obtaining information about benefits claimed and exact working hours needs to be devised - one possibility is to provide a more thorough explanation of why this data is collected and how it will be used and providing assurance regarding anonymity and confidentiality.
- Prompt follow-up of missing data such as Bamford Classification and NIHSS scores with medical staff or from medical notes or gathering of this data by research team or research network staff.

This chapter has reported on the quantitative data collected during the feasibility RCT. The content of intervention delivered in the trial is described in Chapter 5. In order to evaluate the trial fully it was

important to explore and report on the experience of patients and employers who participated. This is the purpose of Chapter 6.

# **CHAPTER 5    CONTENT ANALYSIS OF STROKE SPECIFIC VOCATIONAL REHABILITATION**

## **5.1            Introduction**

Treger et al. (2007), in their review, highlighted a lack of research and knowledge of effective assessments and vocational rehabilitation (VR) interventions following stroke. This was reiterated in a more recent systematic review by Baldwin and Brusco (2011). VR interventions are not described in sufficient detail, in the available research literature, for them to be replicated. Not only is this important clinically when attempting to implement research findings in practice and for informing health policy and clinical guidelines but especially important for planning further research (Wade, 2003). For example, when repeating studies in different regions or countries, when moving from feasibility studies to definitive trials, for describing intervention components and the difference between the active intervention and usual care and when checking the fidelity of an intervention as part of a trial or for making sense of positive or negative outcomes.

The terms 'black box' and 'Russian doll' have been used to describe the hidden complexity of rehabilitation interventions (Whyte & Hart, 2003). Unlike pharmacological interventions whose active ingredients can be identified and defined by dose, route and administration instructions, VR interventions are complex. They consist of theories, involve the actions of several people, consist of processes that interact and are rarely linear (Hart 2009, MRC 2008). They are often individually tailored and

occur as part of complex systems (health and social care, employment and education) which are prone to modification. They may be influenced by many potential 'confounders' other than the intervention in question, for example, environmental factors (such as where the intervention takes place and access barriers e.g. transport), treatment intensity, the therapist's expertise, whether and how feedback is given and both 'therapist' and 'patient' factors such as personality, warmth and communication skills, how the patient engages with the therapist and or process, motivation and effort (Sherer et al., 2007).

Hart (2009) asserts the most important reason why good studies of rehabilitation effectiveness are not carried out is that the interventions are not well defined. She points out that we lack a common language for specifying the critical content or active ingredients of rehabilitation as well as the processes or mechanisms by which we think they exert their effects. Hart et al. (2010) attempted to define and measure vocational interventions and job support following job placements for 65 people with traumatic brain injury (TBI) across five different centres in the USA. The types, locations and durations of interventions were recorded every day that treatment was provided by clinical staff for a period of six months. They created a list of eight treatment categories accompanied by clear definitions of what the intervention involved and compared vocational interventions being provided across different sites and found this varied in terms of amount, types and location. The treatment categories were cognitive/ compensatory strategies, training or advising, emotional/ behavioural/ attitudinal issues, training or

counselling, supervisor/ employer training and education, worksite accommodations (physical environment), worksite accommodations (tasks/schedule/ logistics), life skills training or counselling, case management/ advocacy and family/ significant other intervention.

Ballinger et al. (1999) proposed that the content of therapy input in stroke rehabilitation needs to be understood before the outcomes can be interpreted or measured and they designed and evaluated a tool for recording intervention. This rather crude tool was adapted and developed by Phillips et al. (2010) to record, measure and describe occupational therapy (OT) VR intervention following TBI. This proforma provided far greater depth, breadth and detail than the treatment categories defined by Hart et al (2010) who had concluded it was not feasible to record time spent on each category. So the Phillips et al. (2010) proforma was developed further in the current study in order to record, describe and analyse the content of stroke specific VR intervention being delivered in the feasibility randomised controlled trial.

## **5.2 Aim**

To describe and analyse the content of VR intervention delivered in the feasibility randomised controlled trial.

## **5.3 The research question**

What is the content of intervention being offered in the feasibility randomised controlled trial?

## **5.4 Content analysis**

### **5.4.1 Method**

The purpose of this study was to design a method of recording the intervention being delivered in the feasibility randomised controlled trial so that it could be described and measured. This enhances the reproducibility of the study and its' implementation (Hart, 2009). The development of the proforma is described below.

### **5.4.2 Sampling method**

The proforma was completed on two case study participants and all feasibility trial participants who were randomised to receive the intervention.

### **5.4.3 Instrument**

#### **5.4.3.1 Development of the proforma**

A tool to record and describe stroke rehabilitation therapy input (Ballinger et al., 1999) was adapted by Phillips et al. (2010) for use in a study evaluating VR following TBI. Fifteen categories were identified based on best practice guidelines (British Society of Rehabilitation Medicine, 2004) and current service provision. It was refined through feedback from a number of experts including a service user with a TBI. A decision was made to record intervention in units of 10 minutes, as opposed to the 15 minute units used in the Ballinger study to provide greater depth of detail (Phillips et al., 2010).

In this study the proforma used in the study by Phillips et al. (2010) was adapted for stroke using ideas from clinical practice, existing literature

and the views of an expert panel (Appendix 9). The expert panel was made up of VR providers, stroke specialists and service users.

Explanatory notes for the proforma are in Appendix 10.

The following changes were made:

- 'Pain management' (e.g. advice on management of painful shoulder) was added to the section on physical rehabilitation
- 'Adjustment/ Re-evaluation', referring to the psychological adjustment to the impact of stroke, reflection on and reappraisal of priorities (Radford and Walker, 2008), was added to the 'Dealing with psychological issues' section
- 'Work site visit', where the purpose may be to meet employer, colleagues, assess work environment, was added to the 'Return to Work Process' section.
- 'The Stroke Association' and 'Different Strokes' charitable organisations were added to 'Use of other services' section.
- The hierarchy of return to work outcomes (New Hampshire Department of Labor, 2001) were added to the outcomes section to make outcomes comparable with other VR studies.

Further changes and additions were made following the expert panel discussion:

- 'Upper limb work', 'sensory problems' and 'communication/ speech' were added to the physical rehabilitation section.

- 'Physiotherapy' and 'speech and language therapy' were added to the liaison section
- 'Cycle' was added and 'Works at home' were added to the section on how people got to work
- 'Voluntary work' and 'self-employed' in addition to the new GP fit note categories (a. Phased return to work b. Altered hours c. Amended duties d. Work place adaptations) (DWP, 2010) to the outcomes section.

#### **5.4.4 Procedure**

The proforma was completed by the OT following each intervention session for the case studies and all participants in the feasibility randomised controlled trial who received the intervention. The data was then transferred from paper copies of proformas into Excel and descriptively analysed.

#### **5.5 Data analysis**

SPSS (version 18) was used to analyse demographic data about the case study and trial participants. Excel was used to analyse information from the proformas. Descriptive analysis of the overall time spent on face to face, liaison, administration and travel were calculated in addition to the breakdown of specific components of intervention, location of intervention and outcomes.



## 5.6 Results

### 5.6.1 Sample

Two case study participants and 23 trial participants were included in this study. Baseline characteristics of these individuals are summarised in Table 35.

**Table 35. Baseline characteristics**

<b>Characteristic</b>	
<b>Sex, n (%)</b>	
Men	18 (72%)
Women	7 (28%)
Total	25 (100%)
<b>Age, years</b>	
Mean	58
Range	24-78
<b>Ethnicity, n (%)</b>	
British	25 (100%)
<b>Bamford Classification, n (%)</b>	
PACS	5 (20%)
LACS	7 (28%)
TACS	3 (12%)
POCS	7 (28%)
Missing	3 (12%)
<b>NIHSS, n (%)</b>	
Minor (1-4)	10 (40%)
Moderate (5-15)	6 (24%)
Moderate/Severe (15-24)	3 (12%)
Severe (>25)	0 (0%)
Missing	6 (24%)
<b>Stroke Impact Scale, n (%)</b>	
>65	19 (76%)
50-65	4 (16%)
<50	2 (8%)

<b>Characteristic</b>	
<b>Job Category*, n (%)</b>	
1. Unskilled	2 (8%)
2. Semi-Skilled	2 (8%)
3. Semi-Professional	11 (44%)
4. Professional/ Managerial	10 (40%)
<b>Marital status, n (%)</b>	
Married	17(68%)
Single	4(16%)
Divorced	2(8%)
Living with partner	2(8%)
<b>Length of Stay in Hospital (days)</b>	
Mean	18
Range	0-82

\*Using the Standard Occupational Classification (Office of National Statistics 2000)

## **5.6.2 Content analysis**

### **5.6.2.1 Delivery of intervention**

#### **5.6.2.1.1 *Timing and duration of intervention***

Intervention commenced between 10-53 (mean 30, SD 12) days post stroke. Participants received a mean of 10 (SD 7, range 1-25) intervention sessions and an average session lasted approximately one hour. This data is classified according to stroke severity in Table 36. Where NIHSS scores were missing, Stroke Impact Scale (Version 2.0) scores were used to assist with classification of stroke severity. This was done by equating a Stroke Impact Scale scores of >65 to minor stroke, 50-65 to moderate stroke and <50 to moderate/severe stroke.

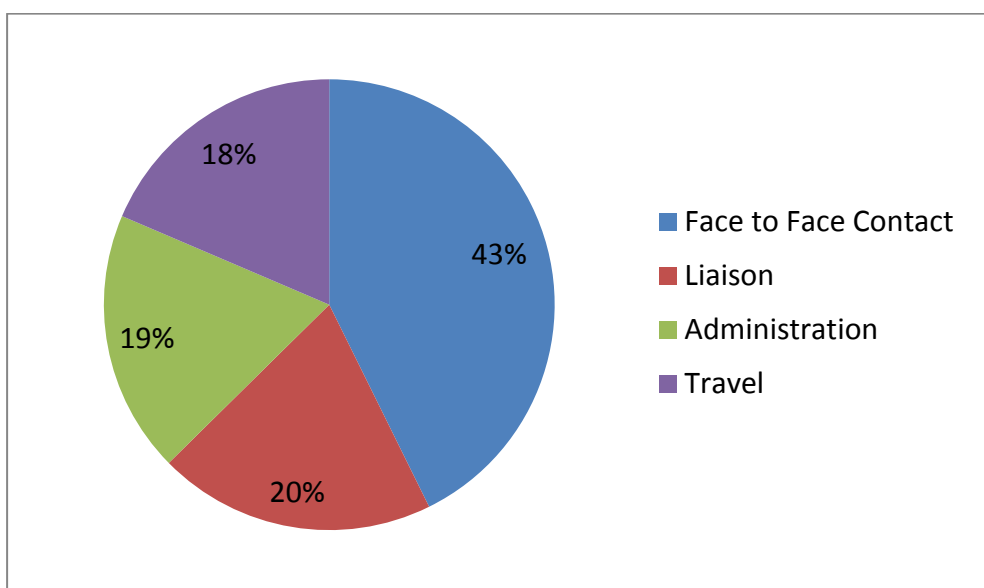
**Table 36. Delivery of intervention related to stroke severity**

	<b>Minor stroke</b>	<b>Moderate stroke</b>	<b>Moderate/ Severe Stroke</b>	<b>Overall</b>
<b>Intervention commenced (days post stroke)</b>				
Mean	29	35	33	30
Range	10-47	16-53	29-37	10-53
SD	11	16	6	11
<b>Number of sessions received</b>				
Mean	9	12	11	10
Range	1-25	1-24	9-13	1-25
SD	6	11	3	7
<b>Duration of intervention (days)</b>				
Mean	222	248	240	231
Range	21-365	48-369	178-302	21-369
SD	109	144	88	112

**5.6.2.1.2 Distribution of OT Time**

Two thirds of OT time was spent on the intervention itself (43% face to face contact and 20% liaison with the participant and others) and the other third split almost equally between administration (19%) (writing notes and reports) and travelling to see participants at home or their work places (18%) (Figure 39).

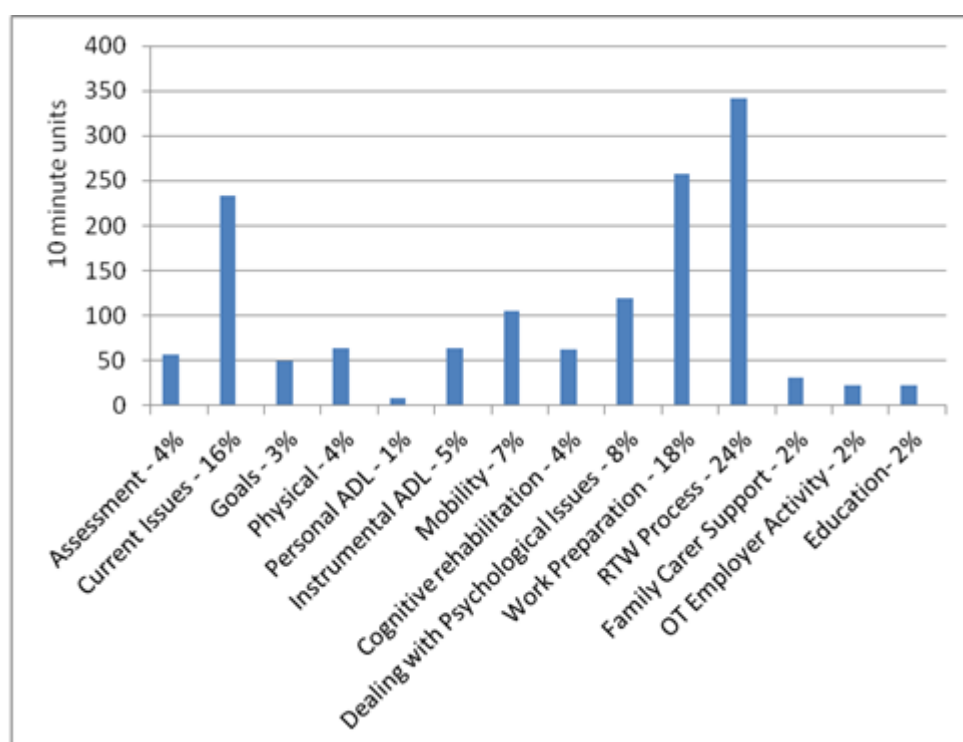
**Figure 39. Overall breakdown of OT time spent**



### 5.6.2.2 Intervention content

The content of intervention is summarised in Figure 40. The largest proportion of time is spent on preparing participants for work (18%) and the return to work process (24%).

**Figure 40. Intervention content**



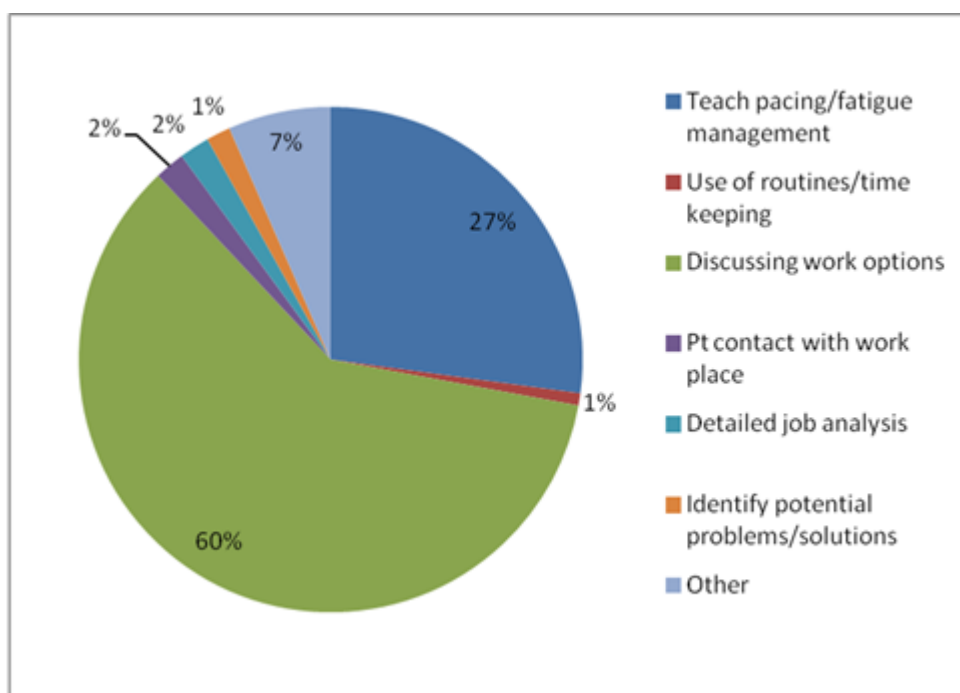
#### **5.6.2.2.1 Work preparation**

Most of the time dedicated to work preparation (Figure 41) was spent discussing possible work options (60%) that were acceptable to the person e.g. regarding the phased return. The therapist asked the participant about their ideas about the timing of going back to work and the hours they felt they would be able to manage. This was important as preparation for planning the return to work before discussing this with the employer or with the individual themselves if self employed or doing voluntary work. It also involved discussing how to phase re-entry into their role and responsibilities at work.

Teaching pacing and fatigue management was the second most common activity (27%) used in preparing someone for returning to work. However, in reality, this latter intervention was also used when reviewing a return to work because sometimes it was only after people had returned that fatigue became a problem.

Other aspects of work preparation (7%) included applying for voluntary work, filling in Criminal Record Bureau check forms, visits to Job Centre Plus and looking for education and retraining opportunities e.g. courses. The remaining 6% of time was spent focusing on the use of routines and timekeeping, patient contact with the workplace, detailed job analysis and identifying potential problems and solutions.

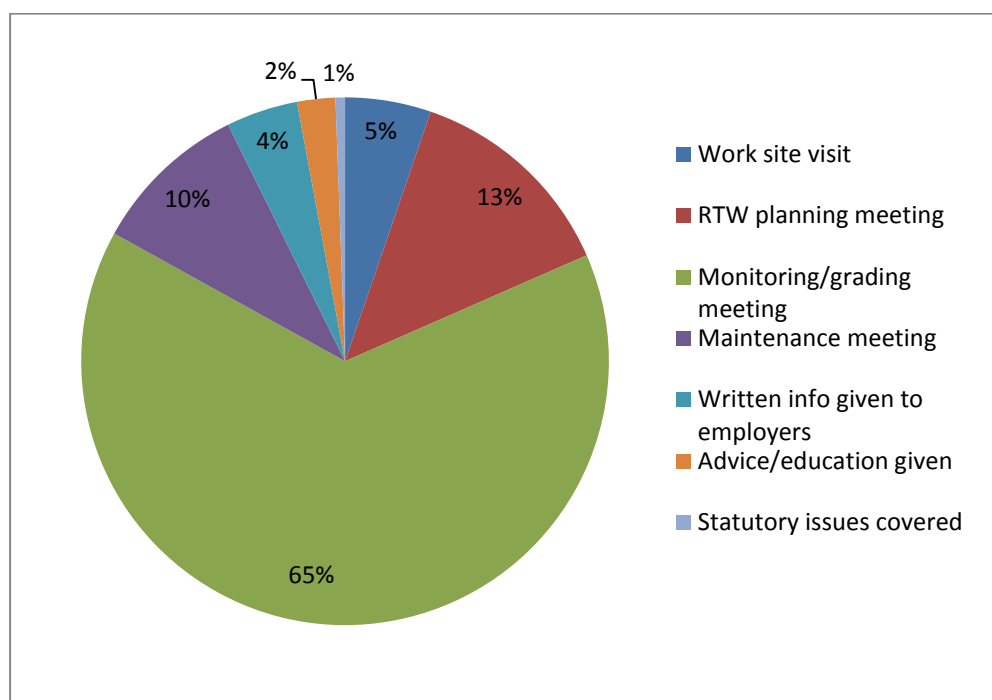
**Figure 41. Work preparation**



#### **5.6.2.2.2 Return to work process**

The return to work process (Figure 42) comprised return to work planning (13%), monitoring and grading (65%) and maintenance (10%) meetings. Sometimes these meetings were with the employer and other times they were only with the participant depending on their work situation. Monitoring and grading meetings took place once the person had returned to work and involved reviewing the return to work plan and making modifications if necessary. These included changes to days or hours of work or duties undertaken. Maintenance meetings occurred after the person had returned to their previous hours and duties to ensure work return was sustained and any difficulties which arose could be resolved. The remaining 12% of time was taken up with work site visits, providing advice, education and written information to employers and covering statutory issues.

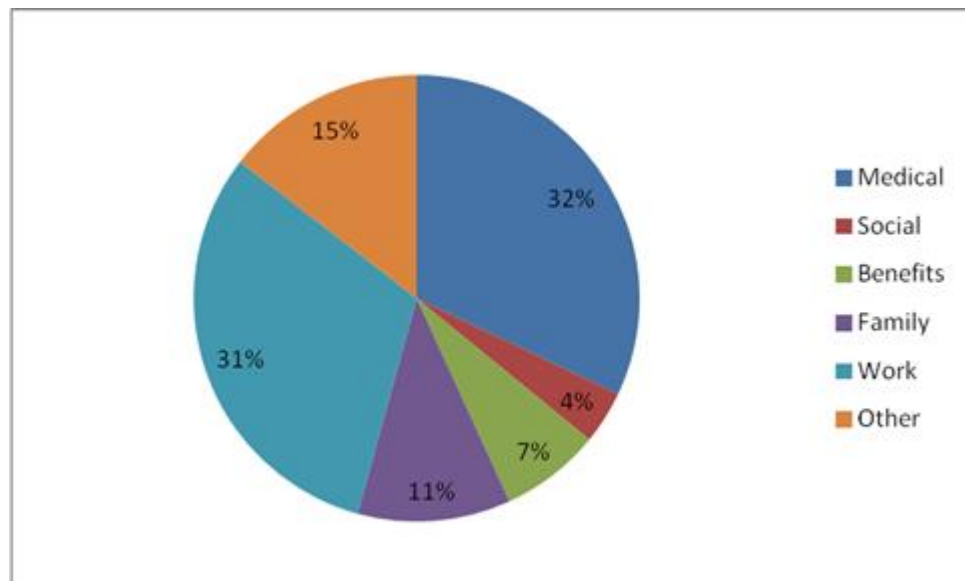
**Figure 42. Return to work process**



#### **5.6.2.2.3 Current issues**

One of the main current issues brought to the attention of the OT by the participants (Figure 43) was medical (32%), for example, discussing the side effects of medication to prevent future strokes or managing diabetes. The other main focus was current work issues (31%), which involved matters which had arisen since the previous meeting in the work place, for example, conversations the employee had had with their line manager or current concerns about work. The third highest proportion was spent on other issues (15%) such as accommodation, financial difficulties or discussing intervention received from other rehabilitation therapists. The remaining 22% of time was spent on social, family and benefit issues.

**Figure 43. Current issues**

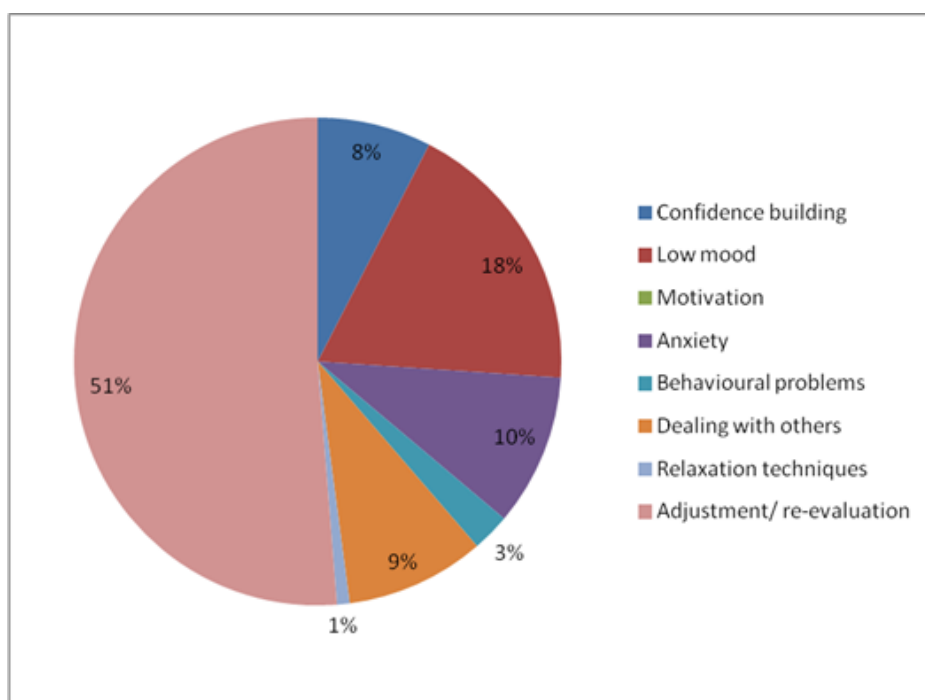


#### **5.6.2.2.4 Dealing with psychological issues**

Just over half the time spent dealing with psychological issues was focused on the adjustment and re-evaluation process following stroke. Low mood and anxiety were prevalent issues (Figure 44). Intervention consisted of providing informal psychological support which included listening to the participant talking about the emotional difficulties they were experiencing, the provision of information and suggesting strategies to enhance coping and adjustment. Two participants were referred for additional psychological support to the stroke coordination and support service due to low mood. The remaining 21% of time was spent on confidence building (providing encouragement and positive reinforcement as they tried to regain skills), motivation, behavioural problems, dealing with others and teaching relaxation techniques.



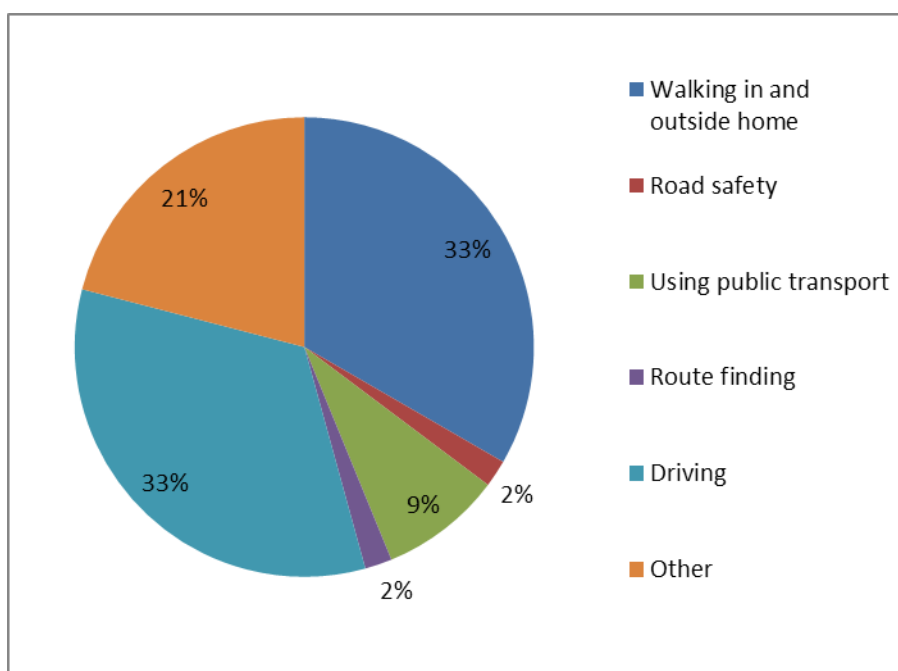
**Figure 44. Dealing with psychological issues**



#### **5.6.2.2.5 Mobility**

Two thirds of the time spent working on mobility was split equally between walking (in and outside the home) and driving (Figure 45). This included advice about walking outside as part of an exercise programme to increase physical stamina in preparation for work return as well as practising walking inside the home. Advice about driving after a stroke through the provision of information booklets and help with forms from the DVLA were part of this aspect of intervention. The other category (21%) included working on standing balance, advice about exercise to increase fitness and stamina and reduce risk of further stroke, assisting with application to a charity for a mobility scooter and advice about a ramp to access garden. The rest of the time (13%) was spent focusing on road safety (2%), using public transport (9%), and route finding (2%).

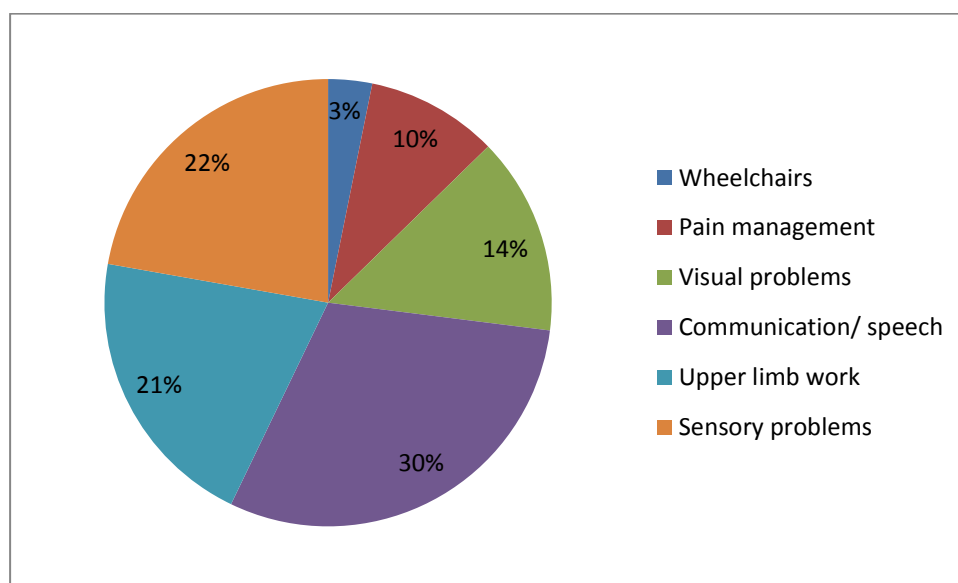
**Figure 45. Mobility**



#### **5.6.2.2.6 Physical intervention**

The key foci of physical interventions were in dealing with communication/ speech difficulties (30%), sensory problems (22%), upper limb deficits (21%), visual problems (14%) and pain management (10%) (Figure 46). This included working on communication and speech as part of the session, sensory re-education activities and advice about safety in relation to sensory loss and teaching compensatory, tracking techniques to those with hemianopia. A limited amount of time (3%) focused on wheelchairs which included advice on how to access rental of an electric indoor wheelchair.

**Figure 46. Physical Intervention**



#### **5.6.2.2.7 Cognitive/ Executive skills**

The prime focus of this area of intervention was education about and rehabilitation of cognitive and executive skills (66%). This included activities involving planning and multitasking (or setting them as homework) and then discussing how they went and providing feedback. Memory strategies were taught to some participants (14%) and standardised tests (13%) were carried out when appropriate, for example, the Rivermead Behavioural Memory Test or the Behavioural Assessment of the Dysexecutive Syndrome (BADS). These tests guided intervention and strategies were developed collaboratively for coping with cognitive difficulties in the workplace (e.g. use of notebook to assist with memory difficulties). Referrals were also made to a clinical neuropsychologist for two participants who required in-depth cognitive assessment and both were then referred on to the local out-patient neurorehabilitation service for a memory group intervention facilitated by a different NHS OT.

#### **5.6.2.2.8 Instrumental Activities of Daily Living (IADL)**

Almost half (45%) of time spent on IADL was focused on leisure activities. These activities were often used as a method of preparing for work e.g. using Facebook to enhance computer skills or reading to improve concentration levels. Keeping a diary using a laptop to monitor activity, energy and concentration levels was included under the 'other' category (25%). Amount of time spent doing these daily activities was recorded in a table with a column for ratings using a Likert scale of 0-10 for levels of fatigue and concentration experienced. This was then reviewed, discussed and progress with increasing activity levels monitored. Time spent focusing on making drinks and meals made up 11% of time in this category and again, this was often in relation to working on cognitive planning and processing difficulties. Dealing with sleep issues took up 6% of the time and was often related to managing fatigue in preparation for work return.

#### **5.6.2.2.9 Liaison**

Most liaison (Figure 47) took place between the therapist and the participant (46%) and this was by phone, letter, email and text messaging. Liaison with health professionals (20%) included general practitioners, consultants, psychologists, physiotherapists, speech and language therapists and other OTs involved with the participants care from intermediate care, early supported discharge and out-patient therapy services. The purpose of this liaison was to explain the role of the vocational OT and to work collaboratively, where appropriate, to help the trial participant return to work.

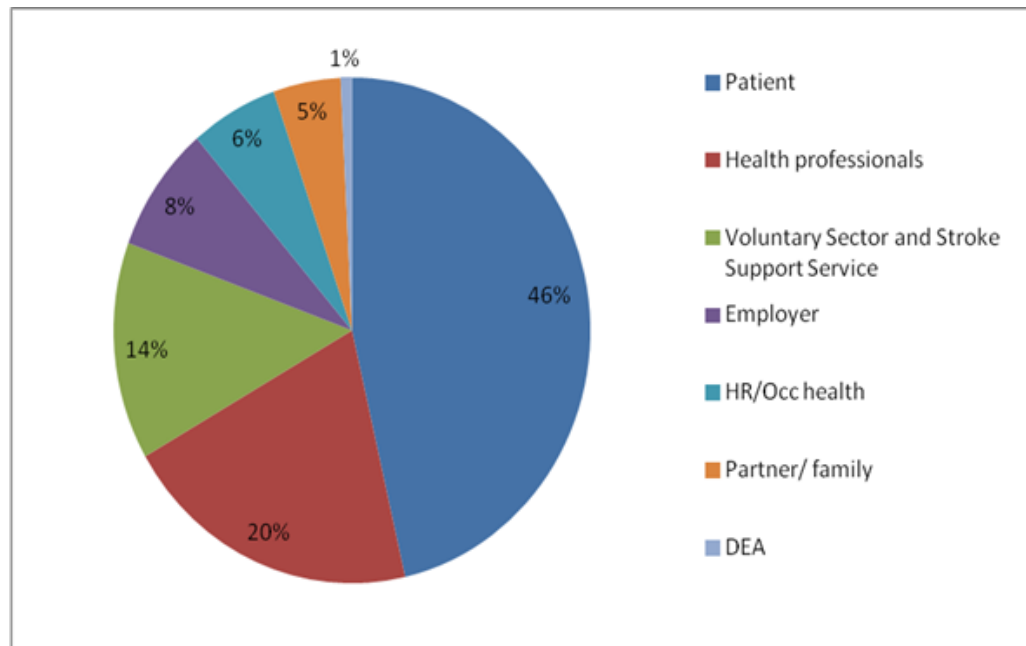
Voluntary organisations included those brokering voluntary jobs (Community Action Derby and Live at Home, a befriending service) and Disability Direct offering leisure activities to stroke survivors and legal advice regarding return to work. The research OT attended appointments with trial participants to the voluntary job brokerage centre and invited the disability rights adviser to participate in meetings with employers in some cases.

The stroke support and coordination service, led by an OT in the south of the county and a nurse in the north of the county is funded jointly by health and social care. Stroke survivors and their families are seen by stroke support workers who offer advice and information about benefits, local services and provide psychological support during the process of adaptation following stroke. This service contacted people while they were in hospital or within three weeks following discharge and acted as a safety net ensuring stroke survivors were getting appropriate services and support. Liaison with this service took place if more support was needed regarding financial difficulties, low mood or social activities.

Liaison with the employer, human resources and occupational health involved attendance at meetings or appointments in an advocacy role. Letters summarising these meetings were sent to the participant and copied to general practitioners and those in attendance. Of the 25 participants direct contact only occurred with the employers/ managers of seven participants, one of whom was a voluntary worker. However, eight were self-employed, three more were engaged in voluntary work

and three others did not have an employer for the OT to liaise with as one was made redundant just prior to the stroke, one lost his job just after the stroke and one was not working at the time of stroke. The four remaining participants did not want the OT to have direct contact with their workplace but three acted as a conduit of information, passing on leaflets, booklets and letters with recommendations from the therapist. Only 5% of time was spent on liaising with partners and family members.

**Figure 47. Liaison**



### 5.6.3 Context of intervention

#### 5.6.3.1 Location of intervention

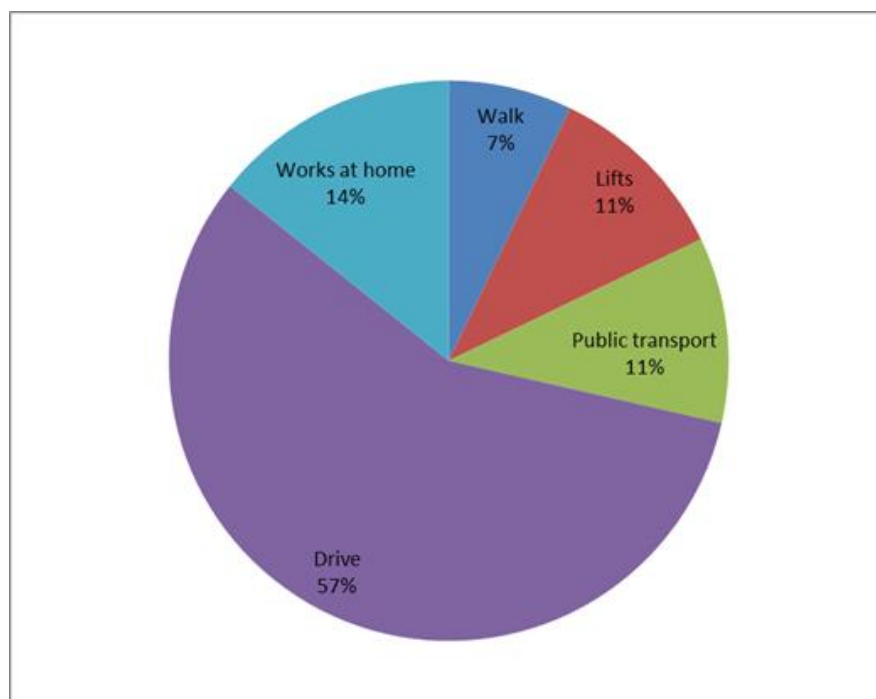
The intervention delivered mostly took place in the community. Almost two thirds of sessions took place in participants' homes (64%), 28% in the workplace (including occupational health and human resources departments) and 1% in Job Centres. Other locations (7%) included the

stroke rehabilitation ward prior to discharge (46%), the meeting room of a disability rights charity (13%) and a voluntary organisation job brokerage centre (7%).

### 5.6.3.2 Method of travelling to work

Figure 48 demonstrates that 57% of participants drove to work at some stage. However, this was not always possible initially and so participants got lifts from work colleagues, family and friends or used public transport as an alternative method of getting to work. Others walked to work or worked from home. The OT encouraged some participants to refer themselves to 'Access to work', a Job Centre Plus provision where people could be taken to work in a taxi if no other method of transport to work was feasible. However, none of them needed to use this service as by the time they returned to work they were able to get to work by other means.

**Figure 48. Method of travelling to work**

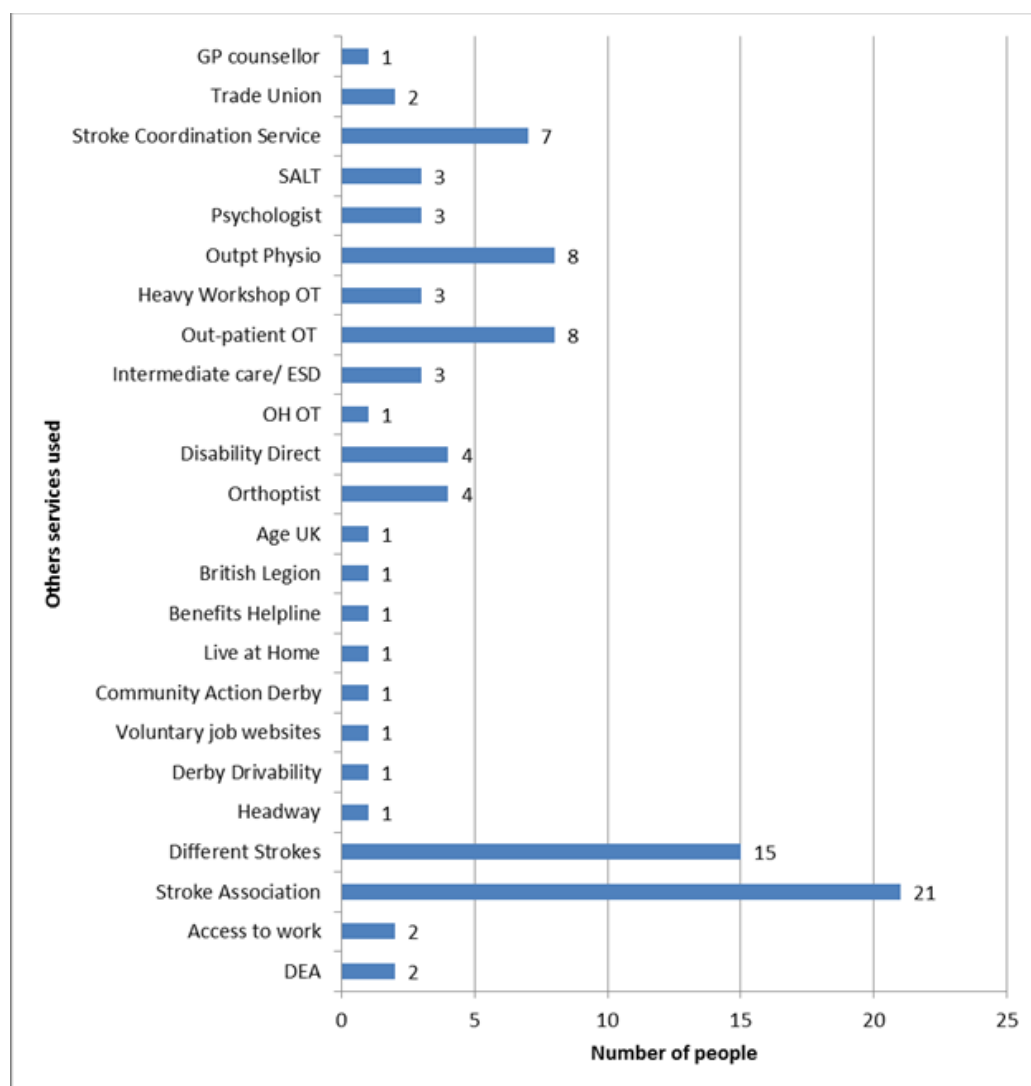


### **5.6.3.2 Use of other services**

A wide range of other services were used by participants as illustrated in Figure 49. Information booklets from charitable organisations such as 'The Stroke Association' and 'Different Strokes' were provided by the OT to participants and their families and employers. Some participants were in receipt of NHS rehabilitation services e.g. Early Supported Discharge services, neurological out-patient OT, OT heavy workshop, out-patient physiotherapy, clinical neuropsychology and community speech and language therapy. The stroke coordination service provided additional support to participants alongside the voluntary sector e.g. disability rights advice and voluntary jobs brokerage.



**Figure 49. Use of other services**



#### 5.6.4 Outcomes of intervention

Of the 25 participants, 19 returned to work to do the same job with the same employer. However, four of the 19 subsequently retired. One of these had planned to retire at 70 and the other three retired, at least in part, due to the impact of the stroke aged 78 (voluntary job), 72 (self-employed) and 58 (full time paid employment). One retired without returning to work (planned to retire at 70). All four people engaged in voluntary work returned to it and of the eight people who were self-employed two did not return to work.

Of the 25 participants, 16 had a phased return to work, nine of these received full pay even though they were working reduced hours but three took a pay cut during the phased return and were only paid for the hours they worked. Six people used annual leave, accrued during the period of sickness, as part of the phased return.

Overall outcomes for the intervention group are described in Table 37 according to whether they were full time or part time, in Table 38 in relation to the type of work they were doing and in Table 39 according to stroke severity.

**Table 37. Overall outcomes for intervention group – number who returned to full time and part time work at some point during the feasibility trial**

	<b>Full time</b>	<b>Part time</b>	<b>Not working</b>	<b>Total</b>
<b>Number</b>	18	6	1	25
<b>Number who returned to work (%)</b>	15/18 (83%)	4/6 (66%)	-	19 (76%)

**Table 38. Overall outcomes – type of work returned to at some point in the trial**

	<b>Private Sector</b>	<b>Public Sector</b>	<b>Voluntary Work</b>	<b>In education</b>
<b>In work prior to stroke, n</b>	15 (8 self-employed)	5	4	1
<b>Returned to work or studies, n (%)</b>	12 (80%) 6 (75%) (self-employed)	3 (60%)	4 (100%)	1 (100%)
<b>Retired aged over 65 (planned retirement), n (%)</b>	-	1 (20%)	-	-
<b>Returned to work then retired aged over 65 (planned retirement), n (%)</b>	1 (7%)	-	-	-
<b>Returned to work then retired aged over 65 due to stroke, n (%)</b>	1 (7%)	-	1 (25%)	-
<b>Returned to work then retired aged under 65 due to stroke, n (%)</b>	1 (7%)			
<b>Living solely on benefits at 12 months, n (%)</b>	2 (13%)	1 (14%)		

NB: One person was in education also did a part time paid job and one was not working so total =25

**Table 39. Overall outcomes at some point in the trial according to stroke severity**

<b>Outcome</b>	<b>Minor</b>	<b>Moderate</b>	<b>Moderate/Severe</b>
<b>Returned to work/ studies, n (%)</b>	16/19 (84%)	2/4 (50%)	1/2 (50%)
<b>Returned to voluntary work, n (%)</b>	4/4 (100%)	-	-
<b>Retired aged over 65 (planned retirement), n (%)</b>	-	1/4 (25%)	-
<b>Returned to work then retired aged over 65 (planned retirement), n (%)</b>	1/19 (5%)	-	-
<b>Returned to work and then retired aged over 65 due to stroke, n (%)</b>	2/19 (11%)	-	-
<b>Returned to work then retired aged under 65 due to stroke, n (%)</b>	1/19 (5%)	-	-
<b>Living solely on benefits at 12 months, n (%)</b>	2/19 (11%)	-	1/2 (50%)

## **5.7 Feasibility of using the proforma**

Intervention sessions took approximately five minutes to record each time the proforma was completed.

Some subcategories were not used: These were ‘splinting’ in the ‘physical’ section as no splints were required by participants, ‘toileting’ in the ‘personal activities of daily living’ section, ‘money/ budgeting’, ‘correspondence’ and ‘managing appointments’ in the instrumental activities of daily living section, ‘motivation’ from the ‘dealing with

psychological issues' section, 'work assessment meeting' in the 'return to work process' section, 'case manager', 'CBT' and 'work provider' in the 'liaison' section and 'information about the rehabilitation process' and 'advice/ support regarding work assessment' in 'OT activity with employer' section.

A number of further modifications were made to the proforma, after the intervention had commenced in the present study. One descriptor needed amendment: 'Walking outside the home' in the 'mobility' section was changed to 'walking' as some participants were working on indoor mobility. The four different types of meeting subcategories of the 'return to work process' section were used to record both formal meetings with employers and also sessions with participants when employers were not involved.

There were some difficulties with the proforma that would need to be considered for future use. Some categories appeared to overlap. For example, 'discussion of work options' under the 'work preparation' heading and 'return to work planning meetings' in the 'return to work process' section. Some discussion of work options took place in these meetings but if this was discussed more informally with the participant in their own home at an earlier stage then it was recorded under 'discussion of work options'. 'OT activity with employer' also overlapped with 'return to work planning meetings' and 'monitoring/ grading meetings' as most activity was an integral part of these meetings. 'General education re stroke and/or RTW ' was sometimes inextricably

linked with 'work preparation' subcategory 'discussing work options' and 'family/ carer support'. 'Education about cognitive skills' and 'other' category of 'instrumental activities of daily living' (e.g. use of computer/ laptop) could also be seen as work preparation but the practical aspects of work preparation are more specifically broken down under other headings. Confidence building can be achieved by doing specific tasks and practical activities and through feedback given at monitoring, grading and maintenance meetings so this was another area of overlap.

It would have been useful to have 'other OT' as a category in the 'liaison' section as liaison with other out-patient and community OTs was recorded under 'other' and had to be separated out later in order to look at overall liaison with health professionals.

## **5.8 Discussion**

Rehabilitation intervention in this study has been described in detail as recommended by previous researchers (Whyte & Hart 2003, Wade 2005, Hart 2009). A proforma, previously developed for use in a study of VR following TBI (Phillips et al., 2010) was adapted for stroke and used as part of feasibility randomised controlled trial to record and categorise the content, context and outcomes of stroke specific vocational rehabilitation.

### **5.8.1 Use of the proforma**

The proforma was quick and easy to complete and enabled the intervention, contextual factors and outcomes to be described. The transfer of information from paper copies to an Excel spread sheet

facilitated data analysis. It was deemed to be a feasible method suited to both clinical practice and research because it had been practically tested out by the research OT working both as a clinician and a researcher during the trial. Given that the proforma was developed in Excel, it could possibly be adapted for completion online or using mobile technology such as smartphones or tablet computers for future use.

The proforma was able to capture the main focus of intervention but there were areas of overlap. The practical challenge of recording the multi-tasking which takes place during intervention sessions was also faced by Phillips et al. (2010) when categorising VR OT following TBI and highlights the problem of describing an intervention which is both complex and multifaceted. In both studies the OTs recorded the main focus of intervention but this may have led to some areas of intervention (e.g. confidence building) being under-represented in the results. This is because in this example, confidence building was being worked on through practical activities or meetings which were perceived as the main focus of the session.

The two therapists, one in the previous TBI study (Phillips et al., 2010) and one in the current stroke study were, after lengthy discussion, able to use the proforma in a similar way, however inter-rater reliability needs to be investigated in future research.

The greatest proportion of time was spent on work preparation and the return to work process in both studies. However, more time was spent on assessment (20%) by Phillips et al. (2010). In the current stroke study baseline data gathered from participants in the feasibility trial were used to inform the assessment by the research OT but a proforma was not completed for the time spent on baseline data collection session as it was not always carried out by the research OT. This may have led to an under representation of time spent on assessment in the current study and may have influenced the number of sessions a participant received. If an estimated figure of 60 minutes spent on baseline assessment were added to each participant's intervention time to then this would mean 13% rather than 4% of time had been spent on assessment. It would also add an additional session for each participant leading to a mean of 11 sessions. Decisions made about which sessions to record need to be considered in future research to ensure consistency.

The proforma was able to distinguish between the intervention provided to different client groups. For example, participants in the TBI study appeared to have fewer physical difficulties whereas in this stroke study a number of people had physical limitations and needed intervention focused on mobility and driving. The research OT also offered support to family members as part of the intervention, which in the TBI study was delivered predominantly by TBI case managers. Hart et al. (2006) did a survey of vocational services for people with TBI and identified three clusters; medical rehabilitation services (train-and-place),



supported employment (place-and-train) or a combination of these with the emphasis on case management. They describe the case management role as involving vocational and adjustment counselling, job coaching, scheduled job site visits and/or phone consultations with the employer, client and family. However, this role appears to have been shared between the OT on the TBI study and the case managers working in the same team whereas there were no case managers available in stroke services and so the research OT assumed two roles, that of a case manager and therapist delivering the intervention.

Although there was consensus among the expert panel that the key areas of intervention were included and the proforma was appropriate for use following stroke, it did not distinguish between practical intervention and monitoring progress under the same headings. For example, a session where the research OT practises travelling on a bus with a patient compared to talking to the patient about how they were managing to use public transport. These two aspects of the intervention could potentially be differentiated by adding a code to the recorded time spent on a particular component (e.g. T for talking about and D for doing activity) and then the proportion of time spent on each could then be calculated. However, if both aspects were covered in a particular session for a single component this could make the measure more complex to use and data analysis would be more involved.

### **5.8.2 Development and future use of the proforma**

The proforma could be used as a clinical tool in its current form but, as demonstrated above, the use of some sub-categories would be open to

interpretation. Further research is needed to refine and develop the proforma for use in research studies to enable detailed description and evaluation of this complex intervention (MRC, 2008). This could start with removing redundant subcategories (e.g. splinting). There also needs to be greater consensus on terminology used and clearer definitions and guidelines to improve consistency and clarity. For example, 'return to work planning meeting' should be differentiated from 'return to work planning discussion' with the former referring to a formal meeting with employer and the latter describing an informal dialogue about return to work with participant at home or they could be recorded separately. The terms 'monitoring' and 'grading' are familiar to OTs for whom this proforma has been designed but if it were to be used by other professionals, then these terms may need to be replaced with 'reviewing' or 'managing' return to work. Inter-rater reliability testing would then be needed to assess the consistency of the refined proforma.

The proforma has the potential to be adapted for use with a wide range of health conditions (e.g. musculoskeletal and mental health) as many core components are generic to VR. However, before this could happen, further work to refine and define the categories and components and check the inter-rater reliability within same or different conditions and professional groups would be needed.

### **5.8.3 Content of intervention**

#### **5.8.3.1 Dealing with psychological issues**

Only 8% of time was recorded as dealing with psychological issues as part of the trial intervention. This is surprising given the importance placed on this aspect of intervention in previous research about return to work after stroke (Glozier et al., 2009; Lindstrom et al., 2009). It is possible that this component is under-represented in the current study due to overlap with other activities as described above in relation to confidence building. Another example would be attending work site meetings with participants or accompanying them to appointments with occupational health or to the job centre which could all be perceived as providing psychological support but the main focus of the session would be recorded as a meeting or liaison with other professionals or services.

Psychological aspects of VR intervention have rarely been described in previous studies. In this current study the time was spent dealing with adjustment and re-evaluation, low mood, anxiety and confidence building. Hartke et al. (2011), in a qualitative interview study with 12 stroke survivors, identified a number of psychological issues faced by stroke survivors preparing to return to work. Coping strategies such as problem solving, risk taking and stress management were identified along with the issues of regaining self-confidence, motivation and readiness to return. They also highlight that their participants re-evaluated their work/life balance in view of the stroke and experience of work stress. The need to focus on the emotional impact of stroke, particularly depression, has been suggested by Glozier et al. (2008) in

order to increase the probability of return to work. However, dealing with anxiety is a neglected aspect of existing stroke rehabilitation research.

### **5.8.3.2 Employer involvement**

Direct employer contact was only recorded in seven cases and this could be explained, in part, by job type as eight participants were self-employed and four were volunteers and therefore there was no employer. However, one volunteer was managed by a voluntary service coordinator/ manager with whom liaison took place. Four participants were offered the opportunity for direct employer contact with the therapist but preferred to manage this aspect of their return to work independently. Possible reasons for this could be a reluctance to disclose or highlight the impact of stroke due to fear of losing their job. Similarly only six out of 21 participants in the Phillips et al. (2010) study on VR following brain injury received intervention directly involving the employer however the reasons for this may be different. Best practice guidelines for VR (Tyerman & Meehan, 2004) recommend employer liaison and previous research studies have cited employer attitudes, knowledge and flexibility as important influences on the success of returning to work after a stroke (Alaszewski et al., 2007; Lock et al., 2005; Coole et al., 2012). Coole et al. (2012) found, in a qualitative interview study with 18 employer stakeholders in relation to helping employees return to work after stroke, that they would welcome advice and support from clinicians as they often feel they lack relevant knowledge and experience. The reasons why stroke survivors may or may not want rehabilitation therapists to liaise with their employer does

not appear to have been investigated to date. Gold et al. (2012) conducted focus groups with employers, employees with disabilities and rehabilitation service providers and found that little is known about why so few employees disclose their disability but state that asking for accommodations can be perceived as a risk. The relationship between employer involvement and return to work outcomes has also not been explored. Gold et al. (2012) suggest job tenure and performance is enhanced by the provision of reasonable work place accommodations. Education of the employer about the specific needs of disabled employees has been suggested to enable appropriate adjustments to be made and as a result improve job retention and work return success (Culler et al., 2011; Gold et al., 2012).

### **5.8.3.3 Family involvement**

The proportion of time spent liaising with family members was low (5%). This was because offers of support were not always taken up and once trial participants had returned to work, meetings were usually held at the workplace or outside the home and so contact with family was limited. Perceptions of a partner or family are purported to influence therapeutic alliance (Sherer et al., 2007) and negative attitudes to return to work in family members are described as a barrier to work return (Culler et al. 2011, Hartke et al. 2011). The influence of family on work return outcomes in this study is described below but the extent to which it was mediated by the therapists support is not clear.

#### **5.8.3.4 Context of intervention**

The findings for location of intervention were similar to the TBI study (Phillips et al., 2010) in that the majority (64%) of sessions took place in the clients' home. However 28% of the stroke study visits were to the workplace compared to 16% in the TBI study. The TBI clinic and job centre were the two other most common locations (16% of which 3.5% were at job centre). This difference was probably due to the TBI OT being based in a clinic whereas in the stroke study the OT was not based in a clinical setting and possibly did fewer visits to the job centre also. This may have been connected to the number of participants looking for a new job being slightly higher in the TBI study (Phillips, 2013).

The method of travelling to work does not appear to have been a barrier to work return for this sample however, two people interviewed by Lock et al. (2005) said that lack of funding for appropriate transport (e.g. for a car) that would enable them to get to work independently was a major difficulty. An American qualitative interview study by Culler et al. (2011) cites inability to drive and lack of public transport in the area as barriers to work return, however, the American context is quite different to the UK both geographically and in relation to availability of public transport. In the current study, as in Lock et al. (2005), the majority of participants had their own means of transport to work.

A range of other services were being used by participants in this study some of which were part of the intervention (e.g. the provision of information from stroke charities) or were facilitated as part of the

intervention (i.e. access to clinical neuropsychology assessment, working with voluntary job brokers and disability employment advisers). However, other out-patient therapy services were part of 'usual care' and the OT liaised with these services to ensure collaborative working and to avoid overlap.

Employer attitudes have also been referred to as influential in whether someone returns to work or not. Employers who are supportive and have an open and positive attitude to making accommodations can enable work return whereas a negative, inflexible attitude can have the opposite effect and be a barrier (Lock et al., 2005; Alaszewski et al., 2007; Culler et al., 2011). The influence of the pre-stroke relationship with the employer does not appear to have been explored in studies on predictors of successful return to work although the attitude of the employer post-stroke could potentially be influenced by this factor.

#### **5.8.3.5 Timing and duration of intervention**

The mean number of intervention sessions was ten (range 1 – 25). This demonstrates a flexible intervention and tailoring to individual participant's needs, which would need consideration before operationalising in a definitive trial or clinical practice. There was also a considerable amount of face to face contact time in this trial (43%) which could be intermittently replaced with telephone or email contact especially in the review and monitoring phase of intervention in order to reduce costs.

### **5.8.3.6 Recording outcomes of intervention**

The GP fit note was being introduced in 2010 when this study began (DWP, RCGP & BMA, 2010). This replaced the traditional sick note and allowed GPs to make recommendations about a phased return to work. It was decided to add the fit note 'return to work' categories (phased return to work, altered hours, amended duties and workplace adaptations) to the outcomes section of the proforma. However, the OT rarely saw the fit note issued by GPs to stroke survivors and mainly used this section of the proforma to record whether they had participated in a phased return to work. However, as the use of the fit note becomes more established amongst GPs it may still be helpful to include this on the proforma in future studies. It is possible, that following a pilot study of a new form, that allied health professionals may be involved in providing additional advisory notes in the future (Thomson & Hampton, 2012) which means that staff working in return to work services have a greater opportunity to inform and influence the process.

The hierarchy of return to work outcomes (New Hampshire Labor, 2001) was under-utilised in that most participants returned to the same job with the same employer. However, the 'other' category was used to record retirement. If the proforma was being used clinically it would be useful to record outcomes in this way. A mapping study of current provision of support for people returning to work after a stroke in Derbyshire demonstrated that data about outcomes of VR intervention is not routinely collected (Sinclair et al., 2014). However, in a research



study more detailed information about outcomes following intervention would be needed to enhance understanding. In this study, this is included in the feasibility trial chapter.

#### **5.8.3.7 Identifying potentially effective components linked with outcomes**

A large proportion of participants who received the stroke specific VR intervention returned to work. However, the relationship between work outcomes intervention components, and contextual factors is complex and dynamic in nature and the mechanisms of success therefore difficult to determine.

In the current study, early intervention and high level of focus on preparing for return to work and the return to work process coupled with sustained involvement to review and maintain the return to work could be important factors. These took up almost half of the face to face intervention time. Participants interviewed by Lock et al. (2005) concluded that rehabilitation was insufficient in duration and scope to address work issues. Culler et al. (2011) recommended maintaining an ongoing relationship with the workplace for at least 90 days after work return to prevent people dropping out of work due to hidden difficulties which are not always immediately obvious when returning to work. Therefore time spent on return to work planning, monitoring, grading and maintenance meetings in this feasibility study is potentially an effective component ensuring that the successful outcome is sustained.

A large proportion of time spent on work preparation involved teaching pacing and fatigue management. This has previously been highlighted,

in a focus group study, as an important feature of OT intervention enabling work return following stroke (Flinn & Stube, 2010).

Other factors linked with successful return to work include support from others such as supportive social networks and specific professional support (Alaszewski et al., 2007; Doucet et al., 2012) and support from employers in making adjustments to the working environment (Alaszewski et al. 2007, Lindstrom et al. 2009). Providing psychological support and facilitating support from other services, professionals and employers are therefore potentially effective components of VR in this study.

It may also be helpful to look at those who did not return to work and the possible reasons for this. This highlights some of the contextual factors, both personal and environmental, which when combined with stroke severity and impact on ability to meet job demands meant retraining and retirement had to be considered as alternative outcomes.

One person was not working at the time of stroke onset (even though he initially said he was at time of recruitment) and had not worked for some time prior to this. One lost his job at the time of the stroke and reasons for this are not altogether clear. With the help of his son he took his employer to a tribunal and won compensation for age and disability discrimination. He was still keen to find a new job, despite being 70 years old. However, his wife was very unwell with a chronic medical condition and needed his support at home and so was reluctant for him to return to work. A third was made redundant and was working

his months' notice at the time of the stroke. Therefore finding a job rather than returning to a previous job was a bigger challenge and this participant withdrew from intervention without giving a reason and therefore outcome was not known.

Three participants who did not return to work had strokes which impacted severely on their ability to do their previous jobs. One was a self-employed gardener and handyman and his stroke meant he was initially in a wheelchair and only started to walk short distances nine months after his stroke. His upper limb was also affected by severe spasticity and he had very little active movement. He decided he would not be able to return to his previous work, he was financially secure due to insurance cover he had taken out (employment and mortgage protection), his wife had a very good job and also he was eligible for the support category of Employment and Support Allowance and Disability Living Allowance. His longer term plans were to retrain and find a new job, possibly in the area of counselling. This is in contrast to the other person in the intervention arm of the trial who had a moderate/severe stroke affecting him physically and cognitively. He was also self-employed and a similar age to the person described above but successfully returned to work. This was linked to a better and faster recovery which enabled him to return to the IT contract work he did for a large global company on a flexible basis. His wife has to increase her hours at work and they received financial help from her parents to pay their mortgage and support their children until work return occurred.

The second had a stroke which impacted on his speech and ability to communicate (dysphasia) verbally and in writing. He was also in a wheelchair and was unable to walk. He had been a parish council clerk and needed to take and circulate minutes using email in addition to physically laying out the room ready for committee meetings. He decided to retire from this role as he had already planned to retire at 70 and this birthday was approaching 12 months post-stroke.

The third was a self-employed electric meter fitter whose stroke meant he no longer had adequate dexterity in his dominant hand to do this kind of work. He applied for Employment and Support Allowance and then when he became 65 he moved over to Attendance Allowance. His wife was extremely protective and felt that he was working too hard prior to the stroke (50 hours a week) and thought this may have caused the stroke. As a result she actively discouraged him from returning to work.

Previous research has shown that difficulties with communication (Black-Schaffer & Osberg 1991; Doucet et al., 2012), mobility (Lindstrom et al., 2009; Vestling et al, 2003) and reduced function of the hemiplegic hand (Saeki & Toyonaga, 2010) impacted on the ability of stroke survivors to return to work which is borne out by the outcomes in this study. White collar work is also a predictor of return to work success (Vestling et al., 2003) and for two of the above participants, who previously did manual work, this was an important factor preventing them returning.

#### **5.8.3.8 Implementing the model of early stroke specific VR OT**

The model of early stroke specific VR OT (Chapter 3) developed for delivery in this feasibility study has been implemented. It is similar to the case coordination model described by Fadyl and McPherson (2009) in that it integrates VR with medical and other non-VR rehabilitation and offers ongoing support in the workplace. However, in the current study intervention was not only coordinated but also delivered by the research OT.

The research OT did reach into the acute services to recruit patients in the early days following their stroke. She also continued to work with them as they were discharged into the community and after they had returned to work. It is clear from the analysis of the content of the intervention that liaison with other professionals, services and the wider VR team was a key feature of the intervention. Liaison with the employer and family members was central to the original model but in reality did not always take place for the reasons discussed above. The intervention did match the three phases described in the model in Chapter 3 with a focus on early intervention and work preparation, the phased return to work and sustaining work return. The highly individualized nature of the intervention is also evident from the wide range in duration and number of sessions provided.

### **5.9 Limitations and strengths of the study**

The proforma was used by one OT working as part of a funded research project seeing 25 stroke survivors in a feasibility randomised controlled trial. This specialist intervention may differ from VR services

which are embedded in broader programmes of neurological rehabilitation following stroke. However, the way the proforma was adapted using the consensus of an expert panel to include broad headings and subheadings intended to embrace the full spectrum of components anticipated in a post stroke VR intervention suggests it should capture the features of most VR interventions for stroke survivors. Further research is now needed to evaluate whether it can when completed by different therapists in different settings in both clinical practice and research.

The usefulness of previous systematic reviews of the evidence for returning to work after stroke (Treger et al., 2007; Baldwin & Brusco, 2011) has been thwarted by poorly described research, lack of methodological detail and a lack of evidence about which VR interventions are effective following stroke. This study has recorded and described the content of a VR intervention delivered as part of a feasibility trial in a first step towards the identification of active ingredients for a successful return to work and a mechanism for assessing fidelity in a definitive trial.

## **5.10 Conclusions**

This study has shown that it is feasible for a proforma to be used to record OT VR intervention following stroke. It could be used in its current form in clinical practice and with further refinement it can be used in future research studies to describe, in detail, the intervention provided to support people with stroke to return to work. Further

investigation of the relationship between intervention components, contextual factors and return to work outcome is required using a larger sample with a broader range of stroke severity and job skill level in order to identify the active ingredients. Data from this study has demonstrated the implementation of a model of early stroke specific VR OT. The perceptions of the trial intervention from the perspective of stroke survivors and employers who received it will now be explored in Chapter 6.

## **CHAPTER 6 THE ACCEPTABILITY AND USEFULNESS OF EARLY STROKE SPECIFIC VOCATIONAL REHABILITATION: VIEWS OF TRIAL PARTICIPANTS AND THEIR EMPLOYERS**

### **6.1 Introduction**

This chapter describes the qualitative interview study which followed the feasibility randomised controlled trial (Chapter 4). Interviewees comprised a sample of stroke survivors and some employers who received the early stroke specific vocational rehabilitation (VR) intervention.

The voice of stroke survivors has been identified as a key priority by the NIHR (2008) when evaluating rehabilitation interventions. It recommends that involving service users in qualitative research is vital to ensure that future services are relevant, effective and meet the needs of recipients. Existing qualitative studies exploring views of stroke survivors have examined barriers and facilitators to return to work (Alaszewski et al., 2007; Gillworth et al., 2009; Hartke et al., 2011; Koch et al., 2005; Lock et al., 2005; Medin et al., 2006). These studies have revealed mixed opinions about the role of rehabilitation in the return to work process.

Lock et al. (2005) conducted five focus groups with 37 young stroke survivors and 12 family members (mainly partners). They found the rehabilitation process itself acted as a barrier to work return. Reasons included negative attitudes of staff, limitations to the duration and scope



of rehabilitation and rare liaison between rehabilitation staff and employers. In contrast, Koch et al. (2005) in interviews with 12 right hemisphere stroke survivors and 13 of their primary caregivers, found successful return to work was facilitated by employers and health professionals providing emotional support and encouragement as well as information and assistance with implementing reasonable adjustments in the workplace. Medin et al. (2006) in interviews with six stroke survivors, also found support from rehabilitation professionals enhanced the ability to return to work. These findings are supported by Hartke et al. (2011). However, despite variable knowledge of and access to vocational rehabilitation, it was regarded as critical.

Alaszewski et al. (2007) recruited 43 stroke survivors from local stroke services for interview and Gillworth et al. (2009) interviewed 13 patients following stroke about expectations and experiences of return to work but rehabilitation did not feature in their findings, which is revealing in itself. This was because participants did not appear to have had access to the information and support they needed to facilitate a return to work. Early intervention and a focus on work during the rehabilitation process were recommended by the authors.

Employer involvement in VR studies has been largely absent and yet their influence is considered important (Alaszewski et al., 2007; Coole et al, 2012; Culler et al., 2011; Hartke et al., 2011; Lock et al., 2005). Lock et al. (2005), found employer factors including positive attitudes and knowledge of stroke (often linked with first-hand or familial experience of stroke) enabled return to work whereas negative

attitudes, inflexibility, failure to implement adaptations and lack of awareness of disability legislation acted as barriers. Hartke et al. (2011) cite mediation with employer by rehabilitation therapists as one of the critical factors influencing return to work success.

Alaszewski et al. (2007) made a distinction between an undermining and a supportive socio-economic context. The former included negative perceptions of employers and unsupportive managers who did not understand the difficulties caused by stroke. Medin et al. (2006) also found that managers who lacked experience of rehabilitation were less competent in facilitating the return to work process. Coole et al. (2012) interviewed 18 employers, 14 with recent experience of supporting an employee return to work after a stroke. This study highlighted the emotional response that employers can experience as a result of their employee having a stroke and the concerns they may have about them returning to work. These concerns included how the stroke may affect the person's ability to do their job and whether returning to work might negatively impact on their health or potentially cause another stroke. The employers' knowledge and understanding of stroke and disability management was limited. Employers in small and medium sized companies did not have access to occupational health or human resource departments and those who did perceived support received from them as variable. In an American study, Culler et al. (2011) interviewed seven employers, experienced in working with people with disabilities, to explore their views on the barriers and facilitators of work return following stroke. Only a few had experience of working with

people following stroke. Some of these employers described the benefits of having support from VR staff and being educated by them about the specific medical needs of the applicants during the hiring process. Only the latter two studies (Coole et al., 2012; Culler et al., 2011) actually interviewed employers, the other two provided stroke survivors and family members' views about employers' involvement in vocational rehabilitation. Therefore, as the employers influence is perceived to be very important, the views of employers, on return to work after stroke, need to be explored further.

A pragmatic approach has been adopted in the current study. A sequential design was chosen where trial participants and their employers in receipt of VR intervention in a feasibility randomised controlled trial were interviewed to explore their view on the intervention they received.

## **6.2 Aims**

The overall aim of this study was to explore the views and perceptions of stroke survivors and their employers of the trial intervention. More specifically the aims were:

- To evaluate the perceived effectiveness of stroke specific VR from the perspective of stroke survivors and employers
- To ascertain which components of intervention were perceived to be most and least useful in promoting successful return to work

- To determine whether the intervention was useful and acceptable to participants

### **6.3 Research Questions**

- What do stroke survivors and employers think of early stroke specific VR (delivered as part of a feasibility randomised controlled trial)?
- Which service components are most and least valued by stroke survivors and their employers?
- Is early stroke specific VR useful and acceptable to stroke survivors and employers?

### **6.4 Method**

Qualitative interviews were chosen to explore the experiences and opinions of stroke survivors and employers who received stroke specific vocational rehabilitation. This method was chosen to complement the quantitative findings of the feasibility trial. By exploring participants' views of acceptability and usefulness of the intervention, we learn more about how work outcomes were influenced from their personal perspective. Semi-structured interviews allow the interviewer to observe non-verbal behaviour and probe to clarify responses which would not be possible in a postal survey (Robson, 2002).

## **6.4.1 Sampling Process**

### **6.4.1.1 Trial Participants**

Ten trial participants, who had completed or were nearing intervention completion, were approached for interview by an independent OT from a different county and who was seconded to work with the study team one day a week. Two others were purposefully selected as they had permitted direct employer engagement and their employers were also approached. The number of interviews conducted and the stage of intervention participants had reached was influenced by the OTs' availability to interview participants.

### **6.4.1.2 Employers**

Employers of all seven trial participants where there had been direct contact with the research OT, were approached for interview (two employed the same trial participant). Interviews were carried out by two independent OTs working in research roles who were clinically experienced in VR and in interviewing.

## **6.4.2 Instrument**

Separate semi-structured interview schedules were prepared for trial participants and employers (Appendices 4 & 11). The trial participants' interview schedule was the same as that used with case study participants (Chapter 3) and designed to evaluate their experiences of the trial intervention. It was based on existing guidelines for vocational assessment and rehabilitation following brain injury (Tyerman & Meehan, 2004) and other research literature about key tenets of such intervention. This included questions about appropriate timing of

intervention (Wolf et al., 2009), employer liaison (Lock et al., 2005; Culler et al., 2011) and work accommodations (Lock et al., 2005). Additional questions were included about participant's expectations and the elements they found useful or not so useful and suggestions of what else might have assisted in their return to work. The employer interview schedule was based on components of intervention highlighted in a UK mapping study of VR for people with long term neurological conditions including assessment, return to work planning and preparation, provision of timely and flexible support, facilitation of work adjustments, working with employer over time and cooperation with other services (Playford et al., 2011). Interviews were conducted face to face where possible but the option of a telephone interview was offered if this was not acceptable.

#### **6.4.3 Ethical considerations**

Informed consent was sought by the interviewer. Source data was anonymised and stored in accordance with the Data Protection Act 1998 (Great Britain, 1998).

#### **6.4.4 Data Collection**

Face to face or telephone interviews were conducted between June 2011 and February 2013. Each lasted approximately one hour, was digitally recorded and transcribed verbatim. Transcripts were checked for accuracy by the interviewer and analysed together with field notes taken by the interviewer.

#### **6.4.5 Data Analysis**

Interview transcripts were imported into a software package (NVivo Version 10; QSR International, 2012) for organisational purposes. Thematic analysis was used (Braun & Clarke, 2006) as described in Chapter 2.

Reflexivity is important in qualitative research (Finlay, 2002) in order to increase rigour and honesty of data analysis. Reflexivity is defined as thoughtful, conscious self-awareness and reflexive analysis is the continual evaluation of subjective responses, the relationship with the researched and the research process itself (Finlay, 2002).

The research OT and the OT seconded to the project each analysed two trial participants' and two employer transcripts independently to increase rigour. These were selected in the order they were completed. A template of themes was agreed (Appendices 12 & 13) and this evolved as the research OT analysed the remaining transcripts. An independent research fellow looked at emerging themes from a non-health perspective and made suggestions about further subcategories and participant and employer commonality.

A thematic map was created (Appendix 14) to combine the themes from trial participants and employers under four main overarching headings.

### **6.5 Results**

#### **6.5.1 Sample**

All 12 trial participants who were approached agreed to be interviewed and demographic information is summarised in Table 40.

**Table 40. Trial participants interviewed: demographic information**

<b>Code</b>	<b>Gender</b>	<b>Age</b>	<b>Job type</b>	<b>Outcome</b>
RTW1	M	58	Foreman – private sector – F/T	RTW
RTW2	M	59	Self-employed IT consultant – private sector – F/T	RTW
RTW3	M	48	Self-employed – owner and only employee of small business – F/T	Did not RTW
RTW4	M	50	Self-employed IT consultant – private sector – F/T	RTW
RTW5	F	45	Deputy office manager – public sector – F/T	RTW
RTW6	M	73	Self-employed - Owner and manager of small business – F/T	RTW then retired
RTW7	M	61	Clerical officer – Small business- private sector – F/T	RTW
RTW8	F	68	Voluntary work – Adhoc/ P/T	RTW
RTW9	M	75	Voluntary work – P/T	RTW
RTW10	F	79	Voluntary work – P/T	RTW then retired
RTW11	F	45	Service worker - Public sector – F/T	RTW
RTW12	F	57	Professional – Public sector – F/T	RTW then retired

\*RTW = returned to work

Six employers were interviewed and their demographic information is summarised in Table 41. Two employers could not be contacted; one had left the company and the other failed to respond to multiple attempts to make contact.



**Table 41. Employers of trial participants: Demographic information**

<b>Code</b>	<b>Gender</b>	<b>Job type</b>	<b>Trial participant managed</b>
E1	F	Office manager - public sector	RTW5
E2	F	Commercial/ logistics manager - private sector	RTW7
E3	F	Professional/ clinical manager - public sector	RTW11
E4	F	Facilities/ non-clinical manager - public sector	RTW11
E5	M	Service manager - public sector	Not interviewed
E6	F	Human resources manager - private sector	Not interviewed

### **6.5.2 Timing of interviews**

While most participants were interviewed following intervention completion, five were interviewed before the end of their intervention (indicated by negative number). This was due to the availability of the research OTs to conduct the interviews. The range was from 70 days prior to and 266 days after intervention ended (mean 72 days post-intervention, SD 48.75 days).

**Table 42. Time (days) to interview**

<b>Code</b>	<b>Days between end of intervention and interview</b>
RTW1	160
RTW2	266
RTW3	6
RTW4	110
RTW5	-1
RTW6	215
RTW7	82
RTW8	-43
RTW9	185
RTW10	30
RTW11	-3
RTW12	-70
E1	7
E2	77
E3	-4
E4	85
E5	141
E6	54

### **6.5.3 Themes and key findings**

Findings are presented under the four overarching headings of 'Intervention Content', 'Intervention Delivery', 'Intervention Outcomes', 'Intervention Future' (Table 43).

**Table 43. Overarching headings and themes**

<b>Overarching headings</b>	<b>Themes</b>
Intervention Content	Support, provision of information education and feedback, communication with the workplace, perceptions of assessment, the value of a phased return
Intervention Delivery	Continuity, timing of intervention, duration of intervention, accessibility of therapist, knowledge and qualities of therapist, individualised intervention, integration and liaison with other services
Intervention Outcomes	Influence of intervention on outcomes. Influence of stroke on outcomes.
Intervention Future	Who should receive intervention? When should intervention be delivered? Suggested improvements for future intervention. Who should fund the intervention?

#### **6.5.4 Intervention content**

##### **6.5.4.1 Support**

Support, especially emotional support, was highly valued and a prevalent theme in the interview data for both trial participants and employers. This involved the research OT offering validation and reassurance regarding the impact of stroke on the individual, having someone to talk to with stroke specific knowledge who could give feedback on stroke recovery and progress with vocational rehabilitation. Another feature was the connection between this psychological support and instilling confidence about returning to work.

'X's (research OT) been very supportive and she has kept in touch to see that it hasn't actually got me down and I've remained positive and she has checked that from the emotional

point of view that that's been. And to be quite honest I don't think I could have got through without X. And when it all started my husband said to me, when all this was going on occy health and the managers he said do you know really Xs the best thing that's happened to you. With all the support that I've had from her'. (RTW12)

'Because I think you need somebody in the early days, somebody that you can talk to, somebody that – again, you can voice these fears and irrational emotions and things. And I think to go from being discharged from hospital to your six month stage and not having any intervention I think would be very difficult for some people'. (RTW5)

'X (research OT) was very good from the psychological aspect, so there was lots of things that I was really struggling with, like walking up and down the stairs, just when I went out for the first time on my own, because I couldn't drive I had to take public transport and getting on and off a bus was such a challenge because of the weakness in my leg. And I talked to X about that, and she was really good. Just being there, someone to talk to, and someone to explain all these irrational fears and what I thought was perhaps silly, X was saying, no, that's perfectly natural, that's a natural reaction'. (RTW5)

*'So if you had to highlight just one thing that the OT provided you with the service in terms of getting back to work what would that one thing be? The most important thing (interviewer)'.*

'The confidence to do it I think'. (RTW8)

'So I think having that support there from (research OT) was quite useful for me and as to how we were going to manage it as well'. (E1)

#### **6.5.4.2 Provision of information and education**

Trial participants described how they, their employers and families had been given booklets, useful websites and verbal information about the impact of stroke and advice/ education on how to manage specific difficulties experienced (e.g. pacing strategies to manage fatigue). They described how this was offered in a timely way and tailored to their individual needs.

'I think probably at the first meeting with X (research OT) she gave me a whole raft of papers about stroke and how it affects you and tiredness. And I was tired'. (RTW2)

'I felt that she (research OT) knew what she was talking about and if she didn't know then she would research it and have an answer for me next time she came you know like doing that neuroplasticity and stuff'. (RTW8)

'And that's why X (research OT) came with me (to the workplace to meet managers). Because she was – she'd got the

professional aspect of it, she understood stroke and she understood the sort of – the effects it has on people and how strokes vary. So your typical image of a stroke person is somebody in their 70s or 80s that have their arm crooked, in a wheelchair, can't speak, drooling, face dropped. That's the stereotype. And having X (research OT) there it was good for her to explain the sort of professional side and how strokes vary and how they – depending on which side of the brain they hit and where in the brain they hit. So that was good'. (RTW5)

'I know even if she didn't know, she could point me in the right direction, you know. It's having - and then I can explain to the research OT, it's having those signposts available that helps a lot because even, okay, I can go and do a search on Google, but trouble is, it gives you so many choices, where do you go? Which one do you take as the right one, you know, whereas if you speak to somebody who's had that experience and, like I say, definitely oh right, yeah, need to go there, speak to such and such, and this is what you do. And that's a great help, definitely, yeah'. (RTW3)

'No, you see because the children aren't at home I'm sure they did meet her but my daughter lives in X so. But she would give me, if she thought there was any literature that was good for them to read. And for like my mum and dad for them to read but I suppose it was mainly me'. (RTW12)

Employers also explained the value of the information they had been given and stated that they would have found sourcing information difficult if the therapist had not been involved. Some explained that they would have only had information obtained from the internet and been uncertain about its validity.

'I mean (research OT) did give me quite a lot of documentation about understanding stroke, which was useful because I read in there that obviously it can cause extreme tiredness. It can go on for 18 months or even more or longer and all the different things. So that was very useful because I didn't know what - really what a stroke holds other than it can be very devastating. It can take people's speech. It can take the use of your limbs and what have you. But I didn't understand the other things, the recovery part. So I think (research OT) was very useful in the fact that she gave me the information that I needed what I've got to expect, what we needed to realise, what our expectations could be of her coming back to work'. (E1)

'Yeah, I mean I think the stuff, the documentation she gave me was very useful. I think that was a good idea because I don't think anybody, you know, realises exactly what it entails, what it is. And I think to do that, obviously it sort of lets managers be more aware. You need to be aware, and I need to know. I mean you know, which she then needs to say to me if she's not having a good day, you know, say look I'm really, really tired, then that is

fine and at least I know as a manager, yes, well I think you probably need to go home, you know' (E1).

#### **6.5.4.3 Provision of feedback**

The importance of the therapist providing ongoing and regular feedback on progress in the journey back to work was highlighted.

'Well knowing that there is somebody that they don't just see it as a stroke and make you realise that you're getting on, you can get on and get things back and that you are in control really'.  
(RTW12)

'It was really mainly aimed at what progress had I made since she last saw me that would enable me to go back to work'.  
(RTW9)

'And I'd keep reporting what had happened in the last month or two weeks since we last met and she says, "Yes, that's good, but try doing this and trying doing that." Yeah.' (RTW4)

Providing feedback may have also played a part in increasing motivation levels as indicated in following quotation.

*'So how do you think it would have been different if X (research OT) hadn't been involved? What do you think might have happened?'*  
*(interviewer).*

'Well I would have spent more time sitting here just twiddling my thumbs, doing nothing'. (RTW1)



#### **6.5.4.4 Communication with the workplace**

The importance of keeping channels of communication open with the workplace and liaison to negotiate phased return to work and workplace accommodations was highlighted by employers.

'We used to have meetings and things were discussed or any issues I'd got or she'd (employee) got. And sometimes the service manager would be involved in the meetings. And then we would always get written documentation back from X (research OT), which obviously I've got all of that in her (employees') file'.  
(E1)

'No I didn't ring her (research OT) because I knew when she was going to give me a ring and I was just making notes for the telephone conversation, or I knew when she was coming in and then I'd say it in front of everybody anyway if I'd got a concern with X (employee) and he would be there when I said it, so he was well aware what my concerns were'.(E2)

In one instance communication had been difficult before the stroke and continued to be difficult during the period of sick leave (E3 and RTW11). Therefore the research OT took on a mediation role, with consent from both parties, in order to maintain contact with the workplace prior to meeting up to plan a phased return to work.

'She (research OT) phoned me when X (trial participant) was off sick and explained where she was and what she was doing with X and about how she was working closely with X. And from then

onwards we would keep in touch regularly. If I was unable to get in touch with X I would speak to the research OT and she was always sort of giving me updates on how X was actually doing’.

(E3)

‘She was very good at coordinating was the research OT because there was a couple of times I couldn’t get in touch with X and I could get in touch with the research OT and it was like a case of can you get in touch with X. This needs to happen. So she was very good at coordinating and like a go-between as well’. (E3)

‘And it kept the communication going as well. Otherwise if we hadn’t had the research OT I don’t think we would have had good communication and I think that would have broken down’. (E3)

#### **6.5.4.5 Perceptions of assessment**

Participants gave mixed and sometimes conflicting responses about whether they had been assessed by the research OT. The first two quotations from the same trial participant demonstrate this point.

‘We didn’t do any assessments, not that I can remember, we didn’t do any sort of assessments’. (RTW5)

‘She asked me what my job entailed. She came to look at the workstation that I work at, and where – she did do a sort of assessment, an ergonomics assessment of my desk, and where the files were in relation to where I was sitting and things that I

would need around me, she did an assessment of my area of work. And said, we need to change this and we need to do this. And then she'd go – she went to see X (manager) and said, I think we should change the position of this, and can we move these? So she did that before I came back to work, she wanted to instigate these changes ready for when I came back. But at home we didn't really do any practical type things'. (RTW5)

This uncertainty may have been connected with participant's perceptions of what the word 'assessment' meant in terms of whether it was formal, such as an assessment of cognitive function or discreet, for example where the therapist's assessment was observational.

'Yeah, it was very informal, and I think she just came to the conclusion that I was quite compos mentis and that I was – it hadn't affected me in that respect'. (RTW5)

'She thought I'd got cognitive problems and she was having me assessed for that'. (RTW11)

*'Did the research OT go through those assessments as well or how did she sort of begin her work with you?' (Interviewer).*

'You know I can't remember whether X (the research OT), I think that now that you've said probably at the start and then as time went on she would just sort of say can you do this or that? But not like on a set, not a rigid thing. It would be something that came into conversation'. (RTW12)

Employers, including employer of RTW5 (E1), explained the workplace assessments the research OT had completed and appeared to be clear about their purpose and the way they had informed the return to work plan.

'Well I think she certainly did a lot of research within the office to see where she sat, the sort of jobs that she was doing. She was involved in how she was going to get to work, obviously because there's that issue, the journey to work from work. Yes, she was, again, quite a bit of input to see what sort of things that she was doing. Was it appropriate, you know, obviously because she does do a desk job so it is'. (E1)

'Yes she did she came up to see the unit and what she was going to be working on...and helping the managers to look at what that person is able to do and are they coming back to the right area'. (E3)

#### **6.5.4.6 The value of a phased return**

A highly prevalent theme was the perceived value of going back to work gradually on a phased return.

'And I just went back one day a week to start off with and then built up to three, four, five. And by the end of, no the start of July I was able to work full time. I did full time in July and August, we were very busy, but then worked dropped off a little bit so I've taken the opportunity to go back to four days a week and that's where I am currently. And I do it as three full days and two half

days. And they're very accommodating. They let me do the full days in the office and half days from home'. (RTW4)

'I was off three months and I went back a couple of days a week, then three days a week then four days a week, then back to five days a week'.(RTW7)

In some cases participants described how they had discussed this with the research OT prior to meeting their manager and how the phased return had been negotiated and regularly reviewed.

'It was through talking to X (research OT), and then she arranged a meeting at work'. (RTW1)

*'And what was the outcome of that then? Were your employers supportive about what you were saying?' (interviewer).*

'Yeah. They were fine about it. They said it would be better going back part time to start with until I got back into the swing of it. We did that for a couple of months, then it changed back to full time after that. But X (research OT) used to come every two weeks she used to come to work for me to meet the managers as well, all the way through'.(RTW1)

Another participant commented on how helpful colleagues had been during the phased return to work and attributed this to them being aware and involved in the process.

'I think the fact they were involved from day one, practically in what was happening and they were aware of what was going on, so they felt part of it as well'. (RTW7)

This participant went on to explain that he probably would not have been offered a phased return if it had not been for input of the OT explaining what was happening to his employer and colleague.

The employer of one participant (RTW5) felt that their employee lacked insight into what was realistic as illustrated by the following quotation.

'At the end of the day I think probably both (research OT) and I both felt we weren't either of us given much input with it (return to work plan) because she'd already done her own schedule! And although we did say, and we did have to pull her back a bit because (research OT) seemed to think it was a bit too much too soon, and so she (trial participant) agreed to make some adjustments to it, which I agreed to, and I thought was just - it was just not doable after what she'd been through, but I don't think she realised herself, or she wasn't prepared to'. (E1)

The employee of E1 (RTW5) gained insight about what was realistic through experience and modifications were made in response to this.

'After building – extending my working day and then going from three days to four days, and then I did do five days, but short days. So I think I did something like 9 until 3. But doing five days, 9 until 3, was too much. So then I spoke to X (research OT), I

said, I'm really struggling, I'm finding it really hard. So then X (research OT) came in and we sat with my managers again and said, actually, can we re-negotiate this?'. (RTW5)

Another example of the research OT working with the trial participant (RTW11) and employers (E3 & E4) to manage the pace of the return to work to make sure it was right for the individual is illustrated in the quotations below.

'X (research OT) was able to; she knew exactly what level Y (trial participant) was able to do. What she was capable of. So if we were saying well no we don't really want you to do that Y. Let's pull you back and you're maybe trying to do too many hours too quickly. I remember she was wanting to do a full day quicker than what. We were saying look, you've got all this time. We can think about it'. (E3)

'I think those meetings (monitoring return to work) were fab. Yes and seeing what we could do to change anything if we needed to. It was great'. (E4)

Phased returns did not only involve gradually increasing hours and days but also increasing the level of duties and responsibility.

'A lot of the responsibility was taken away from me initially. I'm only just starting to take back some of that responsibility. So initially I was given light duties, sort of shuffling papers basically'. (RTW5)

'..we did kick back with her quite a lot on the tasks that she was doing, so that they weren't too stressful. She wasn't put in any stressful situation really. So we've sort of adjusted her role to accommodate her. And it's an ongoing process'. (E1)

'So to start with I didn't do the days together. I'd do like Monday, Wednesday and Friday. And then we started making the days longer. I did so many weeks at Monday, Wednesday, Friday half day and the days went on a bit longer. I didn't start at half past eight. I started maybe half nine, then nine, then slowly bringing that in. And then we would look at maybe doing two days together. And you know do it, take it like that and me slowly taking charge of the team again'. (RTW12)

'Well initially, how we had planned it was that we didn't bring her back here initially. We took her to another area to work to see whether or not she was going to be able to work full stop. Because it was the communication. Cause she has to do a lot of communication skills. How was she going to cope with even say light duties? So there was no point bringing her here onto a heavy unit throwing her in at the deep end'. (E3)

When asked about the costs to the company of a phased return the response below from one employer indicated that budgets allowed for this and it was considered to be a reasonable adjustment.

'Yeah but it's all about, we are committed to a great place to work and colleague engagement and it's about making that



reasonable adjustment to get somebody who has got a disability or needs a bit of extra help back into work and it all comes out of the labour budget and I would imagine somebody, somewhere in an office has built contingency in for that. It's part of X's (company name) policy'. (E6)

## **6.5.5 Intervention delivery**

### **6.5.5.1 Continuity of the intervention**

The continuity of the intervention from in-patient stroke unit to home and then into the workplace was perceived as a positive feature.

'My main memory of the time spent on it (intervention) is positive, I enjoyed being part of it, I enjoyed the continuity of seeing X in the hospital and then out at home. And she was very encouraging and it did help me all the way through to, yes, to keep improving'. (RTW4)

### **6.5.5.2 Timing of intervention**

For most participants, the timing of the intervention was considered appropriate but for one person with a severe stroke and with cognitive difficulties it was perceived as too early.

'Well I think it (intervention) ought to be offered because it's very good, especially the first couple of weeks when you're on your own afterwards, somebody comes in and talks to you, helps you'. (RTW1)

'I mean myself personally I'm happy to help with anything like this so I'd probably have said yes at any time that the research OT had approached me. But thinking about it, it was only really in the last week of my six weeks in hospital that I was anywhere coherent in any way that, you know, I could feel that I could give good information'. (RTW4)

'So for me, I hadn't got the confusion that some people have. So for me it wasn't too early but I think it could be for a lot of people you know'. (RTW8)

'So I'd always had sort of unspoken targets that I wanted to meet. I suppose just in the back of my mind that kept me going really. But I think as I progressed and saw how slow the process was to get back because of how severe the stroke was and me not realising in the early days that it had been so severe, I sort of obviously started changing those long-term goals, thinking okay, maybe, hopefully next year. Or then, even now, I'm not thinking of next year now. I'm thinking probably the year after'. (RTW3)

### **6.5.5.3 Duration of intervention**

The intervention duration was tailored to individual needs and most people appeared satisfied but one felt it could have been shorter and another felt it was not long enough to support a return to work (see quotation in above section). This was connected in each case to stroke severity.

'Yes, as I say, I mean certainly the last couple of visits from X (research OT) certainly weren't necessary, but having said that, they were still very nice to have. But for other people, yes, maybe you need a lot longer'. (RTW2)

One employer would have liked liaison with the research OT to have started earlier and involvement to be sustained over a longer period. In the case of E6 the employee was a university student and a part time worker who prioritised her return to university and this was the reason the intervention with the employer at her place of paid work was delayed.

'I think it'd have been useful if (the research OT) had have come on board early on'. (E6)

'It (a review following return to work) would have been useful yes because if there'd have been any issues or anything that I, because when they first came back obviously there were in an HR environment so we were very sort of cotton woolly and are you okay and you know, this is what you need and I was conscious that I didn't want to over stretch her but on the same, I didn't want to be condescending either'. (E6)

In the latter situation the OT asked the employee if she wanted a review but she did not feel it was necessary as she was not experiencing any difficulties at work, therefore a review did not take place.

Two employers explained that liaison with the research OT had been brief (one and two meetings respectively) and they perceived the research OT to be checking on whether they were following the correct legal procedures and providing reassurance that they were doing the right thing for their employees.

'..thinking about it, it felt like I'd got a union member there saying well you know well why is she not getting this money and why's she not like...? I felt she was checking to make sure I wasn't fiddling her out of any money. That's a bit how it felt'. (E6)

'Well the impression I got of her was the professionalism she was demonstrating I thought she would have been you know, she'd have been on me like a rat up a drain basically if something was going wrong'. (E5)

'And I did get the reassurance that I was actually doing the right thing for the colleague. That was what I thought but I wasn't, you know I'm not a doctor or nurse'. (E6)

Ending intervention by gradually withdrawing was seen by most as acceptable but for one trial participant (RTW5) the anniversary of her stroke and the ending of intervention coincided and this was difficult to manage psychologically as highlighted in the quotation below from her manager (E1).

'She has tailored it off and I'm aware of that and I'm happy for her to do that'. (RTW11)

'It was too much for her, (research OT) pulling back, and it was the year, so they need to either be doing it before or not'. (E1)

*'Yeah, tailor' (interviewer).*

'Yeah, I think so. But that was just for that person. Other people, it might not affect them like that'. (E1)

#### **6.5.5.4 Accessibility of therapist**

Participants and employers perceived the research OT to be accessible via phone and email and this appeared to be linked with the perception of being/ feeling supported.

'She was always available if I needed her, either via email or I could ring her'. (RTW5)

'She explained what she was going to do and if I had any problems. Not to be scared to get on the phone or get in touch with her somehow'. (RTW7)

'She (research OT) has said I can ring her, so I have got that and I have certainly got her card. And I do feel comfortable at doing that if I needed to'. (E1)

In contrast the quotation below from the same employer indicates that they thought the therapist was only acting for their employee but acknowledged they also needed support.

'I have to say, that wasn't made clear to me. I thought she was totally there just for my member of staff. But actually I did feel

that, at the end, at the end of it, I realised that actually I could have fed into it if I needed to. But then how much do you put onto one person? You know, you've got to - you know, but again sometimes managers do need support in getting these people back in'. (E1)

Participants also felt their partners and family members could access support from the research OT.

'Yes and she wasn't too pushy, wasn't too much in your face. But she said if you need me or if you feel that maybe you need my help or maybe X (your wife) needs my help as well. Cause she involved you (wife) in conversations'. (RTW7)

#### **6.5.5.5 Therapist's personal qualities and knowledge**

Participants talked about the personal qualities and knowledge of the research OT during the interviews in a positive way.

'She was very understanding'. (RTW1)

*'Can you describe what you mean by sympathetic? What did she actually say?'* (interviewer).

'Well, attitude, you know, it was – yeah, she was – she's got that gentle manner with her, hasn't she, like reassurance'. (RTW6)

'Yes I could relate to her, very much so'. (RTW8)

'Yeah it's knowing that you've got someone there and you know that you can trust her. She will get back to you'. (RTW11)

'Apart from an OT she also became a friend. If I needed something which I didn't, I knew I could have picked up the phone and phoned her'. (RTW7)

#### **6.5.5.6 Individualised intervention**

The data from the interviews demonstrates the many ways in which the intervention was tailored to individual needs and one participant was able to articulate this due to the nature of her own job.

'I'm sure it's like district nursing. People are individual so you have to tailor what you're doing. So I think X (the research OT) met my needs what was right for me when she could be doing something completely different with another person. But for what I needed and because the sensory thing has been my biggest problem then you know she helped with that'. (RTW12)

#### **6.5.5.7 Integration and liaison with other services**

Trial participants described other services they had received, including input from their general practitioner and other rehabilitation professionals. Some of these were part of usual care and referrals to others were initiated by the research OT, for example, clinical psychologist. The research OT liaised with other services and coordinated care, with respect to return to work, in more complex cases.

'Yes I think the research OT was and still is involving everybody'.  
(RTW11)

'As I say, the majority of the support has been from X (research OT), but I've also had Y (out-patient OT) there and the intermediate care. So from my point of view, I've had a lot of support'. (RTW5)

In the workplace, the research OT attended occupational health appointments and meetings with human resources and trade union representatives on some occasions as part of the intervention.

'I think Y (trial participant) went to the doctor's and the doctor was going to sign her back to work and X (research OT) then, obviously she can't be signed back to work. She has to go through occy (occupational) health and she (research OT) was very good at sorting that out as well'. (E4)

Two examples of cross sector working are when the research OT involved a disability rights adviser from the charitable sector to support a trial participant at return to work planning meetings and when she accompanied another trial participant to an appointment with a disability employment adviser.

## **6.5.6 Intervention outcomes**

### **6.5.6.1 Influence of intervention on outcomes**

Participants expressed views on how the intervention influenced their journey back to work. Some felt they returned to work sooner due to the intervention, others felt they would have rushed back and failed to sustain their return to work without the intervention. Some felt the outcome would have been the same without intervention and others



(stroke survivors and their employers) felt they would not have returned to work without the intervention (RTW11 and E4). Most were aware that the research OT had helped them identify a realistic return to work date which involved challenging their own perceptions at times.

'I don't think I'd have got there as quickly. I think I would have got there, returned a bit later'. (RTW4)

'I'd have got back but I probably, I'd have pushed myself to go back probably too soon if they let me'. (RTW7)

'And I think the people that weren't randomised into the trial, I think – again, maybe that would have been too late, because you'd have sat at home on your own for x amount of weeks, not being able to talk about these things and not knowing where to go and what to do. So it's very difficult. It would be interesting to see the results from the people that weren't randomised into the trial and how they coped. And whether it's different from my experience. I'm sure it would be'. (RTW5)

'It's a very difficult journey, and I don't think people appreciate how hard it can be sometimes. And that's what I'm saying about if I had not had the intervention, how would I have coped with coming back to work and all that, the challenge of coming back to work, the challenge of learning to walk again, the emotional and the psychological side of it. And I just think for some people that would be too much. I don't think they would ever get back to work'. (RTW5)

'No I think I found my own way back but certainly I think she (research OT) gave me the help to pace myself and not to worry if I couldn't do it and to encourage me to do something, carry on doing it you know, that it would get better. So you know, it was just for me, I was really pleased she came'. (RTW8)

'I wouldn't be back at work today without X (research OT)'.  
(RTW11)

*'And do you think you'd have had the same result? Do you think you'd be where you are now? It's a hard one isn't it?' (interviewer).*

I don't actually. I think, no I don't. Without X's (research OT's) support no I don't because as well I also felt I gained, I got confidence. Just knowing that she was about really and that she would like talk about things and ask me different things that would make me think and possibly put things in perspective'.  
(RTW12)

'But I don't know how, if they would have returned as quickly as what X (RTW11) has done because of the support that she was getting from the research OT'. (E3)

*'I know this is a hard question but do you think if the research OT hadn't been involved X would have still achieved the same outcome? If we'd taken her out of the equation' (interviewer).*

'I don't think X (RTW11) would have come back to work to be fair'. (E4)

### **6.5.6.2 Influence of stroke on intervention outcomes**

For one participant the stroke impacted on his ability to return to his previous job and so he was considering alternatives.

‘And in the early days I felt I wanted to go back to the gardening. But as time's progressed, that's - my mind's changed a little about that because one, it's a very physical job, and we don't know how - what my stamina's going to be like. And being able to sit, take a back seat for a while and see how awkward the British weather is and what I just have to deal with, I've looked out some days and I'm thinking thank god I'm not out there working. And slowly I've moved away from wanting to go back outside and think well, one, I'd like - I probably ought to go back into a paid job, employment that gives me more security and out of the elements’. (RTW3)

Another participant decided to retire as he felt he was not able to do job to the standard he had previously achieved due to the physical and cognitive impact of the stroke.

‘The coordination was terrible. Even now I have difficulty – although I'm not left handed, moving this left hand round properly. Like if I'm winding a perm or something like that’. (RTW6)

‘Yes. And I still forget things. I mean, last night I was supposed to – I have a little netbook I'm supposed to key into it every day. I forgot my user number last night, and I've been thinking about it,

and I still don't know what it is. I get these blank spots which I never used to. So I think that's one of the reasons I had to pack that up'. (RTW6)

## **6.5.7 Intervention future**

### **6.5.7.1 Who should receive the intervention?**

A few participants who had had minor strokes valued the intervention but did not feel they needed it.

'So there was very little that I actually need, well I needed nothing, but it was very pleasant to have the research OT to talk to and get the feedback from her on how I was doing'. (RTW2)

Whereas other participants felt it was a service that should be available to all stroke survivors.

'I think it's something that everybody who has had a stroke should take the benefit of somebody who's impartial but is able to stand up for you when you feeling at your lowest'. (RTW7)

Not all participants had defined cognitive or physical deficits but they had hidden disabilities such as low mood and reduced confidence and were able to utilise the benefits of psychological support offered in the trial.

### **6.5.7.2 When should intervention be delivered?**

From data analysed under the previous theme of intervention delivery (timing) there is a sense that early intervention is needed to keep the door to an employer open, increase the impetus and give a sense of

direction to the journey back to work. However, for some the therapist only needed to keep in touch initially, keep work on the agenda and only increased the intensity of intervention when the person was ready to do so.

‘Just to say that I think whilst it was good to have X introduce herself very early on, to actually talk about going back to work was not priority. So I think maybe the explanation and what they're hoping to achieve is good, but then maybe take a back seat for a month or two’. (RTW5)

### **6.5.7.3 Suggested improvements for future intervention**

One participant would have liked more formal assessments to provide objective feedback on improvement.

‘I think you should do more formal type assessments somewhere along the line, of what people’s abilities are at that point in time. I'd like to know how I was improving’. (RTW8)

*‘Yes’ (interviewer).*

‘Because at no point was there any formal assessment’. (RTW8)

Another participant would have liked more detailed information about post-stroke fatigue.

*‘Was there anything that you felt she didn't address with you at the time?’ (interviewer).*

‘No, I don't think so, except perhaps not enough detail’. (RTW10)

*'Right. Okay. So what sort of things would you have liked more detail about?' (interviewer).*

*'The tiredness, the cause of it, how long it's likely to last and what you can do to stop it lasting that long'. (RTW10)*

#### **6.5.7.4 Who should fund the intervention?**

There were mixed views about who should and could fund and run this kind of return to work service in the future.

*'I suppose a more difficult question is if there was that kind of service for everybody who'd had a stroke, you know, a (research OT) for everybody that was going back to work after a stroke, who do you think should fund such a service?' (interviewer).*

*'In an ideal world it should be the NHS!'. (E1)*

*'With the service that he had from (Research OT), this is a study that's being tested through the NHS at the moment, but if that service had been available but you would've had to pay for it, who do you think should supply that service and should it be the NHS or would you be willing to pay for that kind of service?' (Interviewer).*

*'Ah .. that's a good one! I think that... having gone through it now... oh I'm going to have to say the NHS'. (E2)*

*'Because even now I'm not so sure that we would as a company have paid for it, which is a bit unfair and then you can't put it onto the patient because they've had the stroke'. (E2)*

'But you do - I mean it was there when we needed it. We didn't know it was there previous but it's been very, very helpful - but as to whether the company would pay, I mean I don't know whether it was a small amount towards it, maybe, because if it's going to get that person who they want to continue to employ back into a position that they can do their job then it's got to benefit the company hasn't it?'. (E2)

*'Would you expect that is X's (research OT's) role was offered by the NHS would you expect that you'd be seeing somebody that regularly?' (Interviewer).*

'I'd like to see someone but I don't think the NHS would allow it'.  
(RTW11)

## **6.6 Discussion**

This study offers a unique insight into the perceptions of 12 stroke survivors and six employers of their personal experiences of a stroke specific OT led VR intervention.

### **6.6.1 Perceptions of intervention content**

The most valued aspects of intervention content were support (especially emotional support), provision of targeted stroke specific information, education and feedback tailored to individual needs, keeping channels of communication open between the stroke survivor and the workplace and the planning, implementing, monitoring and reviewing of a phased return to work. It is evident that the provision of stroke specific information and education filled the possible gap in

knowledge for employers that was highlighted in previous research as a difficulty (Alaszewski et al., 2007; Coole et al., 2012). Medin et al. (2006), in their qualitative study of stroke survivors, found that support from rehabilitation professionals and flexibility in the workplace enhanced their ability to return to work. The worksite planning and review meetings described by participants in the current study may have increased flexibility with regard to phased returns and making adjustments to enable and sustain work return. Lock et al. (2005) highlighted the importance of liaison between rehabilitation professionals and employers but said it rarely occurred. The provision of feedback on progress is not mentioned in previous studies but appears to play an important role in sustaining motivation for some participants in the current study. Regarding communication with the workplace, one participant from the study by Medin et al. (2006) reported that no dialogue with the manager about returning to work had taken place whereas this was a highly valued feature of the intervention in the current study. This difference may be because in the study conducted by Medin et al. (2006) the primary focus of rehabilitation was restoring bodily functions and a return to activities of daily living rather than promoting return to work but in the current study the primary focus was VR including employer liaison. Gillworth et al. (2009) found the absence of clear guidance and an uncertainty about the most appropriate time to return to work but this study also reported support from an employer for a phased return to work had been effective in facilitating a successful return to work. It appears that employers see



the costs of a phased return to work as a reasonable adjustment which is part of organisational policy and something that enhanced their reputation as a good employer. A report by the Royal National Institute for the Blind (Connolly, 2011) makes the business case for a work retention service and argues that it is cost effective using case studies to illustrate this point. They declare that 92% of respondents in a survey they conducted would have stayed in work if intervention had been offered and adjustments made. However, the number of people surveyed is not stated.

Mixed perceptions about whether assessment had taken place were possibly linked with preconceptions about what 'assessment' involved and its perceived formality. Stroke survivors may equate assessment with formal tests whereas employers appeared to be clear that assessment of the workplace, individual and job were being carried out by the OT during a visit to the worksite. Standardised questionnaires completed as part of the baseline data collection were not perceived to be formal assessments even though the therapist drew on this information to inform intervention. In some cases additional standardised cognitive tests were used as part of the intervention. They included the Rivermead Behavioural Memory Test (RBMT-3) and the Behavioural Assessment of the Dysexecutive Syndrome (BADs). The OT also assessed people informally in reviewing their progress at the beginning of sessions and through observation which was recognised by some participants. These informal assessments contrast with the routine use of functional capacity evaluations in VR in other countries

and in the independent sector in the UK. Functional capacity evaluations are a battery of tests used to measure a person's ability to meet job demands. They are used in work injury rehabilitation in North America and Australia (King et al., 1998; Mitchell, 2008) where insurance companies and the legal profession use the data to decide whether a return to work is possible and to decide compensation when it is not. Functional capacity evaluations are also commonly used in Germany (Streibelt & Bethge, 2013) as part of work-orientated medical rehabilitation for people with chronic musculoskeletal diseases. However, their use in stroke rehabilitation in the UK does not appear to be documented.

#### **6.6.2 Perception of relationship between therapist and employers**

It is possible there was a lack of clarity in the mind of some employers about whether the therapist was there to support the stroke survivor/employee or the employer as well. This may be due to the way the therapist introduced herself at initial meetings and how she described her role and this would need to be made clearer in a definitive trial. It may have also been related to the way managers had previously liaised with occupational health and human resources or OTs deployed by occupational health companies, where the OT is working on behalf of the employer. One manager who was interviewed preferred to manage the return to work process herself whereas another involved these departments directly in planning the phased return. Both managers were employed by the same large public sector organisation. The

therapist, in this study, aimed to promote transparency which meant that three way meetings were held and so it was rare for the therapist to speak to the manager on their own. However, it was made clear that the manager could call or email the therapist if needed and a business card was always provided at the first meeting. One manager in a small private sector company took up this offer. Therefore the size of the organisation and availability of support within it can be influential factors in return to work as previously described (Hsieh & Lee 1997; Alaszewski et al., 2007; Hannerz et al., 2012a). Size and type of employing organisation can affect the process in positive and negative ways. Interviewees in the study by Alaszewski et al. (2007) said large employers could operate bureaucratic procedures which can slow the process down whereas Hsieh and Lee (1997) and Hannerz et al. (2012a) found they offered greater job stability and the facility to make job modifications. The key factor for return to work success in studies by Doucet et al. (2012) and van Velzen et al. (2011) was the availability of occupational health provision. In a definitive trial it may be helpful to provide a leaflet which clarifies the role of the therapist with the employer. The two managers where there had been limited contact (e.g. one or two meetings), appeared defensive as if they perceived the role of the therapist was there to ensure their legal obligations to make reasonable adjustment were being fulfilled. The brief intervention possibly prevented rapport being established. Therefore an increase in number of meetings held with employers might influence the type of relationship formed between the OT and the employer and the potential

for collaborative work to ensue. This may, in turn, impact on the return to work experience and outcome. However, the perceived role of the therapist as an advocate for the employees in this study did not appear to negatively impact on outcome and may in some instances have been necessary in order to negotiate suitable conditions for return to work (e.g. a longer phased return to work than the company normally allow or a graded increase in work load) which potentially enhanced the probability of the return to work being both successful and sustained.

### **6.6.3 Perceptions of intervention delivery**

The most valued aspects of intervention delivery were continuity, accessibility, personal qualities and knowledge of therapist, individualised intervention and liaison with other services. However, for some, the timing and duration of the intervention were not appropriate to their needs and this appeared to be linked with stroke severity. For those with more severe strokes or cognitive difficulties it began too early and did not last long enough. Lock et al. (2005) had previously highlighted the importance of rehabilitation staff having positive attitudes combined with longer term engagement to facilitate return to work following stroke. Medin et al. (2006) said cooperation between different rehabilitation professionals was very helpful but only two out of six participants had experienced this. Personal qualities of a therapist and a perception that the therapist is caring have been recognised as being more valuable than technical expertise (Peloquin 1993; Palmadottir, 2006). Peloquin (1993) presents the results of a previous inquiry into the challenge of creating a climate of caring within a climate

driven by demands for efficiency and productivity by analysing personal narratives. She concluded that OTs providing personalised and meaningful intervention tailored to the needs of the individual must take time to get to know the patient as a person and this was commended in the current study. Palmadottir (2006) explored clients' perceptions of the relationship they formed with their OTs, in the context of rehabilitation, in a qualitative study where 20 people with various health problems were interviewed. The author states that the therapist must explore what form of relationship each client prefers in order to establish an effective, collaborative partnership.

Other aspects of continuity and accessibility were possible because the intervention provided was part of a trial and thus not constrained by a health care system. It could be delivered in a more flexible way including use of a mobile phone and email and accommodate flexible appointment times (e.g. early evening to see partners who were working full time). Another aspect of flexibility is the ability of the therapist to liaise with others and cross service/ agency boundaries which appeared to contribute to the effectiveness of the intervention. This model of intervention is described in chapter 3.

#### **6.6.4 Perceived influence of intervention on outcomes**

Participants, both stroke survivors and their employers felt that the intervention itself influenced the outcome in a number of ways including the timing of return to work and whether or not they returned. Doucet et al. (2012), in a postal survey looking at work status three years after in-patient rehabilitation, concluded that specific professional support and

close cooperation between rehabilitation and occupational health services was needed to speed up return to work for stroke survivors. This need for inter-organisational collaboration has already been highlighted in the field of work disability in connection with musculoskeletal disorders. Loisel et al. (2005) conducted an observational study analysing videotapes of interdisciplinary team discussions about their case work. Strategies, most commonly education and awareness raising, were used by the teams to encourage collaboration. The confidence the stakeholders had in the work rehabilitation plan and process were key influencing factors. Stakeholders' perception of the therapists' credibility and expertise was crucial to successful outcomes. It is possible that in the current study the way the knowledge and experience of the OT was perceived by the stroke survivors and their employers and the confidence this gave them in the process and plans for return to work could have been highly influential in the outcome. The competencies of return to work coordinators were identified in a review of 40 trial and intervention studies in the fields of musculoskeletal, work injuries and traumatic brain injury (Shaw et al., 2008). The ability to facilitate communication and agreement between stakeholders was seen as a potentially greater influence on outcome than knowledge of medical conditions. However return to work coordination was only one component of intervention delivered alongside medical case management and multidisciplinary rehabilitation. In the current stroke study, the OT acted as both a return to work coordinator and a provider of VR hence the skills of

collaborative communication and using medical knowledge were combined to coordinate and deliver the most appropriate services to meet the individual needs of each participant.

There is currently a lack of research evaluating VR following stroke from the survivors' perspective and so this study was much needed. The model of early stroke specific VR was regarded as useful and acceptable by stroke survivors and their employers in this study. Loisel et al. (2001) discuss the concept of a 'golden hour' for preventing low back pain disability and conclude that intervening during the subacute phase of back pain is essential. It appears that early intervention following stroke was also important for most stroke survivors interviewed in this study. However, one participant felt it was possibly too early and envisaged longer time scales than the trial allowed, for them to return to work.

The impact of stroke on return to work outcomes is well documented in previous research. In qualitative studies, stroke severity meant a return to work was not realistic for some (Alaszewski et al., 2007) and factors including fatigue, communication difficulties, poor concentration and memory problems affected return to work success. Lock et al. (2005) also cited fatigue and memory problems as factors preventing work return. In quantitative studies, Lindstrom et al. (2009) and Saeki & Toyonaga (2010) found higher levels of physical dysfunction impacted on return to work probability. Some of these factors affected participants in the current study in preventing work return or in precipitating

retirement. However, it would be simplistic to regard these stroke factors in isolation. Loisel et al. (2001) introduced the disability prevention paradigm in the field of occupational back pain. They looked at evidence from the previous two decades and concluded that the causes of disability are not unique to the person's personal characteristics (physical and psychosocial) but rather the person's environment including the workplace, compensation system and healthcare delivery system. The one self-employed person who did not return to work interviewed in the current study was financially secure due to employment insurance, benefit provision and critical illness insurance which covered mortgage payments. The two participants who returned to paid work and then retired were also financially secure and pensions were not affected due to their age. This paradigm has great resonance with the ICF (WHO, 2001) which also considers the impact of the interaction between impairment, environmental and personal factors on an individual's ability to undertake activities and participate in society. So the ICF framework, usefully underpins the model of intervention adopted in this study which looks at ways the impairment following stroke and specific personal and environmental factors can be tackled to overcome the barriers to participation as a worker in society. Therefore it is an adaptive form of rehabilitation.

#### **6.6.5 Funding and future provision of intervention**

There were mixed opinions about who should fund and receive this kind of service in the future. These related to how much the service cost and whether providing this support (particularly to employers) was within the



NHS' remit, given limited public resource. There is clearly a need for more research into mechanisms for funding support for employers to facilitate return to work after a stroke and how this can be integrated with existing NHS and DWP service provision (Coole et al., 2012).

Radford et al. (2013a) interviewed 16 commissioners of health and social care in three English counties to explore their views on barriers and enablers to commissioning VR following stroke. They found that the commissioners' focus is on costly acute stroke services at the expense of community ones. Commissioners reported that any benefits of post-stroke VR would not be realised in the health budget. The social care budget, restricted due to government cuts, has prioritised those unable to maintain personal care independence. They did, however, suggest that UK Health and Wellbeing Boards with their cross sector remit as a possible way forward for joint health and social care commissioning.

Black and Frost (2011), in their report on sickness absence in the UK, recommended an independent advisory service be set up by the government to assess people who are off sick and provide advice to employers on how they could be supported to return to work. They also recommended that employers provide VR and this should attract tax relief. These recommendations are currently being operationalised by the government in the new 'Health and Work Service' which will assist people to access early assessment and support after being off sick for four weeks (DWP, 2014). This aspect of health and social care delivery is a huge environmental factor which is being tackled at a political level within society. The psychosocial and economic benefits for the

individual, the workplace and society of returning people to work following stroke are a much more desirable outcome than compensating people with benefits which do not necessarily provide adequate financial recompense for work or psychosocial quality of life and are often accompanied by the negative effects of worklessness.

## **6.7 Implications for clinical practice and broader implementation issues**

It is important to consider how valued aspects of any intervention could be implemented in practice, not only at the micro level of day to day clinical work but also at a macro level in terms of their integration with existing services in health and other sectors. This study demonstrates that it is not only the content of the intervention that is important but the way it is delivered and by whom.

The way the intervention should be targeted is highlighted in the interview data in terms of making decisions about who should receive it and if, when and how to involve employers. The issue of appropriate timing in relation to stroke severity is also an important consideration. Whilst some stroke survivors may not be ready to benefit from formal intervention, they still need advice early to remain in contact with their employer and not to make premature decisions about relinquishing work. Another mechanism for ensuring this group can benefit later and avoid duplication of services needs to be put in place. A self-referral system to ensure timing is appropriate and to avoid duplication of services maybe one solution but how this would work in practice is unclear. In the acute and rehabilitation phase following stroke, many

different services and professionals are involved and this can be confusing for the stroke survivor and their family. It is likely that information given as this early stage could be misplaced or forgotten by the time return to work intervention is needed. So using the case coordination model described in Chapter 5, the therapist could implement a review system using phone, email or text (whichever method is preferred by the recipient) to maintain regular contact until active intervention commences. Eligibility, with respect to job type (paid employment/ voluntary work) was not raised by participants but awareness of limited resources and the thorny question of whether costs should be borne by public services or whether employers would contribute could influence targeting of such interventions in the future. Services and funding are often targeted based on severity of need which was evident in the stakeholder interview study (Chapter 2). However, it could be that targeting those who will most benefit from early stroke specific vocational rehabilitation, i.e. those with mild to moderate strokes, would be the most efficient way of using limited resources. However, before this happens, a stronger evidence base is needed to indicate that this is the group who will benefit most from intervention. So a larger scale definitive trial is needed and mechanisms analysis to identify whether the factors identified here are true mechanisms of success. Even with strong evidence for a particular approach as with the disability prevention model used with people with musculoskeletal disorders (Loisel et al., 2005), it is very challenging to implement in practice. This would be similar for return to work after

stroke as implementation needs to overcome political, social, administrative and cultural barriers and influence government policy makers, health and social care providers and commissioners, employers, family members and the stroke survivors themselves. Examples of valued aspects of intervention, highlighted in this study, of the therapist being accessible to stroke survivors including use of text messaging and email and working flexible hours may require organisational policy and cultural change if there were evidence that these specific components enhanced return to work outcomes. It will be interesting to see who receives the new Health and Work Service and whether it meets the needs of those with more complex neurological conditions like stroke.

## **6.8 Strengths**

The data in this study complement findings from the feasibility randomised controlled trial and provide a subjective perspective on how intervention was perceived and which were the most and least valued components. The use of the software package (NVivo Version 10) increased the efficiency and rigour of data organisation and analysis. Part of the data set was analysed by two researchers and themes compared and a template created which enhanced the rigour of the process. However, the template was used flexibly and additional themes were identified as analysis progressed and so it did not restrict or limit data analysis. The use of a thematic map convinced the main researcher that joining the data together from stroke survivors and employers was a useful strategy as there was a high level of agreement

in the themes identified for these groups. The data is rich and specific findings can be used to inform the design of stroke specific VR in future research trials and clinical service development.

## **6.9 Limitations**

### **6.9.1 Sample size**

The sample was actually larger than originally planned for stroke survivors (target was 10) but smaller for employers (target was 10). This was because direct employer engagement only took place with eight employers so target sample size was smaller than anticipated. This means that it has not been possible to explore the views of employers who were not engaged. However, the purpose of qualitative research is exploratory and the aim is not to generalise and therefore sample size is not as important as rigorous in-depth data analysis. The National Centre for Research Methods (Baker & Edwards, 2012) produced a review paper based on the experiences of 14 renowned social scientists and five early career researchers asking 'How many qualitative interviews is enough?' They found that it depended on many practical and philosophical factors. In this study, the qualitative stakeholder interview study and this post-trial interview study precede and follow a feasibility randomised controlled trial hence a mixed methodology study. This context influenced the number of interviews from a philosophical perspective in terms of the purpose of these qualitative studies and in a practical way in relation to time constraints and availability of interviewers. Whether saturation was achieved is a thorny question. Guest et al. (2006) found, in their experiment on data saturation using

thematic analysis of sixty in-depth interviews, that saturation was deemed to have occurred after the first 12 interviews and that six interviews were sufficient to develop meaningful overarching themes and useful interpretations. If these findings are applied to the current study, it is probable saturation was achieved with stroke survivors but more interviews with employers would have been helpful if they had been practically possible.

### **6.9.2 Researcher bias**

There are inherent challenges when the person who delivered the intervention is also involved in conducting research about how it was perceived. However, this was addressed during discussions with the research team and the involvement of independent researchers during data collection and analysis.

Reflexivity was also employed to improve rigour, an example of this being when participants denied knowledge of a particular aspect of the intervention (e.g. assessment) and yet the therapist has a clear recollection and record of conducting assessments on all participants. Interpretation of this finding can lead to rationalising the perception of the participant and explaining their response as lack of understanding or awareness of what assessment actually involves. However, it is important to recognise that for some, more formal ways of measuring their progress would have been preferential and to be open to criticism about the intervention as well as praise is vital. Also when participants expressed a view that the therapist was more than a therapist, that she became a friend, this felt uncomfortable and caused the therapist to

reflect on whether she had stepped over a professional boundary. However, Peloquin (1993) says that images of the therapist as a technician, parent, collaborator or friend dominate patient stories and these beliefs play a part in shaping the kind of care provided. The view of the therapist as a friend in the current study appeared to be connected with her accessibility. This may have differed from the way participants had previously interacted with health care providers and the way the OT had previously interacted with service users as she was not constrained by NHS service delivery models.

## 6.10 Conclusion

Intervention offered in the feasibility randomised controlled trial was seen as useful and acceptable to stroke survivors and their employers. The findings from this qualitative interview study complement quantitative findings from the feasibility randomised controlled trial. Information gleaned from stroke survivors and their employers can be used to inform the design of stroke specific VR intervention in a definitive trial and in clinical practice (Table 44).

**Table 44. Key findings to inform intervention in a definitive trial**

<b>Key finding</b>	<b>How this would inform the intervention in definitive trial i.e. what the therapist needs to do</b>
Provision of ongoing support (especially emotional support) is a highly valued component of intervention	Listen, encourage and support stroke survivors and employers throughout the return to work process
Stroke specific knowledge is valued by stroke	Assess the impact of stroke on each individual and explain the way this may

<b>Key finding</b>	<b>How this would inform the intervention in definitive trial i.e. what the therapist needs to do</b>
survivors and employers	affect work role to stroke survivors and where appropriate, explain to employers to increase understanding and inform negotiation of work accommodations/ reasonable adjustments to reduce this impact
Provision of regular feedback on progress is valued by stroke survivors	Provide feedback on progress at regular intervals in order to increase confidence about returning to work and to help maintain this once achieved
Stroke survivors and employers valued the therapist assisting in keeping communication channels open	Encourage early contact with the workplace and ensure communication channels between the employee and employer are kept open for the duration of the intervention using the telephone, email and face to face meetings as appropriate
Stroke survivors and employers valued the planning, implementation, monitoring and review of a phased return to work	Discuss and plan a phased return to work with the stroke survivor and employer including detail about how hours, roles and responsibilities will be gradually increased and over what period of time. Review this plan regularly and make modifications if required. If/ when the employee returns to previous hours and duties continue to monitor this for a number of months after return to ensure it is maintained in the long term.
Assessment of the individual and the workplace were valued elements of intervention	Assess both informally and formally (where appropriate) and explain the rationale and results of these assessments to the stroke survivor and employer and the way in which they are used to inform intervention
Employers need clarity about support available (to the employer) from the therapist	Make explicit the availability of support for the employer during the return to work process while at the same time providing support and advocacy to the stroke survivor. Maintain transparency and open three way communication. Consider providing a leaflet which describes the intervention being offered.
Continuity and accessibility from a knowledgeable,	Ensure the same therapist is involved from the acute stage and throughout the return to work process and that they are



<b>Key finding</b>	<b>How this would inform the intervention in definitive trial i.e. what the therapist needs to do</b>
personable and experienced therapist were highly valued	<p>accessible by mobile telephone and email.</p> <p>Involve therapists with knowledge and experience of stroke and VR with personal qualities such as approachability and a caring nature.</p> <p>Provide training in stroke specific VR to ensure fidelity and consistency across study sites.</p>
Timing and duration of the intervention have to be individually tailored	<p>Ensure timing and duration of intervention is appropriate for each individual stroke survivor and if the person is not ready for active intervention to commence that regular contact is maintained until they are ready.</p>
Individualisation of intervention was highly valued	<p>Intervention must be tailored to the specific needs of each individual recipient.</p>
Liaison with other services was a valued aspect of intervention	<p>The therapist needs to liaise with other services and agencies as appropriate for each individual. Cross boundary working and case coordination are vital in maximising provision and return to work outcome.</p>

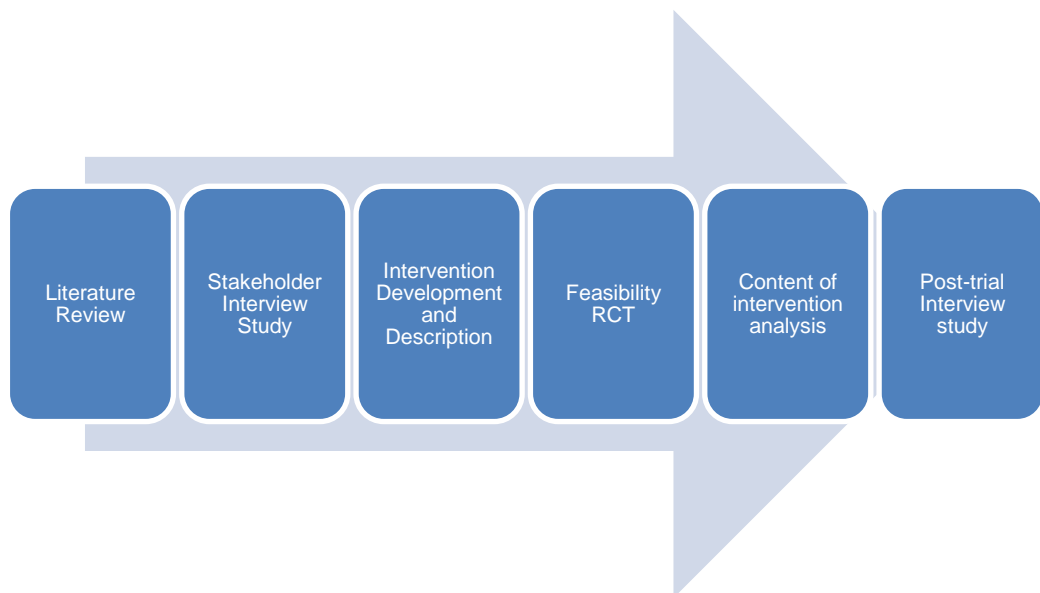
## CHAPTER 7 DISCUSSION

### 7.1 Introduction and overview of thesis

The literature review and component studies of this thesis (Figure 50) have been discussed in the preceding chapters but they are interlinked.

This chapter discusses overall key findings, strengths, limitations, implications for future research, clinical practice and policy. Final conclusions will then be drawn.

**Figure 50. Flow diagram of PhD study**



### 7.2 Key findings

The key findings of this study are summarised in Table 45.

**Table 45. Summary of key findings of each component study**

<b>Component study</b>	<b>Key findings</b>
<b>Stakeholder interview study</b>	<ul style="list-style-type: none"> <li>• Barriers to VR included service design, delivery and demand (affected by geography, informal networks and stroke severity), work place influences (company size, occupational health provision and economic climate) and stroke survivor factors (stroke impact, reduced confidence and family support).</li> <li>• Stakeholders wanted individually tailored, stroke specialist, timely, responsive and case coordinated VR from a multidisciplinary team, mentorship from stroke survivors and more support for family members and employers.</li> </ul>
<b>Intervention development</b>	<ul style="list-style-type: none"> <li>• Early stroke specific VR intervention model developed with in-reach to acute stroke care and outreach to workplace.</li> <li>• Early intervention, work preparation, phased return to work and work maintenance were the key stages of the intervention.</li> </ul>
<b>Feasibility RCT</b>	<ul style="list-style-type: none"> <li>• It is feasible to recruit, randomise and deliver stroke specific VR in a clinical trial.</li> <li>• Primary outcome measurement of occupational status at three, six and 12 months and secondary outcome measures were feasible. 73.9% responded overall (69.6% at 12 months). Questionnaire booklet needs to be shortened and some measures removed (SIS, SPRS, WPAI). More effective ways of collecting data on income and benefits needed.</li> <li>• Early intervention can potentially influence job retention in people with mild to moderate stroke. A larger trial is needed to demonstrate effect.</li> <li>• Stroke severity influenced participation. A different model is needed for people with severe stroke or unable to return to an existing job.</li> </ul>
<b>Content analysis (describing intervention)</b>	<ul style="list-style-type: none"> <li>• A content proforma was simple to use and captured the intervention. Some components were difficult to categorise due to overlap.</li> <li>• Stroke specific VR is an individually tailored complex intervention involving cross sector working.</li> <li>• Employer contact is not always necessary or desired by the stroke survivor due to job type (self-employment and voluntary work included), concerns about job loss, reluctance to disclose</li> </ul>

<b>Component study</b>	<b>Key findings</b>
	or highlight stroke difficulties to the employer and/ or wanting to self-manage return to work.
<b>Post-trial interview study</b>	<ul style="list-style-type: none"> <li>• This flexible, individualised intervention was valued by stroke survivors and employers and positively influenced work outcomes.</li> <li>• Employers viewed the costs of facilitating a phased return to work as a 'reasonable adjustment' which budgets allowed for and which they felt enhanced their reputation as a good employer.</li> <li>• Funding, targeting and implementing this type of intervention require further consideration.</li> </ul>

### **7.3 Discussion of key findings**

This is the first UK randomised controlled trial testing the feasibility of delivering and measuring stroke specific VR. This is surprising given the importance of return to work for a number of stakeholders including the stroke survivor, their family (Robison et al., 2009) and society in general (Saka et al., 2009). Existing trials of VR interventions have taken place in the USA (Trexler et al., 2010) and South Africa (Ntsiea et al., 2014). The former was focused on resource facilitation for people following acquired brain injury (not only stroke), and the latter on a workplace intervention. The numbers in the Trexler study were half those of the current study and the VR services accessed via resource facilitators were not described so comparison is difficult. In contrast, the intervention in the South African study, was solely delivered in the workplace indicating that the target population differed from the current study which included voluntary workers and students. Both studies took place outside the UK, in different health care systems and findings may not be transferable.

This UK trial has demonstrated that it is feasible to recruit and randomise patients to stroke specific VR and that this intervention can be successfully delivered and its' outcomes measured. Clinicians were willing to recruit patients and patients were willing to be randomised. Only one person declined on the grounds of wanting to ensure being in the intervention arm. Not all potentially eligible patients were identified by clinical staff for a number of reasons including the acute setting turnover and focus on hospital discharge. There was also a period of time when there was no research assistant, which resulted in the OT recruiting singlehandedly which may have reduced numbers identified. Despite this, the recruitment figure was near target. Primary outcome of occupational status at 12 months was feasible to record and twice as many people returned to work in the intervention group suggesting that early stroke specific VR has potential to influence the primary outcome. Secondary outcome measurement using a number of standardised measures was also feasible. There was a 73.9% overall response rate to the postal follow-up questionnaire. In the current study completion rates varied from 0-100% as the Work Limitations Questionnaire could only be completed by participants who were in work. The questionnaire needs to be reduced for a definitive study. This is a useful feasibility finding. Finally, compliance rate was high as only one out of 23 participants withdrew from the intervention during the study.

It is interesting to compare the component studies of this thesis. For example, what stakeholders said they required from stroke specific VR with what was actually provided in the feasibility trial and what trial

participants valued about the intervention received. Stakeholders wanted individualised, specialised, timely, flexible and responsive case coordinated stroke specific VR from a multidisciplinary team. In the context of this trial VR was delivered by an occupational therapist (OT) in a case coordination role who liaised with and made referrals to other professionals and agencies as required.

The flexible, individualised and specialised nature of the intervention recommended by stakeholders was valued by participants illustrating resonance between the quantitative and qualitative aspects of the study. The positioning of the therapist in the community and outside existing services meant that she could visit people at home and the work place at times convenient to them and work with them on a one to one basis with understanding of the impact of the stroke on each individual participants' work role. Her specialised knowledge of stroke and VR meant she could analyse the demands of the job and the skills of the employee and creatively bridge gaps, if they existed, by working collaboratively with the employer to negotiate adjustments to hours and tasks. Continuity was also valued and the involvement of the therapist from the acute stage to the return to work stage and beyond meant that this was ensured. Existing service provision meant people with mild strokes fell through the net (Sinclair et al., 2014) and existing provision was patchy. This was because these patients were often independently mobile and discharged from hospital quickly without rehabilitation follow-up. The early intervention model meant this limitation was tackled. However, cost implications of providing this service would need

to be addressed by stroke services commissioners. An interview study with 16 health and social care commissioners (Radford et al., 2013a) indicated that resources are mainly focused on expensive acute care post-stroke with less emphasis on the longer term needs of stroke survivors. Cost-benefit analysis of providing specialist VR to stroke survivors is an area requiring further research and evaluation (Radford et al., 2013a; Radford et al., in press).

For some stroke survivors the early intervention was too early and the intervention duration (maximum of 12 months) insufficient to address work needs due to stroke severity and the need for retraining and finding new work. Returning to work with an existing employer, where reasonable adjustments can be made to accommodate the impact of the stroke is classed as job retention. This may be simpler than applying for new work, once a previous job has been lost or relinquished when the stroke survivor has to contend with disclosure and faces tough competition in an economic climate that favours people without disabilities. The stroke survivor may have to apply for jobs that are completely different to work they have done before and therefore retraining may be necessary. An example from this feasibility trial was a self-employed gardener who considered retraining as a support worker. It is possible this re-training could be funded through Job Centre Plus. However, this process takes time and may require longer term intervention to achieve positive employment outcomes.

Support was one of the most highly valued aspects of intervention for both stroke survivors and employers. However, it was difficult to describe support as a component of intervention when recording content as the proforma categories did not always explicitly reflect the type of support being offered. For example, support might be an integral feature of meetings with employers to plan or review a phased return to work but this would not be named directly as support. Also it is more difficult to describe a supportive relationship with the therapist and yet this may be a vital part of intervention success. The support provided by the therapist appeared to increase the stroke survivors' confidence and may be considered an active ingredient of the intervention. Another factor which may have influenced confidence was the therapist's accessibility by phone, text or email. If the person was struggling they knew they could contact the therapist for support and she would respond. The combination of emotional and practical support appeared to be essential components of intervention in the current study. This was also found in a qualitative interview study with 12 stroke survivors who returned to work (Vestling et al., 2013), for example, they valued encouragement from health professionals and adaptations of the physical environment and assistance with tasks due to physical and cognitive difficulties.

Greater support for family members was something key stakeholders wanted and this was offered to trial participants. Given the influence family members may have on return to work decisions and outcomes (Lock et al., 2005), family support is an area which could be explored



and evaluated further in future research. Participants in the Vestling et al. (2014) study appreciated help, understanding and encouragement from family and friends. They also found that for those who were self-employed a supportive spouse was considered vital, particularly as they did not have colleagues to turn to for help when they experienced difficulties. Therefore, it would be good to explore the role of a therapist in supporting the person who is returning to work with their immediate family members.

Stakeholders also asked for support for stroke survivors' employers. This was provided for seven stroke survivors who wanted direct liaison and the six employers interviewed in the post-trial study were largely positive about this. The low number of cases was surprising but comparable to a study evaluating VR for people with traumatic brain injury (Radford et al., 2013b). It would be interesting to explore the reasons why some participants declined employer contact from the OT.

#### **7.4 Strengths**

One of the limitations of previous research (Treger, 2007; Baldwin & Brusco, 2011) is a strength in this study, i.e. the detailed recording, analysis and description of the intervention delivered in the trial. This is valuable for research, so that intervention components can be explored to evaluate effectiveness (Hart et al., 2006) but also for informing clinical guidelines and practice (Wade, 2003). Hoffman et al. (2014) called for better reporting of interventions and provided a template to enable detailed description and therefore replication (TIDieR). These

guidelines emphasise the importance of giving a name to the intervention and describing the rationale, materials used and training of providers, the processes and activities used in intervention, the provider, mode and location of delivery, the amount of intervention and how it was tailored/ personalised, planned and modified. This thesis addresses all of these elements in some detail which strengthens its rigour and utility.

Wells et al. (2012) stress the importance of not only describing intervention in detail but of understanding context in order that the transferability of complex interventions evaluated in clinical trials can be assessed. The stakeholder interview study preceding the trial, the description of the content and delivery of intervention and the post-trial interviews all shed light on the context and complexity of stroke specific VR. An additional strength of this study is the use of mixed methods as recommended by Kroll and Morris (2009) as a way of addressing rehabilitation research complexity.

The exploration of stroke survivors' and employers' views about the usefulness and acceptability of the intervention in the post-trial interview study is a strength in that it addresses previously neglected perspectives (NIHR 2008, Coole et al., 2012). Positive appraisals of the intervention received were also helpful in assessing the feasibility of intervention delivery and acceptability in preparation for a larger scale study (Thabane et al., 2010).

## 7.5 Limitations

This study was conducted in one geographical region of England and so transferability to different contexts may be limited. However, an England wide mapping study of VR (Playford et al., 2011), found the numbers of people being seen by community neurorehabilitation teams similar to those found in the local mapping study which ran parallel to this feasibility study (Sinclair et al., 2014) which increases generalisability of the findings. A further local pilot study of stroke specific VR OT (Terry et al., 2015) that followed the feasibility trial also found similar numbers of people receiving this intervention.

In the pre-trial stakeholder interview study and the post-trial interview study, it would have been useful to include partners or other family members in the process of developing and evaluating stroke specific VR as their perspective may have complemented that of stroke survivors, employers and other stakeholders. Previously Lock et al. (2005) included family members in UK focus group research about return to work barriers and facilitators. However, it was not always possible to differentiate between the views of people with strokes and their relatives. But as it was a focus group study one of the aims would have been to gain a consensus view. There was recognition of the influence of family on return to work prospects but it did not specifically explore the needs of family members. Gabriele and Renate (2009) examined the differences in quality of life between spouses of patients who had and had not returned to work after stroke. They found quality of life, as measured by the WHO Quality of Life questionnaire,

increased for those whose partner had returned to work and that its association with returning to work appeared to be of greater importance for spouses than stroke survivors. Robison et al (2009) conducted a longitudinal study of 19 people with stroke and eight informal carers 12 months post-stroke and found that the inability to resume work impacted on quality of life and support was needed by some participants to adapt to a changed way of life. The views of stroke survivors and carers were not separated out and all the quotations appeared to be the former, therefore it is not clear what the carers specifically thought about resuming work. Of 55 stroke rehabilitation patients with spouses in a study by Teasell et al. (2000) 14.5% separated within three months of hospital discharge. In the same study, only 9.4% of those working full time were able to return to full time employment but it is not clear whether these two factors were related. In the current study, through personal communication since the trial ended, one of the younger participants is known to have separated from his wife and he was one of the people who did not return to work. The impact of return to work on partners and family members in relation to finances and quality of life is an important area of future research.

This is a single centre feasibility trial with one therapist delivering intervention without the constraints of being embedded in NHS service delivery. Therefore caution must be exercised in generalising the findings but the principles of feasibility can be applied to the development of a larger scale study. However, the independence of the research OT, employed by the university rather than the NHS could be

seen as a strength which enabled a greater degree of flexibility, responsiveness and timeliness which was valued by trial participants. This included the ability to cross and span boundaries across services, agencies and to go into the workplace and liaise with the employer which not all therapists working in usual care services do. This might be because of time constraints, waiting lists, lack of confidence and concerns about legal issues as highlighted by the results. The England-wide mapping of vocational services study (Playford et al., 2011) reflects this too.

In this study, only trial participants who had received the intervention and their employers were interviewed. In a future study, trial participants in the control group receiving usual care and their managers could also be interviewed about their experiences and any support or services they received to assist with return to work. This could be part of a process evaluation (Moore et al., 2015) to analyse how trial intervention and usual care differed or complemented each other. This would provide a greater understanding of context and how existing services could be enhanced if trial intervention was found to be effective.

This early intervention was not appropriate for everyone and some participants, with more severe strokes needed intervention which started later and lasted for longer than the 12 month period the trial allowed for. It also appears that stroke severity impacted on recruitment in the acute setting as the majority of people who joined the study were

those with mild or moderate strokes and no one with a severe stroke was recruited.

Also with respect to recruitment, the sample was almost exclusively white British with only one person from an ethnic minority taking part. It is a known fact that ethnic minority groups are under-represented in clinical trials (Hussain-Gambles et al., 2004). One of the reasons cited is the exclusion from trials of those who do not speak fluent English, which is seen as a major barrier to participation for the British South Asian population. However, this was not one of the exclusion criteria in the current study but it could still have influenced those identifying potential recruits. Hussain-Gambles et al. (2004) suggest that staff may feel less confident about explaining trials to non-English speaking patients and assume they have less interest in participating. The research team in the current study did try to recruit one patient from a south Asian background who did not speak English with the help of relatives but the individual declined participation and did not give a reason. There would be cost implications in a larger study if formal translation or interpreting services were required. An English speaking British Asian patient was identified and approached but her sister was extremely protective and felt it was too early to think about work which was a barrier to recruitment. However, the patient also had a severe stroke, low mood and aphasia and so with this complex set of factors it is difficult to identify which was the most influential in this participant declining participation. In a future multicentre definitive trial, based on suggestions made by Hussain-Gambles et al. (2004), it may be helpful

to include relevant education and training of staff recruiting to the study. This could include encouragement to use an advocacy or community link worker, where appropriate, to assist with trust building during the recruitment process.

The inclusion criteria for this study only included those working at the time of stroke so the trial focused on work retention rather than retraining or finding new job. The latter would have been more challenging in the funded time frame. Also for those who lose their jobs and move onto benefits, the DWP provide return to work support.

Finally, higher levels of attrition in the control group at the six and 12 month follow-ups, which could bias results in a larger scale trial, warrant consideration. A Cochrane systematic review and meta-analysis of strategies to improve retention in 38 randomised trials (Brueeton et al.,2013) found evidence that introducing and offering monetary incentives to be paid on completion were effective in increasing questionnaire response rates. Other ideas explored were shortening the questionnaire where the evidence was less clear and using recorded delivery for questionnaires which was more effective than standard procedure. Another possibility would be to collect follow-up data face to face rather than postally. However, the ethical and cost implications of these strategies would require careful consideration at the trial development stage.

## **7.6 Implications for future research**

It is recommended, following this feasibility randomised controlled trial, that the effectiveness of early stroke specific VR be evaluated in a larger scale multi-centre definitive trial (MRC, 2008). Some areas highlighted as methodological difficulties in previous research studies about return to work after stroke still need to be addressed. For example, the definition of work and whether it includes unpaid work, being a housewife/ husband or a student needs to be clarified. The follow-up period used in this feasibility trial of 12 months could be extended to 18 months or two years in order to further evaluate whether return to work is sustained and whether the ability to change jobs or seek promotion is affected by the stroke. A system of longer term review meetings at six month intervals could be introduced and evaluated. The issue of career advancement was raised in a State of the Science Symposium held in the USA about employment after stroke (Roth and Lovell, 2014). A three or five year follow-up of the cohort of feasibility trial participants should also be conducted in order to explore these factors.

Family member research linked with VR following stroke could be explored further by interviewing partners and other relatives about their influence and involvement in the return to work process. This could take the form of focus group research or individual in-depth interviews.

Family members of people in the current study that did and did not return to work could be included in order to get a broader perspective or relatives in contact with charities like the Stroke Association and



Different Strokes could be a potential pool of participants. In addition, a larger survey could be conducted to see how therapists work with family members in the field of VR at the different stages of the process including preparation and planning for the phased return to work, review and support to sustain work return longer term.

In the current study, the role of colleagues in supporting a return to work was highlighted in the post-trial interviews with stroke survivors and employers (Chapter 6). The relationship with colleagues prior to the stroke and how this impacted on willingness to cover when the stroke survivor is off sick and then support and do extra work during the phased return was discussed but this needs to be explored in more depth. The role of co-workers and colleagues in return to work following stroke has been brought to light in previous research. Alaszewski et al. (2007) interviewed stroke survivors who said their work colleagues understanding of their situation was very important and had a direct impact on their ability to return to work. In another qualitative study, Erikson et al. (2010) found that the workplace was a place where people's sense of belonging could be restored and where participants felt inspired to regain their work and social identity. Culler et al. (2011) asked participants if they were comfortable talking to co-workers about their stroke experience but this did not appear to feature in the findings of this interview study. Lock et al. (2005) cited colleague attitudes as one of the factors influencing return to work after stroke but detail on this sub-category of employer agency factors was not elaborated on. The interpersonal environment of the workplace was seen as critical to

the success of returning to former occupation in a qualitative study by Hartke et al. (2011). They found that being valued was important and being supported by colleagues but without becoming over-protective. Rubenson et al. (2007) in their qualitative study of returning to work after acquired brain injury found that emotional and practical support from the workplace could be very helpful. Participants said that understanding in the workplace was better when both employers and colleagues were given information about acquired brain injury and its consequences. The way this information was given depended on the participants wishes (i.e. whether it was given by a professional or themselves). However, misunderstandings and overprotectiveness still occurred in some participants work places. The impact on the dynamics of work place and how therapists can engage with colleagues to educate and mediate during the return to work process with colleagues and managers would be an interesting topic for future research although the ethical issues of confidentiality in relation to disclosure of health issues would need careful consideration. Roth and Lovell (2014) found that stroke survivors are unsure if and when to disclose the impact of their stroke.

Participants interviewed in the post-trial period of the study were not always aware of when they were being assessed as informal methods were used in tandem with some formal assessments and worksite assessments where needed. One participant interviewed following the feasibility trial would have liked more formal methods of assessment to be utilised. However, employers appeared to be aware that worksite

assessments were being conducted. In the South African randomised controlled trial, Ntsiea and colleagues (2014) used the 'Therapist Portable Assessment Lab' (Valpar International Corporation, 1992) which has 12 work modules to assess specific work skills and the 'Job Content Questionnaire' (Karasek et al., 1998) which explores the individuals' job description and demands. The use of these assessments could be included as part of the intervention in a larger scale trial. However, it is important to consider that the standardised measures used in the trial also contribute to a formal assessment of the participant and maybe the use of these measures in guiding further assessment and intervention needs to be described more explicitly to participants. The 'Therapist Portable Assessment Lab' is a practical test but not all modules will be relevant to every participant. In the South African trial it is possible that this particular assessment was considered suitable because half the participants were doing labour-intensive jobs. However in this UK study two thirds of participants were in professional/managerial posts so it may not be so useful. It may be preferable to offer the individualised informal assessment supplemented by specific cognitive and other specific tests where appropriate in the UK context. Also the other influence on choice of assessments in the South African study was that, OTs there have been using Functional Capacity Evaluation (FCE) in work practice services for decades (Buys & van Biljon, 2007). OTs in the same province where the stroke workplace intervention trial took place (Vinciguerra, 2004) developed a work assessment battery to evaluate work capacity. This included work

samples that had been analysed using MODAPTS (MODular Arrangement of Predetermined Time Standards). This is an international system which was developed in the late 1960s and 1970s to establish a reasonable and sustainable time to complete a job or proposed jobs. It can be used to quantify the degree of disability for particular tasks and therefore measure productivity in an objective way and it is used by OTs in Australia, New Zealand, South Africa, the USA and the UK (MODAPTS, 2015). A future study could test out the use of MODAPTS with stroke survivors returning to work and compare this with the use of more subjective self-report measures of productivity like the Work Limitations Questionnaire (Lerner et al., 2001). However, the disadvantage of providing employers with specific information about the reduced productivity of the stroke survivor is that they may use this information to prevent the person returning to work rather than giving them the opportunity for a phased return where confidence and productivity would gradually increase as they readjust to their work role. Moreover, in this study, assessments in the work place were used to inform the need for adaptations to the job or role, so that the environmental barriers to work return could be addressed and advice offered to the employer and/or stroke survivor on what might be considered reasonable adjustment. Employers and employees could be interviewed about the potential utility of these evaluations in measuring work capacity when returning to work following stroke in the first instance.

The issue of whether workplace assessment, intervention and direct employer liaison are an essential component of the model delivered in a larger scale study requires further exploration. As stated earlier, fewer people than expected, wanted or allowed the OT to come to the workplace and to meet their employer as discussed in Chapter 5. If volunteers and students were excluded from the sample then this element of intervention would potentially be appropriate for a larger proportion of the trial participants. Work simulation as described by Chan et al. (2008) in a Singaporean return to work programme and Kempers (1994) in an American VR programme is not always possible and depends on the nature of the work. The 'train and place' (Hart et al., 2006) or 'programme based' (Fadyl & McPherson et al., 2009) model of VR would involve work simulation whereas the case coordinated approach also described in these papers and adopted in the current study can combine work simulation at home or rehabilitation settings with work site visits and the phased return so that tasks can be analysed, assessed and practiced in the participants work place. This, as long as agreed to by the employee and supported by the employer is a more realistic way to rebuild work skills and tolerance. It would also provide a much greater context-specific appreciation of the organisational culture, employer and colleague attitudes and concerns so that work preparation and other aspects of intervention can be tailored to each individual workplace as well as each individual stroke survivor. The England-wide VR mapping study (Playford et al., 2011) indicated that therapists were reluctant to go into the workplace and this

highlighted a gap between what clinical guidelines recommend and what practice delivers. However, whether intervention in the workplace has a direct impact on outcome has not been evaluated in any study to date.

Roth and Lovell (2014) recommended that a robust economic model needs to be developed to measure the cost-benefit analysis of returning stroke survivors to work in the USA. In the UK measuring cost-effectiveness is also recommended by the Medical Research Council (2008) as part of the process of evaluating complex interventions to make the results useful to decision and policy makers. The CLAHRC-NDL study of which this doctoral study forms a strand included a feasibility economic evaluation of the trial intervention (Radford et al., in press). This would be a vital component of a larger scale definitive trial.

The ability to measure and provide information on the cost to the employer of workplace accommodations will be important in determining whether return to work is feasible. Roth and Lovell (2014) suggest evaluating the use of assistive technology in improving employment for stroke survivors including telecommuting as a reasonable adjustment to manage fatigue and increase efficiency and productivity. However, they found stroke survivors are unsure of how to ask for workplace accommodations and afraid of being labelled difficult employees if they make any demands on their employers.

In the UK the financial contribution of Access to Work (for transport to work, equipment, adaptations and support at work costs) depends on

the size of the employing organisation. Two participants in this study were encouraged by the OT to refer themselves to this service for help with transport to work which they did. However, by the time they returned to work they no longer needed this support as they could manage using public transport or had returned to driving. However, this was a small feasibility study and in a larger scale trial, it is possible participants would find this service helpful. The role of the Equality Act (2010) and the Equality Advisory Service in ensuring discrimination does not occur could also be evaluated by looking at case studies where return to work has been problematic following a stroke. One participant in this study who did not return to work and lost his job at the time of his stroke went to a tribunal with the support of his son and was awarded a small sum in compensation. Participants for future studies could be recruited through charitable organisations like Different Strokes or the Stroke Association. Offering support on-line to people struggling to return to work and making them aware of people (Disability Employment Advisers at Job Centres) and organisations that can help them (e.g. the Equality Advisory Service) is another intervention that could be tested out in future research.

The new UK government 'Health and Work Service' which will assist people to access early assessment and support after being off sick for four weeks is currently being launched (DWP, 2014). This will be especially helpful for those who work for small to medium sized enterprises that have limited access to occupational health services. An

evaluation of this new service from the perspective of stroke survivors is another possible area for future research.

At the other end of the spectrum, those with severe strokes who have longer term needs for rehabilitation should be studied to see whether stroke specific VR at a later stage is helpful in returning them to the workplace, changing jobs, accessing retraining or finding a new job.

One of the ideas proposed by stakeholders in chapter 2 was group intervention and/ or mentorship by other stroke survivors who have been successful in returning to work. This was not provided in the feasibility trial but participants were referred to existing groups, for example, a stroke self-management group. This involved education and peer support and was led by two OTs in a community setting. The use of patients as experts in their own condition to support others and the current drive towards self-management is well established within the NHS and some programmes have been adapted for stroke (Lennon et al., 2013). However, they could also be adapted and tailored specifically for use with those returning to work after stroke or other health conditions. A recent paper evaluates the French experience of innovative support groups for VR for those returning to work after cancer in a qualitative pilot study (DeBlasi et al., 2014). Four monthly sessions of 90 minutes led by a psychologist and an occupational physician (with support from a social worker) and a follow-up session six months later were held for two groups (of 11 and nine patients respectively). A postal survey questionnaire established that 58% of



participants found the group helped them prepare or support their return to work. For 70% of the respondents, the group provided personal, family and relationship help. There was a statistically significant difference with respect to return to work between those who participated and non-participants. A similar programme could be developed and evaluated in the UK.

## 7.7 Summary of key recommendations

A summary of the key recommendations of this study is provided in Table 46.

**Table 46. Summary of key recommendations**

Recommendation	Implementation detail
Conduct a UK multicentre RCT of stroke specific VR	<ul style="list-style-type: none"> <li>• Use a diverse range of sites (geographically &amp; socioeconomically)</li> <li>• Introduce strategies to enhance recruitment of participants from ethnic minority groups (e.g. education and training of recruitment staff, use of community link workers)</li> <li>• Define work clearly (paid/ unpaid)</li> <li>• Reduce length of questionnaire booklet by removing the Stroke Impact Scale, Sydney Psychosocial Reintegration Scale and the Work Productivity &amp; Activity Impairment instrument</li> <li>• Develop more effective ways of collecting accurate annual income and benefits data</li> <li>• Consider a longer term follow-up period (e.g. 18 / 24 months)</li> <li>• Make explicit to intervention group participants, the use of baseline and follow-up standardised assessments in the VR process</li> <li>• Interview control group participants about their experiences during the trial (e.g. any interventions they received and their</li> </ul>

Recommendation	Implementation detail
	return to work experience)
Develop a robust economic model to measure cost-benefit and cost effectiveness of stroke specific VR	<ul style="list-style-type: none"> <li>• Include cost to employer (e.g. of workplace accommodations) and cost of Access to Work provision</li> </ul>
Explore role of employer and colleagues in stroke specific VR	<ul style="list-style-type: none"> <li>• Interview employers and colleagues about their involvement in stroke specific VR</li> <li>• Examine the impact of interpersonal dynamics in the workplace on return to work</li> <li>• Explore whether a worksite visit/ assessment is considered essential</li> </ul>
Explore why stroke survivors do not always permit direct employer engagement by stroke VR therapist	<ul style="list-style-type: none"> <li>• Interview participants about their views on employer involvement</li> </ul>
Explore role of family members in stroke specific VR and impact on return to work	<ul style="list-style-type: none"> <li>• Interview family members about their involvement and their impact in relation to outcome, finances and quality of life</li> </ul>
Develop a model of stroke specific VR for those with severe strokes and longer term needs	<ul style="list-style-type: none"> <li>• Interview participants with longer term needs and more severe strokes about appropriate timing and nature of intervention required</li> <li>• Explore the role of Disability Employment Advisers and Job Centre Plus with stroke survivors</li> </ul>
Explore the potential use of MODAPTS in stroke specific VR intervention	<ul style="list-style-type: none"> <li>• Pilot use of MODAPTS and interview stroke survivors and employers about it's utility</li> </ul>

Recommendation	Implementation detail
Explore the value of mentorship by other stroke survivors during the return to work process	<ul style="list-style-type: none"> <li>• Develop a mentorship scheme and explore perceived value of peer support and education through interviews with stroke survivors and mentors</li> </ul>
Evaluate a self-management group for stroke survivors returning to work	<ul style="list-style-type: none"> <li>• Develop a group self-management programme for stroke survivors who wish to return to work, measure it's value and explore it's impact</li> </ul>
Explore the use of the ICF as an assessment and intervention framework in stroke specific VR	<ul style="list-style-type: none"> <li>• Introduce and evaluate an ICF assessment and intervention framework through piloting and interviewing therapists and stroke survivors on perceptions of it's value</li> </ul>
Explore commissioning of services to support stroke survivors back into work	<ul style="list-style-type: none"> <li>• Conduct a survey of commissioners in England</li> </ul>

## 7.8 Clinical implications

The early stroke specific VR model developed in this study could be implemented more widely in clinical practice once it has been fully tested in a larger scale study. This model is described fully in chapter 3.

The use of the ICF as a framework for assessment and intervention in VR is another potential clinical implication of this study. This would ensure that the complex interaction of impairment, personal and environmental factors are addressed and used to inform and evaluate practice. To tackle environmental issues fully it may be necessary to

involve employers and worksite assessment and therapists may need extra training to increase their confidence to embrace this.

This study took place within the CLAHRC-NDL. The process of implementing research in practice was central to the CLAHRC's purpose. As a result strong links between clinical practice and research were established from the outset and a culture of continuous dissemination and implementation nurtured during the project and beyond (CLAHRC-NDL, 2013).

## **7.9 Policy implications**

The integration of health and social care is government priority (The Care Act, 2014) but joint work between these sectors and the DWP is only just emerging in the form of the Health and Work service. The tendering of contracts for this and other DWP services mean the NHS, independent and third sectors are increasingly involved in providing return to work services (DWP, 2014). However, these services are generic and tend to be geared towards people with mental health and musculoskeletal health conditions. They do not necessarily address the work needs of people with more complex neurological conditions like stroke. The NHS Five Year Forward Plan (NHS England, 2014a) makes a commitment to helping people get and stay in employment as the huge costs of sickness absence are acknowledged. However, the main focus still appears to be targeted help for those with mental health problems.

This study highlights the potential value of commissioning stroke specific VR which is a specialised service (Radford et al., 2013a). Clinical commissioning groups have been given more power to provide what is needed locally (NHS England, 2014a). However, the existing provision of generic return to work services may prove to be a barrier to specialised ones being introduced. OTs working together with key stakeholders are in a prime position to influence practice, policy and the commissioning of VR services.

The wider debate is the future of rehabilitation within NHS (NHS England, 2014b). The Rehabilitation Board has convened a Rehabilitation for Economic Growth working group to deliver a strategic vision of priorities in the provision of rehabilitation services across NHS England (2014b). The focus is improvement of rehabilitation services for long term conditions and return to work. The scope of influence of this working group is broad and includes Clinical Commissioning groups, provider organisations, DWP, Department of Health, Department for Education and Public Health England.

The international perspective is encapsulated in the ICF and policy is one of the environmental factors which must to be addressed. Health services, systems and policies were seen as one of the most important environmental factors by the expert panel that created the Brief ICF core set for stroke (Geyh et al., 2004). The result is viewing return to work after stroke as part of the broader focus on health promotion. This

enables participation in society and a reduction in social exclusion which in turn improves health of individuals and therefore society.

## **7.10 Conclusion**

The views of key stakeholders, in one English county, on barriers to VR following stroke and what they required from stroke specific VR were sought and used to develop an intervention that was tested in a feasibility randomised controlled trial. This is the first trial of its kind in the UK.

It was feasible to recruit and randomise people from a regional stroke unit. A questionnaire booklet administered face to face at baseline and postally at three, six and 12 month follow up captured primary outcomes (return to work and benefits status) and secondary outcomes of mood, disability and instrumental activities of daily living, work and participation in society. More sensitive ways of determining annual income and benefits claimed need to be identified in future studies.

The content of intervention can be measured using a proforma developed for a VR study in traumatic brain injury and adapted for use following stroke. This enabled detailed description of intervention provided in the trial which could be used to implement findings in clinical practice and replicate the intervention in future research.

A qualitative interview study with trial participants and their employers explored the effectiveness of the trial intervention and the way it influenced the timing and success of return to work outcomes from their perspective. The intervention was perceived as useful and acceptable.

It is recommended that a larger scale multicentre definitive randomised controlled trial now be conducted to evaluate this intervention.

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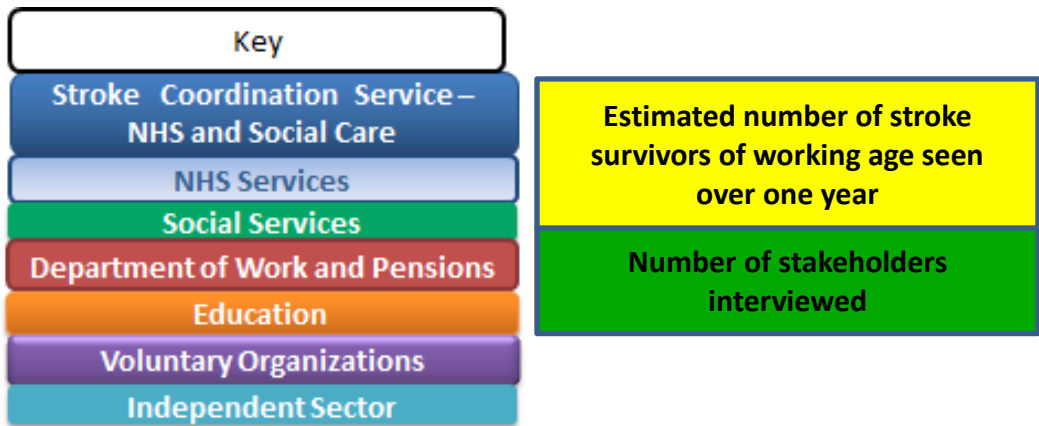
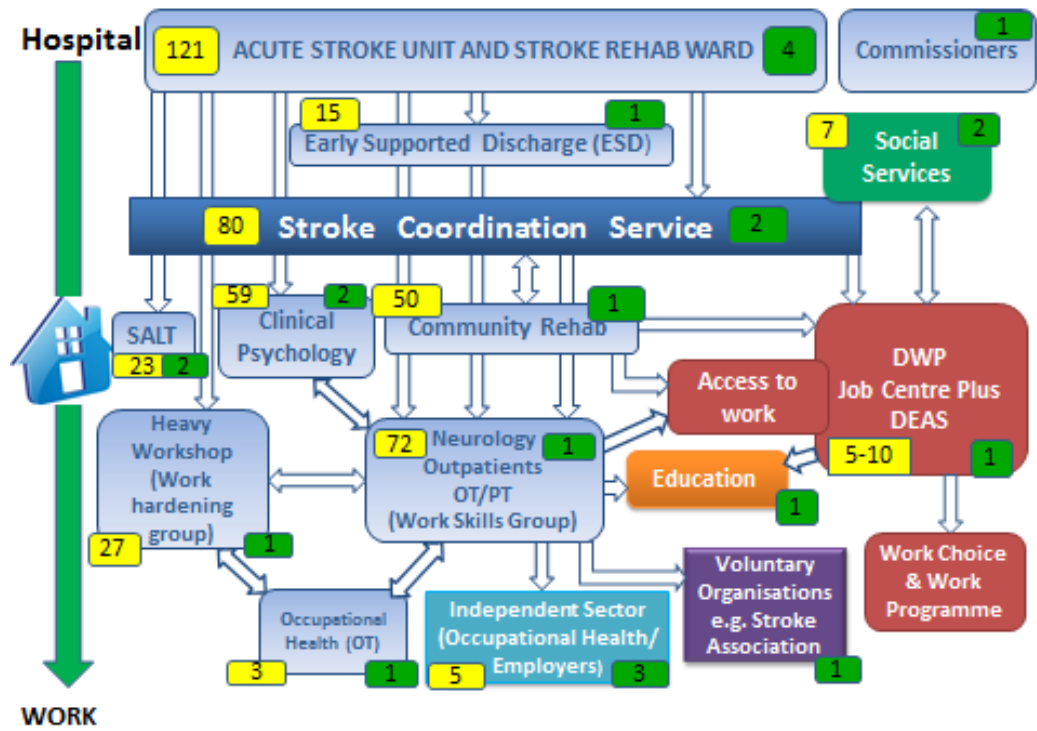
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**APPENDIX 1: Map of existing services to support stroke survivors back to work in Derbyshire**



(Adapted from Sinclair et al. 2014)

## APPENDIX 2: Interview schedule for stakeholder interviews

To help us better understand aspects of stroke specific VR service (SSVR) delivery in the NHS and what helps or hinders the delivery of SSVR services for people we would like to ask you a few questions about the services you provide and your perspective on developing new or reconfiguring existing services to meet the vocational needs of stroke survivors:

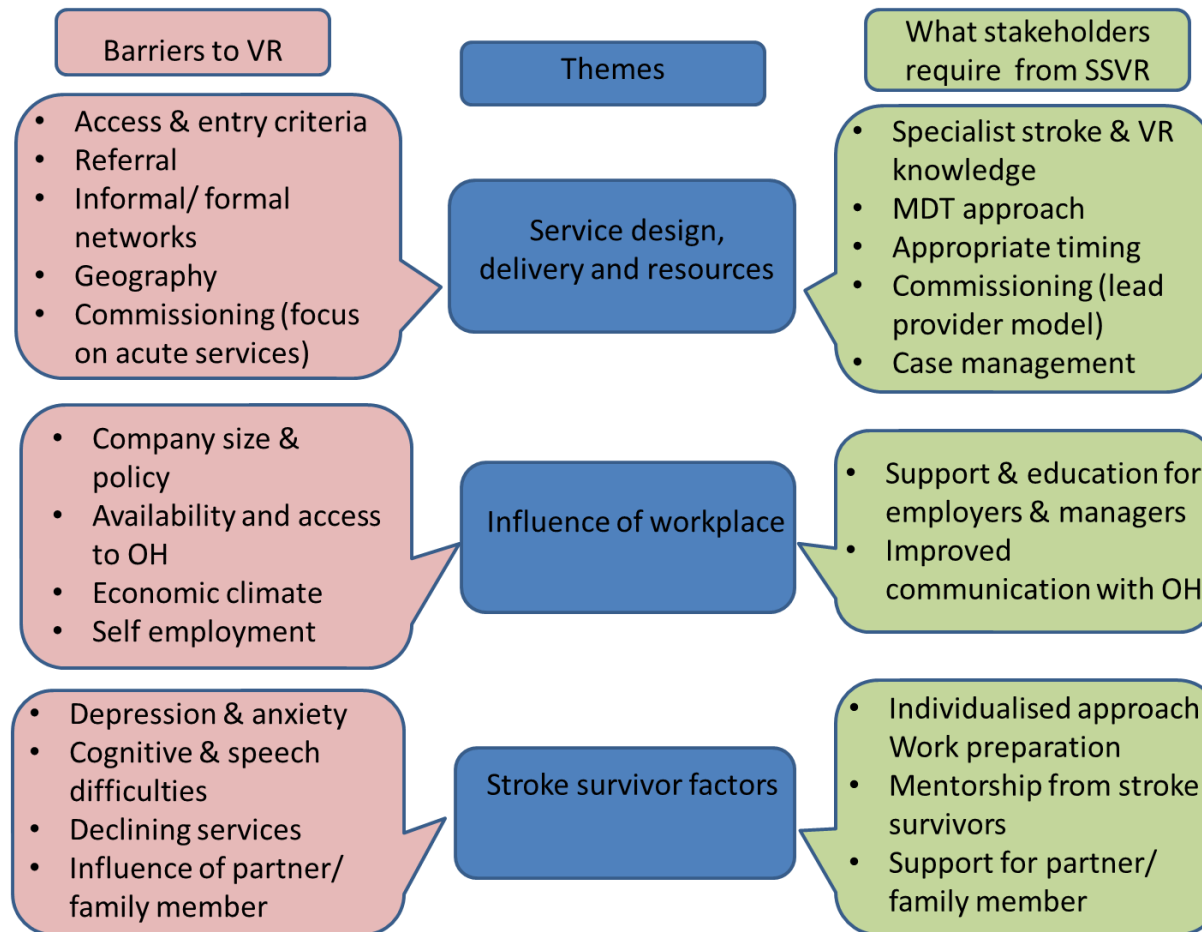
<b>1. Clarification of service and context</b>	<ul style="list-style-type: none"><li>• What VR services currently exist for people with stroke in Derbyshire?</li><li>• How are they organized and delivered?</li><li>• Who can access them?</li><li>• Where do service gaps exist?</li><li>• What are the barriers to existing stroke VR services (for service users, employers, commissioners, providers)?</li><li>• How can existing service providers work more effectively to ensure service gaps are overcome?</li><li>• What training needs exist for service providers?</li><li>• Can you tell me more about the VR service you currently provide</li><li>• When was it set up?<ul style="list-style-type: none"><li>○ By whom?</li></ul></li><li>• Who funds the service?</li><li>• Where is it based?</li></ul>
<b>2. Role and fit within organization and service structure</b>	<ul style="list-style-type: none"><li>• Can you tell me in simple terms what it is you or your service does?</li><li>• Where does this service fit within the existing stroke care pathway?</li><li>• To what extent do you think this service provision meets local needs of people with stroke?</li><li>• Is all of the need met for people with stroke? If not whose needs are not met by this service and why?</li><li>• If a new service or service reconfigurations were needed to ensure need was met, do you anticipate</li></ul>

	<p>any barriers to the uptake of new approaches to care (such as stroke specific VR)?</p> <ul style="list-style-type: none"> <li>○ Which organizational factors are likely to affect this?</li> <li>○ Which professional factors (or people) are likely to affect the way stroke specific VR can be delivered?</li> </ul> <ul style="list-style-type: none"> <li>● If a new SSVR service were needed which roles would need to be re-configured so that this development could happen?</li> <li>● How is stroke specific knowledge/ information shared/ disseminated?</li> <li>● How is VR specific knowledge/ information shared/ disseminated?</li> </ul>
<p><b>Understanding aspects of process (using the CATWOE framework)</b></p> <p>The following questions are designed to help me better understand the VR service.</p> <p>Can you tell me:-</p>	
<p><b>3. Customers</b></p>	<ul style="list-style-type: none"> <li>● Who are the service users? Where and how do they enter this VR service?</li> <li>● How many people are seen each year?</li> <li>● Where/ how is data about them stored?</li> <li>● Who is excluded? Why?</li> <li>● Does this service meet the needs of all people recovering from Stroke</li> </ul>
<p><b>4. Actors</b></p>	<ul style="list-style-type: none"> <li>● Which people provide the VR service? (WTE and grades)</li> <li>● Who else within the service / and or parent organisation is involved in return to work issues?</li> <li>● Who else external to the service / organisation is involved in helping stroke survivors to return to work?</li> <li>● Is there someone who specialises in stroke and or VR who works in this service/delivers the VR?</li> </ul>
<p><b>5. Transformations</b></p>	<ul style="list-style-type: none"> <li>● What does the service do?</li> <li>● Can you describe to me what would happen to someone with a STROKE entering this service?</li> </ul>

	<ul style="list-style-type: none"> <li>• What changes take place during the VR intervention?</li> <li>• When/where/how do people enter the service?</li> <li>• When/where how do they exit the service?</li> <li>• Where to they go after this?</li> <li>• Where and how do the different services providers become involved/ have input/ interact?</li> <li>• What methods of communication exist within this service/ between these related services?</li> <li>• Referrals: <ul style="list-style-type: none"> <li>○ Can you tell me how you accept referrals? How are they made? What happens next?</li> <li>○ Can you refer on to other services? How is this done?</li> </ul> </li> </ul>
<p><b>6. Cross partnership (statutory, voluntary and third sector) working and service inequity.</b></p>	<ul style="list-style-type: none"> <li>• External to it? (e.g. equipment services, driving assessment, social services care packages, Job Centre Plus services e.g. , Disability Employment Advisor , Work Psychologist, Access to Work Support Unit / Advisor)</li> <li>• When do representatives from related services in the private, voluntary or DWP providers who are involved in delivering VR services for people recovering from stroke meet?</li> <li>• What other stroke or VR specific networks exist at a local or national level, which allow knowledge or information about SSVR to be shared? <ul style="list-style-type: none"> <li>○ How are these accessed and by whom?</li> </ul> </li> </ul>
<p><b>7. World View</b></p>	<ul style="list-style-type: none"> <li>• What is good about this VR service/pathway? <ul style="list-style-type: none"> <li>○ Why is this? Who else thinks so?</li> </ul> </li> <li>• What is not so good about it? <ul style="list-style-type: none"> <li>○ Why is this? Who else thinks so?</li> </ul> </li> <li>• If you had suffered a stroke and you knew what you know about this VR service, which elements would give you rise for concern?</li> <li>• What are/ were the policy drivers to the development of this service?</li> <li>• Which policy factors currently influence or affect VR service delivery for stroke?</li> </ul>

<p><b>8. Fit with published guidelines for VR</b></p>	<ul style="list-style-type: none"> <li>• Are you familiar with 'Vocational Assessment and Rehabilitation after acquired brain injury: Inter-agency guidelines (Tyerman A, Meehan MJ, eds, 2004) and 'Vocational Assessment and Rehabilitation for people with LTNC (Tyerman et al., 2009) guidelines?</li> <li>• To what extent do the services you provide for people recovering from stroke fit with these guidelines? (Refer to mechanisms in * VR SERVICES – IDENTIFYING WHAT WORKS, FOR WHOM, IN WHAT CIRCUMSTANCES)</li> <li>• Which other policy documents or evidence influence the way your service is delivered?</li> </ul>
<p><b>9. Owners</b></p>	<ul style="list-style-type: none"> <li>• Who owns or commissions the service? Explore</li> <li>• Are patients or the public involved at a commissioning or managerial level?</li> <li>• How are the services you provide: <ul style="list-style-type: none"> <li>○ Marketed? Sold? To whom?</li> <li>○ Researched?/ Evaluated?</li> <li>○ Audited?/ Reviewed?</li> <li>○ Managed?</li> </ul> </li> </ul>
<p><b>10. Environment</b></p>	<ul style="list-style-type: none"> <li>• Where does service delivery take place?</li> <li>• Do you consider these environments to be appropriate? Modern? Safe? If not why not?</li> <li>• Does/do the environment(s) present any problem/ barrier to the organisation and delivery of this service or services which help stroke survivors return to work?</li> <li>• Do environmental barriers limit access to the service for any group of people recovering from Stroke? <ul style="list-style-type: none"> <li>○ If so, what needs to change?</li> </ul> </li> <li>• In your view, could the environment(s) be improved?</li> <li>• Does language or do cultural barriers limit access for people using the service?</li> </ul>

### APPENDIX 3: Thematic map - stakeholder interview study





#### APPENDIX 4: Participant interview schedule

1.	Can you tell me something about your stroke and how things have been going for you since your stroke?
2.	How did the stroke affect you?
3.	How did the stroke affect your work situation?
4.	Can you tell me about the support you have received since you had the stroke?
5.	Did you have any specific support to help you get back to work?
6.	Have you returned to work since your stroke?
7.	What is your current work situation?
8.	When you joined the return to work after stroke study what were your expectations about what the study would involve? Also what benefits did you anticipate you may get from it?
9.	Were you approached at the right time for you (to join the study/ to think about going back to work)?
10.	Could you tell me about the intervention offered by the study? What was the nature of it? Did it meet your particular needs?
11.	Can you tell me about useful aspects of the intervention (if any) and what else might have helped you in returning to

	work?
12.	What there anything you didn't like or find useful about the intervention?
13.	What other type of intervention or support do you think you may have benefited from?
14.	How many times did you see the OT? Was this the right amount of time for you?
15.	Did the therapist liaise with your employer at all? If not, why not?
16.	Did you feel the therapist respected your need for privacy/ dignity/ confidentiality regarding work matters?
17.	Did you have to make any changes to the way you worked in order to go back to work?
18.	How are you finding managing your condition in the work situation?
19.	Are there any unresolved issues regarding your work situation?
20.	What would you do if any new problems arose related to this stroke in the workplace?
21.	Is there anything else you would like to add or comment on regarding your participation in the study?

## **APPENDIX 5: VR training description**

This three day course covered the fundamentals of VR and the assessment of the individual and the workplace. The return to work process was central to this training and the importance of assessing the worker and analysing the job and then comparing the two to see how well they are matched was highlighted. After this, various modifications may be necessary to the work, the worker or the job tasks in order to make it possible for the person to return to work (Holmes, 2007).

Assessment focuses on the ability of the individual to undertake work tasks and to identify barriers to return to work (Innes & Straker, 2002). Work skills required are assessed looking at the demands of the job and can involve a work site visit and job analysis (Lysaght, 1997; Joss, 2002; Sandqvist & Henriksson, 2004). The work behaviours required are assessed and liaison with employer recommended with the person's consent. Work tolerance needs to be assessed using job simulation or by actually assessing this in the work place (Innes & Straker, 2002). The influence of self-efficacy, the belief in one's capabilities to do a task (Bandura, 1995), related to work is an important consideration.

The rehabilitation phase then follows which is focused on overcoming the barriers to work. It begins with work preparation, where a programme of non-specific job simulation work tasks are carried out (e.g. increasing daily activity tolerance in a general way) (Pratt & Jacobs, 1997; Stuckley, 1997). A phased return to work, negotiated with the employer, is then planned and specific hours and duties are agreed

and written up. This is then monitored ensuring there are mechanisms for review and problem solving any issues that arise. Once the individual returns to full duties then a monitoring and support role involving occasional meetings with employers is recommended over a three month period (Holmes, 2007).

Sometimes when work return is not possible or appropriate then referrals to other services may be necessary including education, skills training (via Disability Employment Adviser and Job Centre Plus) or voluntary work opportunities explored. Once this process is complete, the case will be closed and outcomes documented (Holmes, 2010). The hierarchy of return to work was recommended on this course for documenting outcomes (New Hampshire Department of Labor, 2014) (see below) alongside the use of standardised measures and satisfaction questionnaires.

Hierarchy of return to work (New Hampshire Department of Labor, 2014)

- Return to same job, same employer
- Return to same job modified, same employer
- Return to different job, same employer
- Return to same job modified, different employer
- Return to same job modified, different employer
- On the job training
- New skill training or retraining
- Other educational/ academic programme
- Other

**APPENDIX 6: Case study participant intervention presented to expert panel**

**Case Study 1**

<b>Gender:</b>	Male
<b>Age:</b>	69 years
<b>Occupation:</b>	Minor stroke
<b>Stroke Severity (NIHSS):</b>	Owner and Manager of Clothing Shop
<b>Stroke Type:</b>	Posterior circulation stroke (POCS) - Left homonymous hemianopia
<b>Length of stay in hospital:</b>	Four days
<b>Past medical history:</b>	Heart disease, diabetes, myocardial infarction at 50 years old, kidney cancer (treated)
<b>Other services received:</b>	Saw GP regarding driving
<b>Social situation:</b>	Lives with wife who does not go out to work, grown up children and grandchildren
<b>Lifestyle issues:</b>	Likes to drink whisky and smoke cigars – had reduced alcohol intake since stroke

**Early intervention and work preparation**

*Assessment:* Initial interview at home to determine impact of stroke, carry out detailed job analysis and assess how stroke may affect ability to do job

*Presenting problems:* Fatigue, left homonymous hemianopia resulting in difficulty walking around shops and unsteadiness on feet, unable to drive

due to hemianopia and needs transport for work, fear of having another stroke.

### **Early intervention**

*Provision of information:* Stroke Association leaflets on tiredness, visual problems and driving after stroke. Different Strokes information booklets on 'Work after Stroke: Information for Family and Friends'.

*Plan of action:* Education on compensatory strategies for hemianopia, strategies for managing fatigue and building up fitness with exercise and light jobs around the house.

### **Phased return to work**

*Planning a phased return to work*

Planned to go back part time, working from home some days and doing shorter days at work, support from wife and daughter in driving and help with business.

### **Progress made with phased return to work at the time of expert**

#### **panel:**

- Took time out from work for first 3 weeks after discharged from hospital but was in contact with work by email and phone, having a sleep in the day.
- Did first trip to buy stock (wife drove car) 3.5 weeks after stroke.
- Started to go into work for 2 hours a day 5 weeks after the stroke and working at home.

- Went on holiday 6 weeks after stroke.
- Started to go into work for 4-5 hours a day, 4 days a week, 7 weeks after stroke but going to bed at 8.30pm.

**Situation at time of expert panel:**

- Hemianopia not resolved and frustrated about this in relation to not being able to drive.
- Stress levels increased due to plans to close shop due to financial and legal issues and more intense work pattern.
- Able to pace self and regularly checks blood pressure.
- Plans to increase working hours leading up to Christmas and shop closure in January.

**Sustaining work return**

*Monitoring progress*

Monthly meetings to discuss return to work, working hours, work duties, monitoring impact on fatigue levels and how to manage this.

*Intervention*

Ongoing.

## Case Study 2

<b>Gender:</b>	Female
<b>Age:</b>	58 years
<b>Occupation:</b>	Manager of Fish and Chip Shop
<b>Stroke Severity (NIHSS):</b>	Minor Stroke
<b>Stroke Type:</b>	POCS - Right homonymous hemianopia
<b>Length of stay in hospital:</b>	Three days
<b>Past medical history:</b>	None
<b>Other services received:</b>	Saw GP and referral made to see orthoptist as out-patient
<b>Social situation:</b>	Lives with husband and two grown up children who all work
<b>Lifestyle issues:</b>	Smoked heavily for 40 years but gave up the day of the stroke

### Early intervention and work preparation

*Assessment:* Initial interview at home to determine impact of stroke, carry out detailed job analysis and assess how stroke may affect ability to do job

*Presenting problems:* Fatigue, feeling lightheaded and dizzy when tired, right homonymous hemianopia, unsteadiness when walking, unable to drive due to hemianopia but needs transport for work, highly anxious about having another stroke (affecting sleep and causing low mood), financial impact of stroke (put on



statutory sick pay by employer immediately after stroke)

### **Early intervention**

*Provision of information:* Stroke Association leaflets on tiredness, visual problems and driving after stroke. Different Strokes information booklets on 'Work after Stroke: Information for Family and Friends'

*Plan of action:* Education on compensatory strategies for hemianopia, strategies for increasing confidence walking outside, going to shops and using public transport

### **Phased return to work**

*Planning a phased return to work*

Conversation with husband who contacted me because he was concerned that his wife wanted to return to work full time straight away but was extremely fatigued by going food shopping, letter to employer via participant making recommendations about return to work including lighter duties, taking breaks, hours of work and transport to work and including Different Strokes 'Work after Stroke - Information for Employers'. Provision of Access to work information.

**Progress made with phased return to work at the time of expert panel:**

- Vision gradually improved to normal, tested by orthoptist and allowed to drive 4 weeks after stroke – prior to this, confidence increased by using public transport (including train to visit mother).
- Started phased return 4 weeks after stroke, 3 days a week, 3 hours each day.
- Increased hours more rapidly than originally planned during second and third weeks back at work.
- Managed well with computer work.
- Wanted to test herself on heavier duties and setting up shop alone.

**Situation at time of expert panel:**

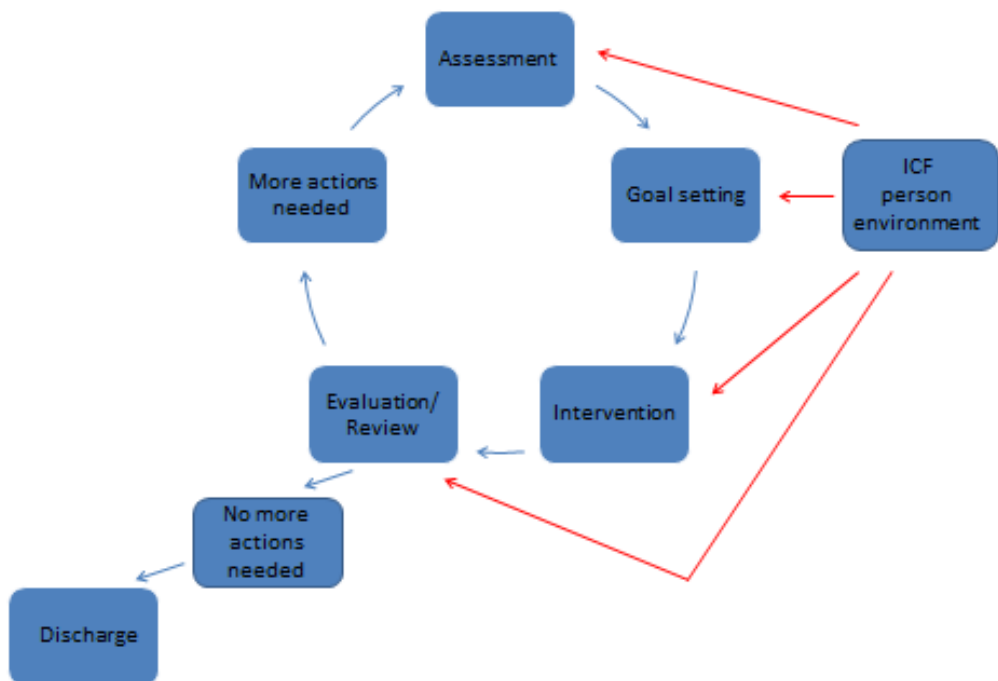
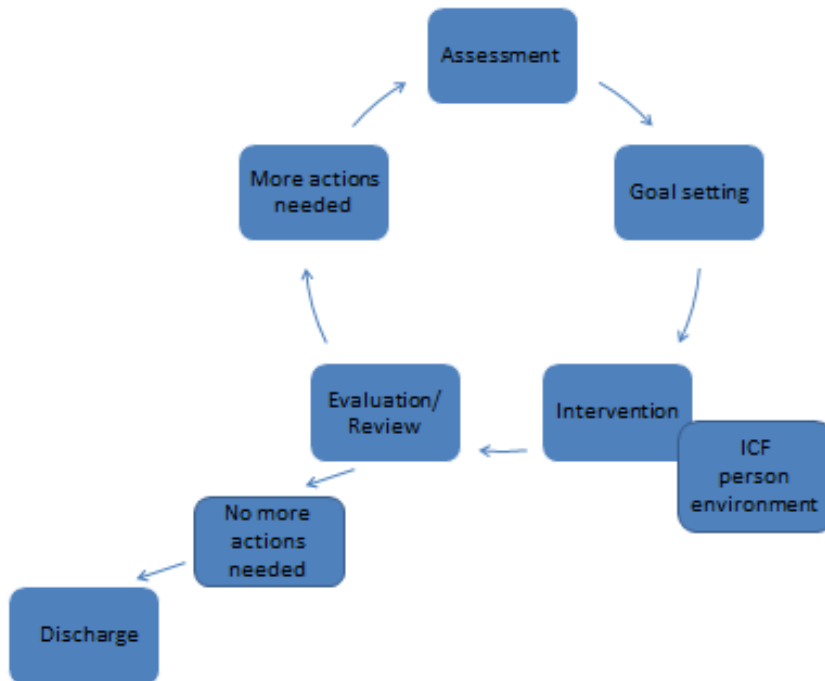
- On holiday abroad at time of panel.
- Wants to return to full time hours on return from holiday but only working one evening and then to reassess the situation.
- Longer term plans, feels she wants to work there until after Christmas but then may look for a more local job in a supermarket.

**Sustaining work return**

*Monitoring progress*                      Fortnightly meetings to discuss return to work hours, ability to fulfil work duties and monitoring fatigue levels.

*Intervention*                                      Ongoing.

**APPENDIX 7: The rehabilitation process – original and adapted (Wade, 2005)**



## APPENDIX 8: Baseline questionnaire booklet

### Section 1

<b>Participant Number:</b>		
<b>Are you currently?</b>		
Single <input type="checkbox"/> 1	Married <input type="checkbox"/> 2	Separated <input type="checkbox"/> 3
Divorced <input type="checkbox"/> 4	Widowed <input type="checkbox"/> 5	Living with partner <input type="checkbox"/> 6
Separated and living with a new partner <input type="checkbox"/> 7	Divorced and living with a new partner <input type="checkbox"/> 8	Widowed and living with a new partner <input type="checkbox"/> 9

### Section 2

We are trying to find out what you are doing now. Please **tick all** the following statements that apply to you now.

#### 1. What are your living arrangements?

Are they the same as before your stroke? Yes <input type="checkbox"/> 1 No <input type="checkbox"/> 2
If no, please explain

#### 2. Are you still married or living with the same long term partner as you did before your stroke?

Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	I did not have a long term partner before my stroke <input type="checkbox"/> 3
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#### 3. Driving: If you were driving before your stroke:

Have you started driving again?	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If you are not driving, has it affected your ability to work?	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2
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**4. What is your current medical situation? (tick all those that apply)**

I am fully recovered from my stroke	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2
I am on sick leave at present, because of my stroke	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2

**5. Are you planning to return to work or education? By work or education we mean any paid or unpaid (voluntary) work or education of at least 1 hour per week.**

<i>If yes, please go to question 6</i>	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2
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**6. If you are trying to return to work or education, please tick the following statements that apply now**

I intend to return to what I was doing before my stroke	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2
I am on a programme to help me find work	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2
I am unemployed and actively looking for work	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2
I am hoping for a phased return to work or education (by this we mean gradually increasing your hours)	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2
Other (please tell us more about your current work situation)		
<b>Is your job part time or full time?</b>	Part time <input type="checkbox"/> 1	Full time <input type="checkbox"/> 2
<b>When are you hoping to return to work?</b>		

**7. Are you planning to tell your employers / college / voluntary work about your stroke?**

Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2
Any comments	

**With the following questions, we are trying to find out how your income has been affected?**

(This information is only required for this research and will remain completely confidential)

**8. What benefits are you currently claiming as a result of your stroke?**

None <input type="checkbox"/> 1	Disability Living Allowance <input type="checkbox"/> 2
Income Support <input type="checkbox"/> 3	Incapacity Benefit / Employment and Support Allowance <input type="checkbox"/> 4
Job Seekers Allowance <input type="checkbox"/> 5	Carers allowance <input type="checkbox"/> 6
Sick Pay / Statutory Sick Pay <input type="checkbox"/> 7	Other (Please specify):

**9. What is your annual income from paid employment at this point in time?**

£
---

10. **Do you think you would better off financially if you returned to paid work?**

Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	Don't know <input type="checkbox"/> 3
If no, please state why?		

14. **What services have you received as a result of your stroke?** (We appreciate it is sometimes difficult to remember which people you have seen, if you can remember their names, or the service they work for, this would be helpful). Please write this information below. If unsure, please put in your best guess.

Do not include services received while you were an in-patient in a hospital.

1.	Consultant/hospital doctor	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
2.	GP	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
3.	Psychologist	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
4.	Occupational Therapist	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
5.	Physiotherapist	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	

6.	Speech and Language Therapist	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
7.	Social Worker	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
8.	Other: (please give details)				

**16. Please tell us if you have had contact with any of the people listed below as a result of your stroke?**

1.	Benefits advisor	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
2.	Disability employment advisor	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
3.	Other services arranged by the job centre	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
4.	Solicitor	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	
5.	Other services aimed at helping you get or stay in work or education – please specify	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?	



6.	<p>A self-help group:</p> <p>Please state which one:</p>	Yes <input type="checkbox"/> 1	No <input type="checkbox"/> 2	If yes, how many times?
7.	Please say if you have seen anyone else who has helped you since discharge from hospital			

### **Section 3 - Questionnaires**

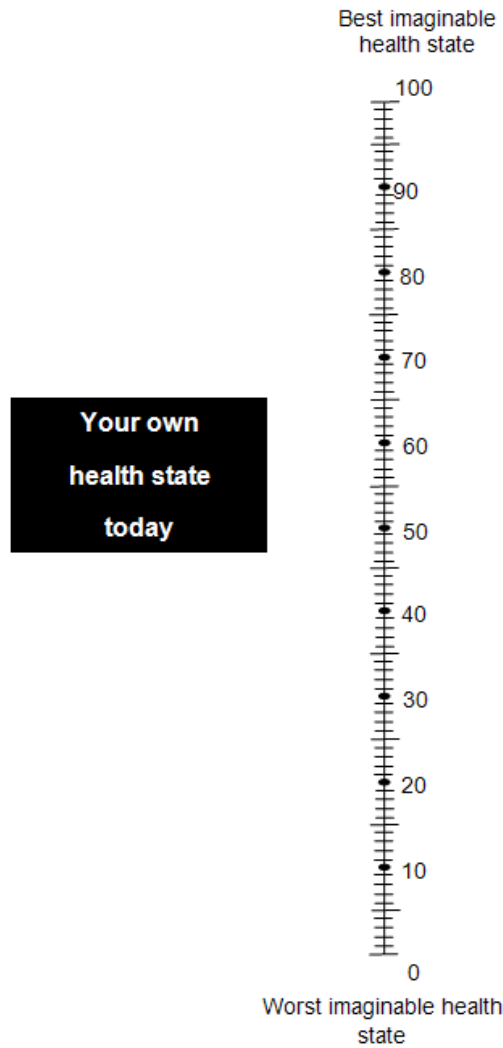
#### **Questionnaire 1 (EQ-5D)**

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

<b>Group 1: Mobility</b>	
I have no problems in walking about	
I have some problems in walking about	
I am confined to bed	
<b>Group 2: Self-Care</b>	
I have no problems with self-care	
I have some problems washing or dressing myself	
I am unable to wash or dress myself	
<b>Group 3: Usual Activities</b> ( <i>e.g. work, study, housework, family or leisure activities</i> )	
I have no problems with performing my usual activities	
I have some problems with performing my usual activities	
I am unable to perform my usual activities	
<b>Group 4: Pain/Discomfort</b>	
I have no pain or discomfort	
I have moderate pain or discomfort	
I have extreme pain or discomfort	
<b>Group 5: Anxiety/Depression</b>	
I am not anxious or depressed	
I am moderately anxious or depressed	
I am extremely anxious or depressed	

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.



[This completes questionnaire 1](#)

## Questionnaire 2 (HADS)

We should like to know how your health is affecting your mood and how you have been feeling **IN THE PAST WEEK OR SO**. Please answer **ALL** the questions by putting a tick in the box which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

<b>I feel tense or 'wound up':</b>		<b>I feel as if I am slowed down:</b>	
Most of the time	<input type="checkbox"/>	Nearly all the time	<input type="checkbox"/>
A lot of the time	<input type="checkbox"/>	Very often	<input type="checkbox"/>
Time to time, Occasionally	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	Not at all	<input type="checkbox"/>
<b>I still enjoy the things I used to enjoy:</b>		<b>I get a sort of frightened feeling like 'butterflies' in the stomach:</b>	
Definitely as much	<input type="checkbox"/>	Not at all	<input type="checkbox"/>
Not quite so much	<input type="checkbox"/>	Occasionally	<input type="checkbox"/>
Only a little	<input type="checkbox"/>	Quite often	<input type="checkbox"/>
Hardly at all	<input type="checkbox"/>	Very often	<input type="checkbox"/>
<b>I get a sort of frightened feeling as if something awful is about to happen:</b>		<b>I have lost interest in my appearance:</b>	
Very definitely and quite badly	<input type="checkbox"/>	Definitely	<input type="checkbox"/>
Yes, but not too badly	<input type="checkbox"/>	I don't take as much care as I should	<input type="checkbox"/>
A little, but it doesn't worry me	<input type="checkbox"/>	I may not take quite as much care	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	I take just as much care as ever	<input type="checkbox"/>
<b>I can laugh and see the funny side of things:</b>		<b>I feel restless as if I have to be on the move:</b>	
As much as I always could	<input type="checkbox"/>	Very much indeed	<input type="checkbox"/>
Not quite so much now	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>
Definitely not so much now	<input type="checkbox"/>	Not very much	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	Not at all	<input type="checkbox"/>

<b>Worrying thoughts go through my mind:</b>		<b>I look forward with enjoyment to things :</b>	
A great deal of the time		As much as I ever did	
A lot of the time		Rather less than I used to	
From time to time but not too often		Definitely less than I used to	
Only Occasionally		Hardly at all	
<b>I feel cheerful:</b>		<b>I get sudden feelings of panic :</b>	
Not at all		Very often indeed	
Not often		Quite often	
Sometimes		Not very often	
Most of the time		Not at all	
<b>I can sit at ease and feel relaxed:</b>		<b>I can enjoy a good book or radio programme or TV:</b>	
Definitely		Often	
Usually		Sometimes	
Not often		Not often	
Not at all		Very seldom	

This completes questionnaire 2

### Questionnaire 3 (WPAI)

The following questions ask about the effect of your stroke on your ability to work and perform regular activities. *Please fill in the blanks or circle a number, as indicated.*

1. Are you currently working(paid or voluntary)/ studying? \_\_\_\_\_ NO \_\_\_ YES  
*If NO, tick "NO" and skip to question 6.*

The next questions are about the **past seven days**, not including today.

2. During the past seven days, how many hours did you miss from work/ study because of problems associated with your stroke? *Include hours you missed on sick days, times you went in late, left early, etc., because of your stroke. Do not include time you missed to participate in this study.*

\_\_\_\_\_ HOURS

3. During the past seven days, how many hours did you miss from work/ study because of any other reason, such as vacation, holidays, time off to participate in this study?

\_\_\_\_\_ HOURS

4. During the past seven days, how many hours did you actually work/ study?

\_\_\_\_\_ HOURS *(If "0", skip to question 6.)*

5. During the past seven days, how much did your stroke affect your productivity while you were working (paid or voluntary)/ studying?

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If stroke affected your work only a little, choose a low number. Choose a high number if stroke affected your work a great deal.

Consider only how much stroke affected your productivity while you were working/ studying.

Stroke had no effect on my work	0 1 2 3 4 5 6 7 8 9 10	Stroke completely prevented me from working
CIRCLE A NUMBER		

6. During the past seven days, how much did your stroke affect your ability to do your regular daily activities, other than work at a job/ course?

*By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If stroke affected your activities only a little, choose a low number. Choose a high number if stroke affected your activities a great deal.*

Consider only how much stroke affected your ability to do your regular daily activities, other than work at a job.

Stroke had no effect on my daily activities	0 1 2 3 4 5 6 7 8 9 10	Stroke completely prevented me from doing my daily activities
CIRCLE A NUMBER		

WPA/SHF V20 (US English)

This completes questionnaire 3

### **Questionnaire 4 (NEADL)**

Please answer these questions by ticking ONE box for each question. Please record WHAT YOU HAVE ACTUALLY DONE IN THE LAST WEEK.

<b>Do you.....</b>	<b>not at all</b>	<b>with help</b>	<b>on your own with difficulty</b>	<b>on your own easily</b>
Walk around outside?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Climb stairs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get in and out of a car?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walk over uneven ground?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cross overroads?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel on public transport?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Manage to feed yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Manage to make yourself a hot drink?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Take hot drinks from one room to another?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do the washing up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Make yourself a hot snack?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Manage your own money when you are out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wash small items of clothing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do your own housework?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do your own shopping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do a full clothes wash?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Read newspapers or books?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use the telephone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Write letters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Go out socially?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Manage your own garden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drive a car?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This completes questionnaire 4

**Questionnaire 5: (MS Cognitive Screen)**

The following questions ask about problems that you may experience. Rate how often these problems occur **AND** how severe they are. Base your ratings on how you have been **over the last 3 months**. Please **TICK (√)** the appropriate box

	Very often	Quite often	Occasionally	Very rarely	Never or does not occur
	4	3	2	1	0
Are you easily distracted?					
Do you lose your thoughts while listening to somebody speak?					
Are you slow when trying to solve problems?					
Do you forget appointments?					
Do you forget what you read?					
Do you have trouble describing shows or programs recently watched?					
Do you need to have instructions repeated?					
Do you have to be reminded to do tasks?					
Do you forget errands that were planned?					
Do you have difficulty answering questions?					
Do you have difficulty keeping track of two					

things at once?					
Do you miss the point of what someone is trying to say?					
Do you have difficulty controlling impulses?					
Do you laugh or cry with little cause?					
Do you talk excessively or focus too much on your own interests?					

This completes Questionnaire 5

**Questionnaire 6 (SPRS)**

1. What is your current occupation/ what course are you studying?	
2. What are your work duties at present?	
3. What was your job at the time of the stroke?	
4. What were your work duties in that job?	
5. How many jobs have you had since the stroke (not including work trials or voluntary work)?	

<p>6 &amp; 7. What are/were your leisure interests, recreation, hobbies and club membership, at present and at time of stroke?</p> <p><b>6. At time of Stroke</b>                      <b>7. Present</b></p>	
<p>8 &amp; 9. What is/was your weekly programme of work, leisure/recreational activities at present and at time of stroke?</p> <p><b>8. At time of Stroke</b>                      <b>9. Present</b></p>	
<p><b>10.</b> Who was in your circle of close friends at time of stroke?</p>	
<p><b>11.</b> Who is in your circle of close friends at present?</p>	
<p><b>12.</b> Who did you live with at time of stroke?</p>	
<p><b>15.</b> Who do you live with at present?</p>	

<b>WORK and LEISURE</b>			
<b>1. Current work:</b>			
Have the hours of work (or study), or the type of work (study) changed because of the stroke? <i>(if you are a student, answer the question in this section in terms of changes in your studies)</i>			
Please tick the appropriate box			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Now work less hours per week, OR work duties (study) have changed for easier/lighter ones	3
	<b>Moderately:</b>	Work casually, OR have some help from others in doing some work (study)	2
	<b>A lot:</b>	Now unemployed, OR in rehabilitation, OR in a supported work programme, or doing volunteer work, OR receive remedial assistance in studies	1
	<b>Extreme:</b>	Am almost unable to work (study) OR am unable to at present	0
	<b>Unable to assess:</b>	Did not work before the stroke and still do not work	NA
<b>2. Work skills:</b> Have the work (study) skills changed because of the stroke?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Not quite as good, e.g. have to put in a lot of effort to get the same result, get tired easily, lose concentration	3
	<b>Moderately:</b>	Definitely not as good, e.g. sometimes make mistakes	2
	<b>A lot:</b>	Much worse, e.g. I am slower	1
	<b>Extreme:</b>	Very much worse, e.g. make many mistakes, am very	0

19

		slow, work is of poor quality, need constant supervision and/or reminders at present	
<b>3. Leisure:</b> Has there been any change in the number or type of leisure activities or interests because of the stroke?			
	<b>Not at all:</b>	Same or more and done as often or more	4
	<b>A little:</b>	Have most of the same activities and interests, OR have the same activities and interests but do them less often	3
	<b>Moderately:</b>	Definitely less but may have developed new activities and interests	2
	<b>A lot:</b>	Only have some of the leisure activities and interests and have not developed new ones	1
	<b>Extreme:</b>	Almost none or no leisure activities or interests at present	0
	<b>Unable to assess:</b>	Did not have leisure activities before the stroke and still do not have leisure activities	NA
<b>4. Organising Activities:</b> Has there been any change in the way you organise work and leisure activities because of the stroke?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Need prompts or supports from others	3
	<b>Moderately:</b>	More dependent on other people to organise activities, e.g. others suggest what to do and how to go about it	2
	<b>A lot:</b>	Need other people to do the organising, e.g. making arrangements, providing transport	1
	<b>Extreme:</b>	Almost completely OR completely dependent on other people to suggest and organise activities at present	0

20

RELATIONSHIPS			
5. Spouse or Partner: Did you have a partner or spouse at the time of the stroke?			
[a] If YES has the relationship changed because of the stroke? If NO, GO to Part [b] below			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Not quite the same but am still able to get along	3
	<b>Moderately:</b>	Definitely not the same	2
	<b>A lot:</b>	A lot of changes <u>but</u> I might have the skills to form a new relationship	1
	<b>Extreme:</b>	Nature of relationship has changed in a major way (e.g. partner takes on most responsibilities or is the primary care-giver/relationship has broken down) <u>and</u> I probably do not have the skills to form a new relationship	0
[b] If NO, how much change is there in your ability to form and maintain such a relationship, compared to before?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Not quite the same	3
	<b>Moderately:</b>	Definitely not the same	2
	<b>A lot:</b>	A lot of changes but I might have the skills to form a new relationship	1
	<b>Extreme:</b>	Probably do not have the skills to form a new relationship	0



<b>6. Family:</b> Have your relationships with other family members changed because of the stroke?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Not quite the same	3
	<b>Moderately:</b>	Definitely not the same	2
	<b>A lot:</b>	A lot of changes in relationships with some family members	1
	<b>Extreme:</b>	Changed in a major way OR a breakdown of relationships with some family members due to effects of the stroke	0
	<b>Unable to assess:</b>	Did not have contact with family before the stroke	NA
<b>7. Friends and other people:</b> Have your relationships with other people outside family (such as close friends, work mates/colleagues, neighbours) changed because of the stroke?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Not quite the same but still see some friends weekly or more, make new friends and get along with work mates/colleagues and neighbours	3
	<b>Moderately:</b>	Definitely not the same but still see some friends once a month or more and can make new friends	2
	<b>A lot:</b>	Only see a few friends (or other people outside family) and do not make new friends easily	1

	<b>Extreme:</b>	See hardly any friends or see none at all (or other people outside the family)	0
<b>8. Communication:</b> Have your communication skills (that is, talk with other people and understand what others say) changed because of the stroke?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Some changes, e.g. ramble and get off the point, talk is sometimes inappropriate, have some trouble finding the words to express myself	3
	<b>Moderately:</b>	Definite changes, e.g. difficulty thinking of things to say, joining in talk with groups of people, only talk about myself	2
	<b>A lot:</b>	A lot of changes, e.g. having trouble understanding what people say	1
	<b>Extreme:</b>	Major changes but can communicate basic needs OR use aids for communication or communication is almost impossible	0
<b>LIVING SKILLS</b>			
<b>9. Social Skills:</b> Have your social skills and behaviour in public changed because of the stroke?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Some changes, e.g. am awkward with other people, do not worry about what other people think or want	3
	<b>Moderately:</b>	Definite changes, e.g. can act in a silly way, am not as tactful or sensitive to other people's needs	2
	<b>A lot:</b>	A lot of changes, e.g. am more dependent on other people, am socially withdrawn	1

	<b>Extreme:</b>	Major changes, e.g. have difficulty interacting appropriately with other people, behaviour is unpredictable, have temper outbursts in public, require supervision when with other people	0
<b>10 Personal Habits:</b> Have your personal habits (e.g. your care in cleanliness, dressing and tidiness) changed because of the stroke?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Do not take as much care as before	3
	<b>Moderately:</b>	Attend to my hygiene, dress and tidiness but have definitely changed in this area; need supervision	2
	<b>A lot:</b>	Need prompts, reminders or advice from others, but respond to these; need stand-by assistance	1
	<b>Extreme:</b>	Need prompts, reminders or advice from others, but respond to these only after repeated requests; need hand-on assistance; am totally dependent for assistance	0
<b>11. Community Travel:</b> Has your use of transport and travel around the community changed due to the stroke?			
NOTE: Do not include the driver of transport, or other passengers using such transport in rating whether you can travel "alone" or "by yourself"			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Unable to use some forms of transport (e.g. driving a car) but can still get around in the community by using other forms of transport without help	3
	<b>Moderately:</b>	Definite changes in use of transport but after training can travel around the community on my own	2

	<b>A lot:</b>	Need assistance to plan use of transport but with such help can travel around the community on my own	1
	<b>Extreme:</b>	Very restricted in use of transport but with supervision can make short familiar journeys around the community on my own (e.g. going out to the local shop) OR am unable to go out into the community alone.	0
<b>12. Accommodation:</b> Has your living situation changed due to the stroke?			
	<b>Not at all:</b>	Same or better	4
	<b>A little:</b>	Live in the community but with emotional or social supports provided by other people such as family, friends or neighbours. Cannot be left alone without supports for a two-week period	3
	<b>Moderately:</b>	Definite changes and cannot be left alone for a weekend unless someone was available to check everything was OK	2
	<b>A lot:</b>	Live in the community but in support accommodation such as a group home, boarding house, transitional living unit, in family home but require daily supervision or assistance	1
	<b>Extreme:</b>	Almost unable to live in the community, even with daily supervision or assistance OR need care which may be at home requiring extensive daily supervision, OR other care, OR in an institution such as a nursing home, residential service, rehabilitation unit	0

This completes Questionnaire 6

## **Questionnaire 7 (WLQ)**

### **Instructions**

Health problems can make it difficult for working people to perform certain parts of their jobs. We are interested in learning about how your health may have affected you at work during the past two weeks.

- (1) The questions will ask you to think about your physical health or emotional problems. These refer to any ongoing or permanent medical conditions you may have and the effects of any treatments you are taking for these. Emotional problems may include feeling depressed or anxious.
- (2) Most of the questions are multiple choice. They ask you to answer by placing a mark in a box.

For example: How satisfied are you with each of the following . . . ?

*(mark one box on each line a. and b.)*

	Not at all satisfied	Moderately satisfied	Very Satisfied
a. Your local schools.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input checked="" type="checkbox"/> 3
b. Your local police department...	<input type="checkbox"/> 1	<input checked="" type="checkbox"/> 2	<input type="checkbox"/> 3

These marks tell us you are very satisfied with your local schools and moderately satisfied with your local police department.

Questions 1 to 5 ask about how your health has affected you at work during the past two weeks. Please answer these questions even if you missed some workdays.

- Mark the "Does not apply to my job" box only if the question describes something that is not part of your job.
- If you have more than one job, report on your **main** job only.

1 In the <u>past two weeks</u> , how much of the time did your physical health or emotional problems <b>make it difficult</b> for you to do the following? (mark one box on each line)						
	Difficult all of the time (100%)	Difficult most of the time	Difficult some of the time (50%)	Difficult a slight bit of the time	Difficult none of the time (0%)	Does not apply to my job
Work the required number of hours	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Get going easily at the beginning of the workday	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Start on your job as soon as you arrived at work	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Do your work without stopping to take breaks or rests	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Stick to a routine or schedule	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

These questions ask you to rate the amount of time you were <u>able</u> to handle certain parts of your job <b>without difficulty</b> .	
2 a	In the <u>past two weeks</u> , how much of the time were you <b>able</b> to walk or move around different work locations (for example, go to meetings), <b>without difficulty</b> caused by physical health or emotional problems?
	<i>(mark one box)</i>
All of the time (100%)	<input type="checkbox"/> 1
Most of the time	<input type="checkbox"/> 2
Some of the time (about 50%)	<input type="checkbox"/> 3
A slight bit of the time	<input type="checkbox"/> 4
None of the time (0%)	<input type="checkbox"/> 5
Does not apply to my job.	<input type="checkbox"/> 6
b	In the <u>past two weeks</u> , how much of the time were you <b>able</b> to lift, carry, or move objects at work weighing more than 10lbs (4.5kg), <b>without difficulty</b> caused by physical health or emotional problems?
	<i>(mark one box)</i>
All of the time (100%)	<input type="checkbox"/> 1
Most of the time	<input type="checkbox"/> 2
Some of the time (about 50%)	<input type="checkbox"/> 3

A slight bit of the time	<input type="checkbox"/> 4
None of the time (0%)	<input type="checkbox"/> 5
Does not apply to my job.	<input type="checkbox"/> 6
<b>c</b> In the <u>past two weeks</u> , how much of the time were you <b>able</b> to sit, stand, or stay in one position for longer than 15 minutes while working, <b>without difficulty</b> caused by physical health or emotional problems?	
<i>(mark one box)</i>	
All of the time (100%)	<input type="checkbox"/> 1
Most of the time	<input type="checkbox"/> 2
Some of the time (about 50%)	<input type="checkbox"/> 3
A slight bit of the time	<input type="checkbox"/> 4
None of the time (0%)	<input type="checkbox"/> 5
Does not apply to my job.	<input type="checkbox"/> 6
<b>d</b> In the <u>past two weeks</u> , how much of the time were you <b>able</b> to repeat the same motions over and over again while working, <b>without difficulty</b> caused by physical health or emotional problems?	
<i>(mark one box)</i>	
All of the time (100%)	<input type="checkbox"/> 1



Most of the time	<input type="checkbox"/> 2
Some of the time (about 50%)	<input type="checkbox"/> 3
A slight bit of the time	<input type="checkbox"/> 4
None of the time (0%)	<input type="checkbox"/> 5
Does not apply to my job.	<input type="checkbox"/> 6
e In the <u>past two weeks</u> , how much of the time were you <b>able</b> to bend, twist, or reach while working, <b>without difficulty</b> caused by physical health or emotional problems?	
<i>(mark one box)</i>	
All of the time (100%)	<input type="checkbox"/> 1
Most of the time	<input type="checkbox"/> 2
Some of the time (about 50%)	<input type="checkbox"/> 3
A slight bit of the time	<input type="checkbox"/> 4
None of the time (0%)	<input type="checkbox"/> 5
Does not apply to my job.	<input type="checkbox"/> 6
f In the <u>past two weeks</u> , how much of the time were you <b>able</b> to use hand-held tools or equipment (e.g. a phone, pen, keyboard, computer mouse, drill, hairdryer or sander), <b>without difficulty</b> caused by physical health or	

30

emotional problems?						
	<i>(mark one box)</i>					
All of the time (100%)	<input type="checkbox"/> 1					
Most of the time	<input type="checkbox"/> 2					
Some of the time (about 50%)	<input type="checkbox"/> 3					
A slight bit of the time	<input type="checkbox"/> 4					
None of the time (0%)	<input type="checkbox"/> 5					
Does not apply to my job.	<input type="checkbox"/> 6					
<b>These questions ask about difficulties you may have had at work</b>						
3 In the <u>past two weeks</u> , how much of the time did your physical health, or emotional problems <b>make it difficult</b> for you to do the following?						
	Difficult all of the time (100%)	Difficult most of the time	Difficult some of the time (50%)	Difficult a slight bit of the time	Difficult none of the time (0%)	Does not apply to my job
Keep your mind on your work	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Think clearly when working	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Do work carefully	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Concentrate on your work	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Work without losing your train of thought	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

31

Easily read or use your eyes when working	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>The next questions ask about difficulties in relation to the people you came into contact with while working. These may include employers, supervisors, co-workers, clients, customers or the public.</b>						
4 In the <u>past two weeks</u> , how much did your physical health, or emotional problems <b>make it difficult</b> for you to do the following?						
	<b>Difficult all of the time (100%)</b>	<b>Difficult most of the time</b>	<b>Difficult some of the time (50%)</b>	<b>Difficult a slight bit of the time</b>	<b>Difficult none of the time (0%)</b>	<b>Does not apply to my job</b>
Speak with people in-person, in meetings, or on the phone	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Control your temper around people when working	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Help other people to get work done	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>These questions ask about how things went at work overall.</b>						
5 In the <u>past two weeks</u> , how much did your physical health, or emotional problems <b>make it difficult</b> for you to do the following?						
	<b>Difficult all of the time (100%)</b>	<b>Difficult most of the time</b>	<b>Difficult some of the time (50%)</b>	<b>Difficult a slight bit of the time</b>	<b>Difficult none of the time (0%)</b>	<b>Does not apply to my job</b>
Handle the workload	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Work fast enough	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

Finish work on time	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Do your work without making mistakes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Feel you've done what you are capable of doing	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

This completes Questionnaire 7

### **Questionnaire 8: (SIS)**

The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from ***YOUR POINT OF VIEW*** how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to relate how much you think you have recovered from your stroke.

These questions are about the physical problems which may have occurred as a result of your stroke.

In the past week, how would you rate the strength of your:-	A lot of strength	Quite a bit of strength	Some strength	A little strength	No strength at all
Arm that was <u>most affected</u> by your stroke?	5	4	3	2	1
Grip of your hand that was <u>most affected</u> by your stroke?	5	4	3	2	1
Leg that was <u>most affected</u> by your stroke?	5	4	3	2	1
Foot/ankle that was <u>most affected</u> by your stroke?	5	4	3	2	1

These questions are about your memory and thinking.

In the past week, how difficult was it for you to:-	Not difficult at all	A little difficult	Some what difficult	Very difficult	Extremely difficult
Remember things that people just told you?	5	4	3	2	1
Remember things that happened the day before?	5	4	3	2	1
Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
Remember the day of the week?	5	4	3	2	1
Concentrate?	5	4	3	2	1
Think quickly?	5	4	3	2	1
Solve everyday problems?	5	4	3	2	1

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.

In the past week, how often did you:-	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Feel sad?	5	4	3	2	1
Feel that there is nobody you are close to?	5	4	3	2	1
Feel that you are a burden to others?	5	4	3	2	1
Feel that you have nothing to look forward to?	5	4	3	2	1
Blame yourself for mistakes that you made?	5	4	3	2	1
Enjoy things as much as ever?	5	4	3	2	1
Feel quite nervous?	5	4	3	2	1
Feel that life is worth living?	5	4	3	2	1
Smile and laugh at least once a day?	5	4	3	2	1

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation

In the past week, how difficult was it to:-	Not difficult at all	A little difficult	Some what difficult	Very difficult	Extremely difficult
Say the name of someone who was in front of you?	5	4	3	2	1
Understand what was being said to you in a conversation?	5	4	3	2	1
Reply to questions?	5	4	3	2	1
Correctly name objects?	5	4	3	2	1
Participate in a conversation with a group of people?	5	4	3	2	1
Have a conversation on the telephone?	5	4	3	2	1
Call another person on the telephone, including selecting the correct phone number and dialling?	5	4	3	2	1



The following questions ask about activities you might do during a typical day.

In the past two weeks, how difficult was it to:-	None of the time	A little of the time	Some what difficult	Very difficult	Could not do at all
Cut your food with a knife and fork?	5	4	3	2	1
Dress the top part of your body?	5	4	3	2	1
Bathe yourself?	5	4	3	2	1
Clip your toenails?	5	4	3	2	1
Get to the toilet on time?	5	4	3	2	1
Control your bladder (not have an accident)?	5	4	3	2	1
Control your bowels (not have an accident)?	5	4	3	2	1
Do light household tasks/chores (e.g. dust, make a bed, take out household rubbish, washing up)?	5	4	3	2	1
Go shopping?	5	4	3	2	1
Do heavy household chores (e.g. vacuum, laundry or gardening)?	5	4	3	2	1

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The following questions are about your ability to be mobile, at home and in the community

In the past two weeks, how difficult was it to:-	Not difficult at all	A little difficult	Some what difficult	Very difficult	Could not do at all
Stay sitting without losing your balance?	5	4	3	2	1
Stay standing without losing your balance?	5	4	3	2	1
Walk without losing your balance?	5	4	3	2	1
Move from a bed to a chair?	5	4	3	2	1
Walk down one street?	5	4	3	2	1
Walk fast?	5	4	3	2	1
Climb a flight of stairs?	5	4	3	2	1
Climb several flights of stairs?	5	4	3	2	1
Get in and out of a car?	5	4	3	2	1

The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.

In the past two weeks, how difficult was it to use your hand that was affected by your stroke to:-	Not difficult at all	A little difficult	Some what difficult	Very difficult	Could not do at all
Carry heavy objects (e.g. bag of shopping/groceries)	5	4	3	2	1
Turn a door knob?	5	4	3	2	1
Open a can or jar?	5	4	3	2	1
Tie a shoelace?	5	4	3	2	1
Pick up a coin (e.g. 20 pence)?	5	4	3	2	1

The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.

In the past four weeks, how much of the time have you been limited in:-	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Your work (paid, voluntary or other)?	5	4	3	2	1
Your social activities?	5	4	3	2	1

Quiet recreation (crafts, reading)?	5	4	3	2	1
Active recreation (sports, outings, travel)?	5	4	3	2	1
Your role as a family member and/or friend?	5	4	3	2	1
Your participation in spiritual or religious activities?	5	4	3	2	1
Your ability to control your life as you wish?	5	4	3	2	1
Your ability to help others?	5	4	3	2	1

**This completes Questionnaire 8**

**Questionnaire 9:**

Please score the following statements on a rating scale of 1-5 to indicate how you feel:

1 = not at all confident

2 = somewhat confident

3 = confident

4 = very confident

5 = extremely confident

	1	2	3	4	5
I feel confident that I can work					
I feel confident that I will be able to find work					
I feel confident in my ability to manage my condition in a work environment					
I feel confident that, in general, working would NOT make my condition worse					

This completes Questionnaire 9

## APPENDIX 9: Content analysis proforma

Participant number:		Intervention session date:		Intervention session number:	
Record in 10 minute units		Length of session:		Travel time for session:	
<b>1. Assessment</b>		<b>5. Personal ADL</b>		<b>9. Dealing with psychological issues</b>	<b>14. Liaison (face to face, letter, phone, email)</b>
Medical history		Dressing		Confidence boosting	Case manager
Social situation and roles		Toileting		Low mood	CBT
Pre-morbid lifestyle		Bathing/ Showering		Motivation	Psychologist
Current difficulties		Other		Anxiety	GP
Current abilities		<b>6. Instrumental ADL</b>		Behavioural problems	Family
Family views		Making drinks and meals		Dealing with others	Employer
<b>2. Current issues</b>		Housework/ laundry		Relaxation techniques	Human Resources/ Occupational health
Medical		Money/ budgeting		<i>Adjustment/ re-evaluation*</i>	Disability Employment Adviser (DEA)
Social		Shopping		<b>10. Work preparation</b>	Work provider
Benefits		Correspondence		Teach pacing/ fatigue management	Carer/ partner
Family		Use of phone		Use of routines/ time keeping	Patient
Work		Managing appointments		Discussing work options	<i>Speech and language therapist*</i>
Other		Being left alone		Detailed job analysis	<i>Physiotherapist*</i>
<b>3. Goals</b>		Leisure activities		Identify potential problems & solutions	Other
Identifying problems		Sleep issues		Other	<b>15. OT activity with employer</b>
Identify/ set realistic goals		Other		<b>11. Return to work (RTW) process</b>	General advice/ education re stroke
Task analysis		<b>7. Mobility</b>		Work site visit	Specific advice re individual and work
Homework tasks set		Walking outside home		RTW planning meeting	Information re rehab process
Reviewing/ modifying goals		Road safety		Work assessment meeting	Advice/ support re work assessment

<b>1. Physical</b>	Using public transport	Monitoring / grading meeting	Advice/ support re graded RTW	
Transfers	Route finding	Maintenance meeting	Specific advice re any problems	
Splinting	Driving	Written info given to employers	Information about liaison with statutory services e.g. DEA	
Wheelchairs	Other	Advice/ education given	Other	
Assistive devices & adaptations	<b>8. Cognitive / executive skills</b>	Statutory issues given	<b>16. General education re stroke or RTW</b>	
<i>Pain management*</i>	Educate re cognitive/ executive skills	<b>12. Family/ Carer Support</b>	Patient	
<i>Visual problems*</i>	Memory aids/ strategies	<b>13. Administration</b>	Carer	
<i>Communication/ speech*</i>	Attention skills	Note writing	Employer	
<i>Upper limb work*</i>	Problem solving	Report writing	Written info given	
<i>Sensory problems*</i>	Standardised tests		Other	
	Other			

*\*Subcategories in italics are those added to make proforma stroke specific*

<b>Context and Outcomes</b>			
<b>Where seen</b>	<b>Use of other services</b>	<b>RTW Outcomes</b>	
Home	DEA	Same job, same employer	
Work	Permitted work	Same job modified, same employer	
Job Centre	Work step	Different job, different employer	
Other	Work psychologist	Same job, different employer	
<b>Method of travelling to work</b>	Other work provider	Same job modified, different employer	
Walk	Social Services	Different job, different employer	
Lifts	Stroke Association	On the job training	
Public transport	Different Strokes	New skill training	
Drive	Headway	Other educational programme	
Access to work	Support workers in education	Other (e.g. retired)	
Cycle	Insurance scheme provision	Voluntary work	
Works at home	Other	Self employed	
<b>Pay</b>		<b>GP Fit Note Categories</b>	
RTW on full pay but reduced hours		a. Phased return	
Pay cut for graded return		b. Altered hours	
On benefits		c. Amended duties	
Other		d. Workplace adaptations	

## APPENDIX 10: Content analysis proforma – explanatory notes

<b>Assessment</b>	
Medical history	
Social situation	May change over time.
Pre-morbid lifestyle	Include leisure, roles, work, attitudes and behaviours.
Current difficulties/problems	Impact of skill deficits on occupational performance in self-care, productivity and leisure.
Current abilities	Assess communication, physical, sensory, fatigue levels, cognitive, emotional, behavioural functioning and level of insight.
Family views	Family views and expectations and knowledge of stroke and recovery
<b>Current issues</b>	
Medical	Ongoing treatment, appointments etc.
Social	Living arrangements
Benefits	Benefit claims, housing issues
Family	Change of roles, increased time together,
Work	Explain RTW process, check job secure
Other	e.g. critical illness insurance – may need advice about this
<b>Goals</b>	
Identifying problems	
Identify/set realistic goals	Use SMART goals
Task analysis	Breakdown the goals
Homework tasks set	
Reviewing and modifying goals	Encourage client to reflect and judge success of goal and alter goal if needed



<b>Physical</b>	
Transfers	Advice/ practice of transfers needed for work
Splinting	Information and advice given about splinting affected side/ referral to OT out-patient services for splints to be custom - made
Wheelchairs	Information given about wheelchair provision
Assistive devices and adaptations	Advice given about assistive devices and adaptations
Pain management	e.g. Advice about managing a painful shoulder caused by stroke
Visual problems	e.g. Education about hemianopia and how to compensate
Communication/speech	Working on communication difficulties – verbal and written
Upper limb work	e.g. Work on dexterity and grip
Sensory problems	Education about safety awareness when sensation reduced or altered
<b>Personal ADL</b>	
Dressing	
Toileting	
Bathing	
Other	
<b>Instrumental ADL</b>	
Making drinks/meals	
Housework/laundry	
Money/Budgeting	e.g. correct change for bus, working out weekly limit
Shopping	
Correspondence	e.g. written, phone or email
Use of phone	Answering, using answer phone
Managing appointments	Use of diaries, calendar function on phone
Being left alone	In house
Leisure activities	Encourage them to restart previous activities if possible or develop new leisure activities.

Sleep issues	Look at sleep patterns and sleep routines if affected by stroke
Other	
<b>Mobility</b>	
Walking to shops	Alone, accompanied
Crossing roads	Choosing safe places etc.
Using public transport	Buses etc.
Driving	Notification to DVLA
Other	e.g. Organising lifts
<b>Dealing with psychological issues</b>	
Confidence Building	Increase activities, positive reinforcement
Low mood	Encourage leisure activities
Motivation	Set very specific tasks linked with interests
Anxiety	Teach anxiety management techniques
Behavioural problems	Increased irritability, use of pacing
Dealing with others	Identify specific problems and work out relevant strategies. Discuss what to disclose about the stroke and its effects
Relaxation techniques	Teach methods needed to relieve stress and tension
Adjustment / Re-evaluation	Support during psychological adjustment to the impact of the stroke and re-evaluation of life priorities
<b>Cognitive/executive skills</b>	
Education re cognitive/executive skills	Memory, attention, multitasking, planning, problem solving and insight.
Memory aids/strategies	Use of diary, phones, calendars, other people, notice boards, remembering appointments
Attention skills	e.g. plan plenty of breaks
Problem solving activities	Organising and planning activities e.g. day trip, holiday.
Standardised tests	e.g. Rivermead Behavioural Memory Test
Other	
<b>Work Preparation</b>	
Teach pacing/fatigue management	Home practice first e.g. meals, sleep, rest
Use of routines/time	Time keeping activities e.g. get up by a

keeping	specific time
Discuss work options	Discuss possible options e.g. graded return
Pt contact with employer	Ensure client or OT has been in contact at start of intervention and informed re RTW process
Detailed job analysis	Use job description and analyse demands of job
Identify potential problems/solutions	Get clients to think of problems and solutions.
Other	
<b>RTW process</b>	
Work site visit	Describe work site visit, its purpose and whether combined with any of the meetings stated below
RTW planning meeting	<p>Ensure client is aware of sickness and RTW procedure and expectations</p> <p>Agree plan of action e.g. client/OT to notify employer when nearly ready to go back to work</p> <p>Agree with client – disclosure of stroke impact</p> <p>Client encouraged to keep in touch with work place</p> <p>Return to plan made covering hours, days, duties, pay, feedback, contingency plan</p> <p>Inform GP of proposed intervention</p>
Work Assessment meeting	On site assessment with workplace assessor.
Monitoring/grading meeting	Worksite meeting to monitor and grade return to work
Maintenance meeting	To monitor situation
Written info given to employers	Formal write up of all work meetings for clients and employer
Advice/education given	To employer, work colleagues, HR etc
Statutory issues covered	Benefits, driving etc
<b>Family/ Carer support</b>	
Psychological support for family members	

<b>Administration</b>	
Note writing	Writing up intervention sessions
Report writing	Writing reports following formal meetings
<b>OT Activity with Employer</b>	
General advice / education re stroke	Advice that could apply to anybody following stroke, inform re possibility of cognitive, physical and psychological problems
Specific advice re individual and work	Specific advice concerning the persons actual ability based on severity of stroke, functional assessment, neuropsychological tests and how difficulties may impact on their ability to work e.g. known fatigue levels, specific memory problems, etc. Explain potential length of time off and return to work process
Information about rehab process	Inform employer what the rehabilitation process consists of for that person e.g. the need for the person to gradually build up their activity levels.
Advice and support re graded return to work	Ascertain with patient and employer minimum level of ability the person needs to be able to obtain before starting back to work and advice on detail of phased return.
Advice/monitoring/support re graded return to work	With employer and patient, assess and develop a graded return to work plan covering hours at work, rest breaks, work load, level of responsibility, supervision/feedback and review schedule.
Specific advice re any problems encountered at work	Any problems that become apparent during assessment or graded return may need addressing e.g. how to deal with increased fatigue etc.
General support/Monitoring	Once person has reached their maximum level at work maintain contact with employer in person, or by phone or email to provide ongoing support, monitoring to ensure person is able to sustain employment.

Information about/liaison with statutory provision	Provide information about and liaison with Disability Employment Advisors, Access to Work etc.
Other	
<b>Education re Stroke &amp;/or RTW</b>	
Client	Explain about stroke, rehab and RTW processes
Carer	Concerns, needs and expectations, knowledge of stroke
Employer	As above + timescales
Other	e.g. Disability Employment Advisor

## **APPENDIX 11: Employer interview schedule**

### **Framework for employer interviews**

**Questions will be asked on the following topics. Some examples of questions are given below.**

#### **Timely and long-term support**

*Research shows it is ideal to intervene as early and as rapidly as possible. This would be viewed as timely intervention.*

Explore employers perceptions of timeliness in relation to VR provided  
e.g. Was the intervention timely?

*Services need to be flexible and responsive to the needs of stroke survivors.*

Explore responsiveness to the needs of the employee and employer during the course of the vocational rehabilitation. Ask about expectations and perceptions of how they were met in relation to responsiveness.

#### *Support following return to work*

What kind of support did we offer following return to work and how effective was this in helping someone remain in work? Explore expectations and practicalities of this support being offered.

## **Assessment**

### *Vocational assessment*

Did we make an accurate assessment of the individuals work/ training ability, general functional capabilities and social/ behavioural characteristics?

### *Employment assessment*

Did we make an accurate assessment of whether the individual can perform tasks required by the job, sustain employment and where appropriate, develop in the job?

## **Planning and preparing for return to work**

How useful was the return to work plan?

How effective was the preparation for return to work?

## **Providing Interventions**

### *Facilitating single or multiple work adjustments*

Examples:

- Provision of explicit verbal and written advice
- Worksite meetings
- Provision of specialist equipment
- Assistance with travel to work

Did we facilitate appropriate work adjustments? Explore specific adjustments made and perceptions of these adjustments.

### **Working with employers**

#### *Engagement with employers over time*

How did we engage with employers over the time frame of the vocational rehabilitation? Did we meet expectations regarding engagement?

### **Working with whole systems**

#### *Cooperation with other services*

How effectively did we cooperate and liaise with other services (e.g. Disability Employment Advisers/ Occupational Health and Human Resources)?



**APPENDIX 12: Template for trial participant interview data analysis**

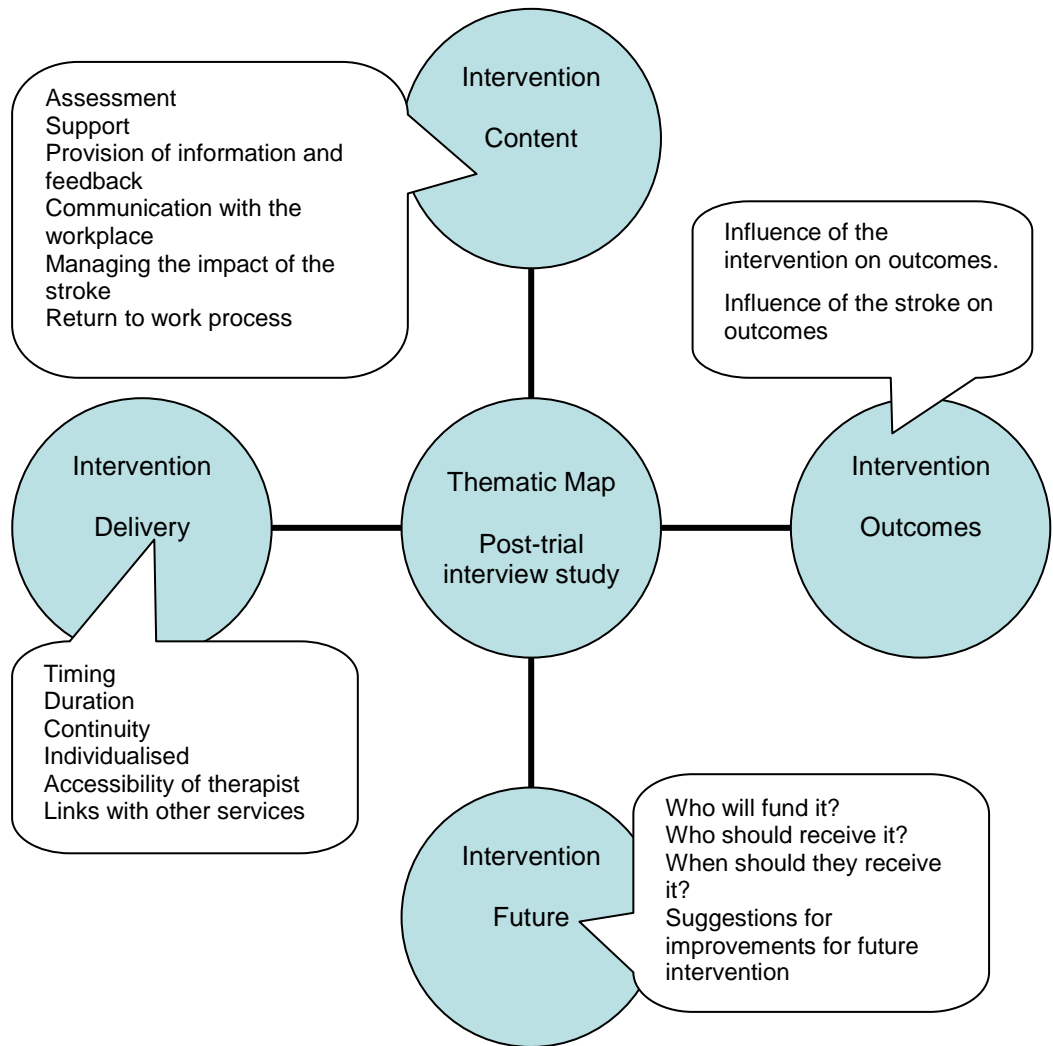
<b>Themes and subcategories</b>	
<b>Support</b>	
Emotional support (someone to talk to)	
Practical support	
Ongoing/ follow-up support	
Work place support (employer, colleagues or work place visit/ meeting)	
Expectations about support (feel abandoned by NHS/ expectations of support from NHS or others)	
<b>Feedback</b>	
Validation of effects of stroke (e.g. fatigue)	
Feedback on progress	
Feedback on self-help strategies/ lifestyle changes	
Feedback building on self efficacy/ self-belief/ empowering	
<b>Education</b>	
Provision of information (written, verbal, internet) – personalised and targeted – at right times as needed – responsive to individual needs	
Fatigue management	
<b>Assessment</b> (individual, workplace and job)	
<b>Delivery of intervention</b>	
Individualisation/ personalisation of intervention ( tailoring to individual needs – client centred)	

<p>Timing</p> <ul style="list-style-type: none"> <li>- recruitment to study and commencement of intervention</li> <li>- duration of intervention</li> <li>- length of sessions</li> <li>- number of sessions</li> <li>- spacing of sessions/ intervals between sessions</li> </ul>	
<p>Therapist qualities (e.g. approachability, accessibility etc.)</p>	
<p><b>Stages of return to work</b></p>	
<p>Work preparation</p>	
<p>Phased return</p>	
<p>Monitoring and reviewing work return</p>	
<p><b>Outcomes of intervention</b> (e.g. whether they returned to work or not, lifestyle changes made etc.)</p>	
<p><b>Perceptions of intervention (e.g. satisfaction</b></p>	

### APPENDIX 13: Template for employer interview data analysis

<b>Themes and subcategories</b>	
<b>Communication</b> <ul style="list-style-type: none"> <li>- OT and employer</li> <li>- Employer/ employee</li> </ul>	
<b>Impact of stroke</b> <ul style="list-style-type: none"> <li>- Reaction to stroke</li> <li>- Emotional impact</li> <li>- Impact of fatigue</li> <li>- Impact on the workplace</li> </ul>	
<b>Intervention</b> <ul style="list-style-type: none"> <li>- Assessment</li> <li>- Timing</li> <li>- Provision of information</li> <li>- Workplace adjustments</li> <li>- Outcomes</li> <li>- Future funding of service</li> </ul>	
<b>Support</b> <ul style="list-style-type: none"> <li>- OT for employer</li> <li>- OT for employee</li> <li>- Manager for employee</li> </ul>	

**APPENDIX 14: Thematic map - post-trial interview study**



## **APPENDIX 15: List of publications and presentations arising from this study**

### **Publications**

#### **Papers**

Coole, C, Radford KA, Grant M, Terry J (2012) Returning to work after stroke: perspectives of employer stakeholders, a qualitative study. *Journal of Occupational Rehabilitation*. Published online, 5 December 2012. DOI:10.1007/s10926-012-9401-1.

Sinclair E, Radford K, Grant M, Terry J (2013) Developing stroke specific vocational rehabilitation: a soft systems analysis of current service provision. *Disability and Rehabilitation*. Published online, May 2013. DOI:10.3109/09638288.2013.793410

Grant M, Radford K, Sinclair E, Walker M (2014) Return to work after stroke: recording, measuring, and describing occupational therapy intervention. *British Journal of Occupational Therapy*, 77(9), 457-465.

#### **Published abstracts**

Grant M, Rowley E, Bailey S, Walker MF, Radford KA (2011) Implementing support for returning to work after stroke: a qualitative exploration of existing provision. *International Journal of Stroke* 2011: 6 (Suppl 2): 13

Radford KA, Grant MI, Terry J, Marr L, Brain N. (2011) Developing stroke specific vocational rehabilitation; mapping current service provision. *International Journal of Stroke*, 2011 (Suppl 2):49

Grant M, Sinclair E, Walker MF, Radford KA. (2011) Vocational rehabilitation following stroke: describing intervention. *International Journal of Stroke*. 2012; 7 (Suppl 2):29.

Grant MI , Radford KA, Sinclair EJ, Walker MF (2013) Vocational rehabilitation following stroke: describing intervention. Proceedings of SRR. *Clinical Rehabilitation*, 27:1052-1053.

#### **Posters and Presentations**

December 2010, Ongoing Trials Poster presentation at 5<sup>th</sup> UK Stroke Forum, Glasgow: KA Radford, M Grant, J Terry , M Horrocks, S Bailey, MF Walker, NB Lincoln, J Phillips, A Drummond, K Muhiddin, L Marr, G Currie, M Yang, M James, M Jarvis, M Jenkinson. *Return to work (RTW) after Stroke, Feasibility RCT and Economic Analysis*.

February 2011, Poster presentation at Society of Research in Rehabilitation Winter Meeting, Cardiff: KA Radford M Grant, J Terry, S Bailey, MF Walker, NB Lincoln, J Phillips, A Drummond, K Muhiddin, L

Marr M Yang, M James, M Jarvis, M Jenkinson. *Return to Work after Stroke, Feasibility RCT and Economic Analysis*

May 2011, Presentation at CLAHRC Return to work after stroke Engagement Event Derby. *Vocational Rehabilitation for Stroke Survivors in Derbyshire: What is on offer? A qualitative interview study with key stakeholders.*

June 2011, Poster presentation at School Postgraduate Research Conference. *Developing, delivering and evaluating stroke specific vocational rehabilitation in Derbyshire.*

December 2011, Presentation at 6<sup>th</sup> UK Stroke Forum Glasgow: Grant M, Rowley E, Bailey S, Walker MF, Radford KA (2011) *Implementing support for returning to work after stroke: a qualitative exploration of existing provision.* International Journal of Stroke 2011: 6 (Suppl 2): 13

December 2011, Poster presentation at 6<sup>th</sup> UK Stroke Forum Glasgow: Radford KA, Grant MI, Terry J, Marr L, Brain N. *Developing stroke specific vocational rehabilitation; mapping current service provision.* International Journal of Stroke, 2011 (Suppl 2):49

December 2011, Ongoing trials poster presentation at 6<sup>th</sup> UK Stroke Forum Glasgow: Radford KA, Grant MI, Ford E, Terry J, Walker MF, Lincoln NB, Phillips J, Muhiddin K, Drummond A, Brain N, Rowley E, Stainer K, *Return to work after stroke: feasibility RCT and economic analysis.*

April 2012, Invited speaker at Stroke Showcase Nottingham University. *Return to work after stroke: a case study.*

May 2012, Poster displayed at Northern Ireland Multidisciplinary Association for Stroke Teams/UKSF Stroke Conference, Lisburn: Radford, KA, Grant, MI, Terry, J, Marr, L, Sinclair, E., Brain, N, *Developing Stroke Specific Vocational Rehabilitation: Mapping Current Service Provision.* Won best poster prize.

June 2012, Poster displayed at HSRN Conference, Manchester: Rowley E, Grant M, Terry J. *The Strength of Weak Ties or 'Kerplunk'<sup>TM</sup>: Delivering Vocational Rehabilitation after Stroke.*

September 2012, Invited Speaker and Workshop Leader at COTSS-Work Annual Conference, London: *Return to work after stroke.*

December 2012, Poster presentation at 7<sup>th</sup> UK Stroke Forum Harrogate: Grant M, Sinclair E, Walker MF, Radford KA. *Vocational rehabilitation following stroke: describing intervention.* International Journal of Stroke. 2012; 7 (Suppl 2):29. Won best poster presentation prize.

February 2013, Poster presentation at The Society for Research in Rehabilitation Winter Meeting, Bath: Grant M, Sinclair E, Walker MF, Radford KA *Vocational rehabilitation following stroke: describing intervention*

June 2013, Paper Presentation at COT Annual Conference Glasgow: Grant MI, Radford KA, Sinclair EJ, Walker MF *Vocational rehabilitation following stroke: describing intervention*

July 2013, Poster presentation at The Society for Research in Rehabilitation Summer Meeting, Nottingham: Grant MI, Terry J, Crompton A, Radford KA *Usability and acceptability of stroke specific vocational rehabilitation: a post-trial interview study*

September 2013, Presentation at Stroke Theme End of CLAHRC Feedback Event, University of Nottingham. Grant MI, Radford KA, Sinclair EJ, Terry J, Walker MF, Lincoln NB, Drummond A, Phillips J, Coole C, Watkins L, Rowley E, Guo B, Brain N, Muhiddin K, Jarvis M, Jenkinson M, Sampson C, Edwards C. *Return to work after stroke: a feasibility randomised controlled trial.*

September 2013, Presentation at OPSYRIS (**O**rganisation for **PSY**chological **R**esearch **I**nto **S**troke) Annual Conference, University of Nottingham. Grant M, Sinclair E, Walker M, Radford K. *Vocational rehabilitation following stroke: describing intervention.*

June 2014, Presentation at 16<sup>th</sup> WFOT Congress, Yokohama, Japan. Grant MI, Radford KA, Sinclair EJ, Terry J, Walker MF. *Stroke Specific Vocational Rehabilitation: A Feasibility Randomised Controlled Trial.*