

*'Time to spread my wings'*

**An investigative study exploring the effects of inpatient mental health rehabilitation**

***What is the effect of inpatient mental health rehabilitation on an individual's functional performance and do changes impact quality of life?***

A Thesis Submitted for the Degree of Doctor of  
Philosophy

By

Rachel Amy Dadswell

College of Health and Life Sciences  
Brunel University London

26<sup>th</sup> September 2019

## **Abstract**

This mixed methodology, 3-phase study at one NHS rehabilitation unit explores the experiences of 19 participants recruited over a 2 year period. Participants engaged in individual semi-structured interviews, and were invited to complete both the Lancashire Quality of Life Profile and the Assessment of Motor and Process Skills at admission, discharge and follow-up.

Not all participants reached the point of discharge in the study period, and a few became too unwell to continue. At the point of follow-up, of the 10 remaining participants one dropped out due to work or educational commitments, three were re-admitted to hospital, and one did not come for appointments as agreed.

To illustrate change over time, five participants have been brought to the fore through the use of case studies. The case studies synthesise the quantitative changes in the individual's quality of life and functional performance with a personal narrative of their experience of their stay in the rehabilitation unit.

The findings of the study are rich. Firstly, they highlight the range of losses experienced prior to rehabilitation and the importance of understanding this narrative as part of the recovery journey. Secondly, rehabilitation creates a sense of hope, but not all interactions with staff in the unit were viewed as hopeful. Hope was at its lowest when participants were not included in key decisions. Thirdly, while for some participants occupational performance and quality of life increased over time, for others it decreased. This study indicates tentative links between occupational performance and quality of life.

Recommendations include enhancing client involvement in key decisions regarding rehabilitation choices, routine assessment of occupational performance levels, formally expanding rehabilitation into the community and considering grief work alongside more traditional rehabilitation interventions. Areas for further research include exploration of the links between quality of life and occupational performance levels.

## Contents

Contents			Page	
<b>Chapter One</b>	<b>1.1</b>	<b>Introduction</b>	1	
	<b>1.2</b>	<b>The recovery movement</b>	2	
	<b>1.3</b>	<b>Rehabilitation through time: the impact of recovery on rehabilitation</b>	4	
	<b>Introduction and context setting</b>	1.3.1	Rehabilitation in the institutions	4
		1.3.2	Rehabilitation during deinstitutionalisation	4
		1.3.3	Rehabilitation at the turn of the millennium	6
		1.3.4	Recovery oriented rehabilitation	7
	<b>1.4</b>	<b>Rehabilitation as a complex intervention</b>	9	
	<b>1.5</b>	<b>The rehabilitation unit</b>	9	
	<b>1.6</b>	<b>Evolution of the study</b>	11	
	<b>1.7</b>	<b>About the author of this study</b>	11	
1.7.1	Occupational therapy	13		
<b>1.8</b>	<b>Relevance to practice</b>	14		
<b>1.9</b>	<b>Broad area of research</b>	15		
<b>1.10</b>	<b>Summary</b>	16		
<b>Chapter Two</b>	<b>2.1</b>	<b>Introduction</b>	17	
	<b>2.2</b>	<b>Search strategy</b>	19	
	2.2.1	Critical appraisal	21	
	<b>2.3</b>	<b>Studies included in the narrative review</b>	22	
	<b>2.4</b>	<b>Evaluating the effect of rehabilitation</b>	22	
	<b>2.5</b>	<b>Functioning as a measure of change</b>	24	
	2.5.1	Global functioning	24	
	2.5.2	Social functioning	26	
	2.5.3	Cognitive Functioning	27	
	2.5.4	Summary of measures of functioning	28	
	<b>2.6</b>	<b>Symptoms as a measure of change</b>	28	
	2.6.1	Summary of measures of symptoms	31	
	<b>2.7</b>	<b>Behaviour as a measure of change</b>	31	
	2.7.1	Summary of measures of behaviour	33	
<b>2.8</b>	<b>Costs and benefits of rehabilitation</b>	33		
2.8.1	Occupied bed days and readmission rates	34		
2.8.2	Destination and care needs on discharge	35		
2.8.3	Summary of costs and benefits of rehabilitation	36		
<b>2.9</b>	<b>Patient experience as a measure of satisfaction</b>	36		
2.9.1	Summary of measures of patient experience	37		
<b>2.10</b>	<b>General health and quality of life as a measure of change</b>	38		
2.10.1	Summary of measures of general health and quality of life	38		
<b>2.11</b>	<b>Need as a measure of change</b>	38		
<b>2.12</b>	<b>Summary of the review</b>	39		
<b>Chapter Three</b>	<b>3.1</b>	<b>Introduction</b>	42	
	<b>3.2</b>	<b>Methodology</b>	42	
	3.2.1	The philosophical spectrum	42	
	3.2.2	A positivist and post-positivist approach to research in health care	43	
	3.2.3	A constructionist approach to research in health care	44	
	3.2.4	A pragmatist approach to research in health care	45	
	3.2.5	Researcher's philosophical stance	46	
	3.2.6	Validity and reliability	47	
	<b>3.3</b>	<b>Design of the Study</b>	47	
	3.3.1	Data collection tools	49	
	3.3.2	Semi structured qualitative interviews	49	
3.3.2.1	Trust worthiness and authenticity	50		
3.3.3	Assessment of Motor and Process Skills	51		
3.3.3.1	Validity and reliability	53		

	3.3.4	Quality of Life	53
	3.3.4.1	Quality of life and mental illness	54
	3.3.4.2	Pilot study	55
	3.3.4.3	Lancashire Quality of Life Profile – European Version	56
	3.3.4.4	Validity and reliability	56
	<b>3.4</b>	<b>Ethical Approval</b>	56
	<b>3.5</b>	<b>Method</b>	57
	3.5.1	Recruitment and selection	57
	3.5.2	Informed consent and ethical practice	58
	3.5.3	Data collection processes	58
	3.5.3.1	Qualitative interviews	59
	3.5.3.2	Assessment of Motor and Process Skills (AMPS)	60
	3.5.3.3	Lancashire Quality of Life Profile – European Version	60
	<b>3.6</b>	<b>Processes of Analysis</b>	61
	3.6.1	Thematic analysis of the interviews	61
	3.6.2	Assessment of Motor and Process Skills and Rasch analysis	63
	3.6.2.1	Interpreting the Assessment of Motor and Process Skills results	63
	3.6.3	Quality of Life: Data inputting and cleaning of data	65
	3.6.3.1	Quality of Life and statistical analysis	67
	<b>3.7</b>	<b>Summary of Methodology</b>	67
<b>Chapter Four Findings (1)</b>	<b>4.1</b>	<b>Introduction</b>	68
	<b>4.2</b>	<b>Section one - Participant and unit overview</b>	68
	<b>4.3</b>	<b>Participants' Vignettes</b>	69
<b>Understanding the participants – thematic analysis of phase one</b>	4.3.1	Participants who completed all three phases	70
	4.3.2	Participants who completed P1 & P2 & parts of P3	71
	4.3.3	Participants who completed P1 & P2	72
	4.3.4	Participants who completed P1	73
	<b>4.4</b>	<b>Vignette of the unit</b>	75
	<b>4.5</b>	<b>Summary of section one</b>	76
	<b>4.6.1</b>	<b>Section two - Phase 1 Interviews</b>	76
		<b>Loss after loss, after loss</b>	77
		a) <i>Loss of a relationship</i>	77
		b) <i>Loss of a home</i>	78
		c) <i>Loss of self - Hopeless and beyond help</i>	79
	4.6.1.1	Summary of Loss after loss, after loss	79
	<b>4.6.2</b>	<b>Power and Control</b>	80
		a) <i>You make the decisions</i>	80
		i) <i>Moving Day</i>	81
		ii) <i>Structuring my day</i>	81
		b) <i>Am I Invisible?</i>	82
		c) <i>Active Involvement</i>	83
		i) <i>The time is right</i>	83
		ii) <i>You understand me</i>	83
		d) <i>Being ordinary</i>	84
		i) <i>I want ordinary things</i>	84
		ii) <i>The responsibility of ordinariness</i>	85
	4.6.2.1	Summary of Power and Control	86
	<b>4.6.3</b>	<b>The paradox of rehabilitation</b>	86
		a) <i>Hope and expectation</i>	87
		b) <i>You are not to be trusted</i>	89
	4.6.3.1	Summary of the paradox of rehabilitation	91
	<b>4.6.4</b>	<b>A sense of belonging</b>	91
		a) <i>Home from home</i>	92
		b) <i>Excluded and abandoned</i>	93
		c) <i>Making connections</i>	94
	4.6.4.1	Summary of Sense of belonging	94
	<b>4.7</b>	<b>Chapter summary</b>	95
<b>Chapter Five</b>	<b>5.1</b>	<b>Introduction</b>	96

<b>Findings (2)</b>  <b>Thematic analysis of phase two and three</b>	<b>5.2</b>	<b>Section One - Phase 2 interviews</b>	96
	<b>5.2.1</b>	<b>Redefining a life of meaning</b>	97
		a) Mental wellbeing	98
		b) Meaningful relationships	99
		c) Meaningful occupations	99
	5.2.1.1	Summary of redefining a life of meaning	100
	<b>5.2.2</b>	<b>Moving forward</b>	101
		a) Time to spread my wings	101
		b) Resigned acceptance	102
	5.2.2.1	Summary of moving forward	103
	<b>5.2.3</b>	<b>The balance of getting it right</b>	103
		a) Happy, hopeful and engaging	104
		b) Decrease opportunities for some	105
	5.2.3.1	Summary of the balance of getting it right	106
	<b>5.2.4</b>	<b>Summary of phase 2</b>	107
	<b>5.3</b>	<b>Section Two - Phase 3 interviews</b>	107
	<b>5.3.1</b>	<b>Maintaining Wellness</b>	108
		a) Embedding occupation in routine	109
		b) Being responsible	110
	c) One step at a time	110	
5.3.1.1	Summary of maintaining wellness	111	
<b>5.3.2</b>	<b>Being respectful</b>	111	
	a) Building self-respect	112	
	b) Respecting others	113	
5.3.2.1	Summary of being respectful	114	
<b>5.3.3</b>	<b>Some things are not quite right</b>	114	
	a) Feeling unsafe	115	
	b) Feeling excluded	115	
5.3.3.1	Summary of some things are not quite right	116	
<b>5.4</b>	<b>Summary of phase 3</b>	116	
<b>5.5</b>	<b>Chapter summary</b>	117	
<b>5.6</b>	<b>Overall summary of thematic analysis</b>	117	
<b>Chapter Six Findings (3)</b>  <b>The Descriptive results and the results of the Assessment of Motor and Process and of the Lancashire Quality of Life Profile</b>	<b>6.1</b>	<b>Introduction</b>	119
	<b>6.2</b>	<b>Demographic findings</b>	119
	<b>6.3</b>	<b>Overview of QoL and AMPS</b>	121
	<b>6.4</b>	<b>Overview of group changes across both QoL and AMPS</b>	122
	6.4.1	Group QoL changes	122
	6.4.2	Group AMPS changes	123
	<b>6.5</b>	<b>Individual QoL and AMPS results</b>	123
	<b>6.6</b>	<b>Marco</b>	124
	<b>6.7</b>	<b>Frank</b>	128
	<b>6.8</b>	<b>Jason</b>	132
	<b>6.9</b>	<b>Nigel</b>	136
	<b>6.10</b>	<b>Mabel</b>	140
	<b>6.11</b>	<b>Mark</b>	144
	<b>6.12</b>	<b>Rita</b>	148
	<b>6.13</b>	<b>Susan</b>	152
	<b>6.14</b>	<b>Steve</b>	156
	<b>6.15</b>	<b>Mohammad</b>	160
	<b>6.16</b>	<b>Case studies presentations</b>	164
	6.16.1	Marco	164
6.16.2	Frank	166	
6.16.3	Jason	167	
6.16.4	Nigel	168	
6.16.5	Mabel	169	
<b>6.17</b>	<b>Understanding the reasons for dropout</b>	171	
<b>6.18</b>	<b>Chapter summary</b>	172	
<b>6.19</b>	<b>Summary of key findings</b>	173	

<b>Chapter Seven</b>  <b>Discussion</b>	<b>7.1</b>	<b>Introduction</b>	174
	<b>7.2</b>	<b>Study participants</b>	175
	<b>7.3</b>	<b>The impact of loss</b>	176
	<b>7.4</b>	<b>The interplay of relationships with others and its impact on hope</b>	178
	<b>7.5</b>	<b>Meaningful occupation and hope</b>	181
	<b>7.6</b>	<b>A sense of control and hope</b>	182
	<b>7.7</b>	<b>The link between occupational performance levels, quality of life and discharge readiness</b>	184
	<b>7.8</b>	<b>Summary of discussion</b>	188
	<b>7.9</b>	<b>Critique of the study</b>	190
		a) Semi structured interviews	190
		b) Lancashire quality of life	191
	c) Assessment of Motor and Process skills	192	
	<b>7.10</b>	<b>Recommendations</b>	193
		a) Recommendations for the practice of rehabilitation	193
		b) Recommendations for occupational therapists working in a rehabilitation setting	194
		c) Recommendations for further research	194
	<b>7.11</b>	<b>Chapter Summary</b>	195
<b>Chapter Eight</b>  <b>Personal Reflections</b>	<b>8.1</b>	<b>Introduction</b>	196
	<b>8.2</b>	<b>Some basic assumptions</b>	196
	<b>8.3</b>	<b>Conflicts and challenges</b>	198
		a) Researcher/ therapist	198
		b) Data collection and analysis	199
		c) Presentation of results and discussion	202
	<b>8.4</b>	<b>Reflections of the unit</b>	202
	<b>8.5</b>	<b>Concluding comments</b>	203
<b>Glossary of terms</b>	<b>9.0</b>		205
<b>References</b>	<b>10.0</b>		208
<b>Appendices</b>	<b>11.0</b>		234

## Tables and Figures Index

Chapter	Table / Figure	Title	Page
<b>Chapter One</b>	Table 1.1	Seven main areas of rehabilitation	8
<b>Chapter Two</b>	Table 2.1	Search parameters using PICOS	19
	Table 2.2	Search terms used in initial literature search	20
	Table 2.3	Inclusion and exclusion criteria	20
	Table 2.4	Summary of the measures used across the studies in the literature review	23
	Figure 2.1	Search strategy flow chart	21
<b>Chapter Three</b>	Table 3.1	Comparison of positivism/post positivism, constructivism and the pragmatic approach to research	43
	Table 3.2	Inclusion and exclusion criteria	57
	Table 3.3	Summary of missing Quality of life data	66
	Figure 3.1	The concurrent, convergent, mixed methods design	48
	Figure 3.2	ADL Motor Scale, highlighting two different assessments (time 1 & time 2)	64
	Figure 3.3	ADL Process Scale, highlighting two different assessments (time 1 & time 2)	65
<b>Chapter Four</b>	Table 4.1	Overview of study participant's	69
	Table 4.2	Overview of participant data completion	69
	Figure 4.1	Themes that emerged from phase 1 interviews	76
	Figure 4.2	Loss after loss, after loss	77
	Figure 4.3	Power and Control	80
	Figure 4.4	The paradox of rehabilitation	86
	Figure 4.5	Sense of belonging	92
<b>Chapter Five</b>	Table 5.1	Overview of participants in phase 2 data collection	96
	Table 5.2	Overview of participants in phase 3 data collection	107
	Figure 5.1	The themes and sub themes that emerged from phase 2 interviews	97
	Figure 5.2	Redefining a life with meaning	97
	Figure 5.3	Moving forward: the tensions identified	101
	Figure 5.4	The balance of getting it right	104
	Figure 5.5	The themes and sub themes that emerged from phase 3 interviews	108
	Figure 5.6	Maintaining wellness	108
	Figure 5.7	Being respectful	112
	Figure 5.8	Some things are not quite right	115
	Figure 5.9	Participant's view of a rehabilitation journey	118
<b>Chapter Six</b>	Table 6.1	The mean age of participants	120
	Table 6.2	Percentage of participants with key social and personal factors	121
	Table 6.3	Participants who completed the QoL at each of the 3 phases	121
	Table 6.4	Participants who completed the AMPS at each of the 3 phases	121
	Table 6.5	Summary of MDC across perceived QoL, psychological wellbeing and self esteem	122
	Table 6.6	Summary of statistical significance across ADL Motor and ADL Process skills	123
	Table 6.7	Summary of Marco's QOL across the test phases	124
	Table 6.8	Change in Marco's Motor and Process logits across the test phases	125
	Table 6.9	Summary of Frank's QOL across the test phases	128
	Table 6.10	Change in Frank's Motor and Process logits across the test phases	129
	Table 6.11	Summary of Jason's QOL across the test phases	132
	Table 6.12	Change in Jason's Motor and Process logits across the test phases	133
	Table 6.13	Summary of Nigel's QOL across the test phases	136
	Table 6.14	Change in Nigel's Motor and Process logits across the test phases	137
	Table 6.15	Summary of Mabel's QOL across the test phases	140
	Table 6.16	Change in Mabel's Motor and Process logits across the test phases	141

Table 6.17	Summary of Mark's QOL across the test phases	144
Table 6.18	Change in Mark's Motor and Process logits across the test phases	145
Table 6.19	Summary of Rita's QOL across the test phases	148
Table 6.20	Change in Rita's Motor and Process logits across the test phases	149
Table 6.21	Summary of Susan's QOL across the test phases	152
Table 6.22	Change in Susan's Motor and Process logits across the test phases	153
Table 6.23	Summary of Steve's QOL across the test phases	156
Table 6.24	Change in Steve's Motor and Process logits across the test phases	157
Table 6.25	Summary of Mohammad's QOL across the test phases	160
Table 6.26	Change in Mohammad's Motor and Process logits across the test phases	161
Table 6.27	Reason for participant dropout	171
Figures 6.1a & 6.1b	Marco's ADL motor and ADL Process Scales	126
Figures 6.2a & 6.2b	Frank's ADL motor and ADL Process Scales	130
Figures 6.3a & 6.3b	Jason's ADL motor and ADL Process Scales	134
Figures 6.4a & 6.4b	Nigel's ADL motor and ADL Process Scales	138
Figures 6.5a & 6.5b	Mable's ADL motor and ADL Process Scales	142
Figures 6.6a & 6.6b	Mark's ADL motor and ADL Process Scales	146
Figures 6.7a & 6.7b	Rita's ADL motor and ADL Process Scales	150
Figures 6.8a & 6.8b	Susan's ADL motor and ADL Process Scales	154
Figures 6.9a & 6.9b	Steve's ADL motor and ADL Process Scales	158
Figures 6.10a & 6.10b	Mohammad's ADL motor and ADL Process Scales	162

## Appendices Index

Chapter	Appendix	Title	Page
<b>Chapter Two</b>	2.1	Rationale for exclusion from main literature review	234
	2.2	Summary of the literature included in the review	235
	2.3	A critique of the measures identified In the literature review	242
<b>Chapter Three</b>	3.1a	Ethical Approval	246
	3.1b	Ethical Approval amendments	247
	3.2	Letter of Invitation	248
	3.3	Declaration of Interest	249
	3.4	Patient Information Sheet	250
	3.5	Consent Form	254
	3.6	Interview schedule :phase 1	255
	3.7	Interview schedule :phase 2	257
	3.8	Interview schedule :phase 3	257
	3.9	Example from P1 of in text coding	260
<b>Chapter Seven</b>	7.1	Hierarchy of tasks	261



## **Acknowledgements**

My thanks go to my supervisors Dr Cherry Kilbride, Dr Elizabeth McKay and Dr Alison Blank who have guided, supported and encouraged me to complete this study, despite some of the challenges I have met along the way. Thank you for seeing me through some difficult times when the PhD had to go on hold for a while. A special thank you also goes to Professor Chard and Dr Tess McGuire who have provided me with expert advice, warmth and a belief in myself; for that I am truly grateful - you are both inspirational women.

I also wish to thank the clients and staff at the unit where this study took place, without who none of this would have been possible: the staff who took an interest in what I was doing and were as passionate of mental health rehabilitation as I was and the clients who actively engaged with me and the research process. My thanks also goes to my university work colleagues who recognise the determination that goes into completing a doctoral thesis.

Lastly, my heartfelt thanks go to my husband Michael and our two daughters Louise and Georgina. Thank you for your patience, understanding and love, you have all supported me to complete this thesis in your own, unique ways, and for that I love and thank you.

This thesis is dedicated to my Dad; John Douglas Bulmer who sadly passed away before I was able to finish it and my Mum who has shown her own determination and courage over the years.

# Chapter One

## Introduction

### **1.1 Introduction**

Good mental health is something experienced by an individual, interwoven with their personal expectations but also dependent on external variables. Everyone is in pursuit of good mental health together with a balanced lifestyle which bring meaning to life. Yet nearly half of the population of the United Kingdom at some point in their adult life will report a diagnosable mental illness (Mental Health Foundation, 2016).

Over the past 20 years there has been a move within the first world countries to increase the awareness of mental ill-health, bringing it into mainstream discourse and placing it on a par in terms of acceptance and treatment with other illnesses such as cancer and coronary heart disease (NHS England, 2016b; HM Government, 2011). While conditions such as anxiety, depression and post-traumatic stress disorder are more readily accepted, with treatment options available, the understanding and acceptance of psychotic illnesses is less so, and is still portrayed negatively in popular media (Owen, 2012), adding to its stigmatisation.

Approximately 1% of the UK population have a diagnosis of schizophrenia and typically, although not exclusively, symptoms such as hallucinations and delusions, social withdrawal and a loss of interest in activity. This can start as the young person transitions into adulthood (National Institute for Clinical Excellence, 2014). For some people these symptoms are resolved after one or a few episodes of psychosis (Hollis, Kendall and Birchwood, 2013) - others may go on to develop longer term needs requiring lengthy treatment to address recurrent symptoms, and may experience stigma, social isolation, poor relationships and occupational injustices (Townsend and A. Wilcock, 2004). It is this latter group of people who typically may require extensive periods of intervention, often in inpatient mental health rehabilitation units. Rehabilitation units, although small in number across England, use between 25-50% of the mental health financial budget (Killaspy *et al.*, 2016).

This thesis explores the role of recovery oriented inpatient mental health rehabilitation. In doing so it seeks to understand what rehabilitation brings to an individual's pursuit of recovery from long term mental illness - does it make a positive contribution to their quality of life and does it equip them with the necessary skills to live independently?

This chapter starts by providing an overview of the recovery movement. It moves on to explore the evolution and complexity of rehabilitation against the backdrop of the recovery

movement. The contribution of occupational therapy to rehabilitation is presented, as well as the rationale for undertaking this study viewed through an occupational lens.

## 1.2 The recovery movement

Recovery is a non-linear process where an individual's real life experiences inform and mould a new sense of self as they accept and overcome the challenges of disability to rediscover who they can be and what they can do (Deegan 1988). Recovery as a recognised concept started to gather momentum across the western world in the early 1990's from personal narratives, particularly in relation to a sense of oppression. The narratives came from those who had lived with mental illness for many years and 'survived' (Repper and Perkins, 2006; Repper and Perkins, 2003; Deegan, 1988). This anecdotal and narrative evidence was supported by evidence emerging from longitudinal studies on people recovering, despite many years of institutional care (Harding *et al.*, 1987). As a result, people who had been oppressed due to long-term mental illness were calling for an end to the unfair and damaging effects of suppression which were often associated (Davidson, 2008).

The recovery movement soon developed into a model for mental health practice (Repper and Perkins, 2006), and as a concept, recovery started to challenge the notion that once someone had become unwell with a serious mental illness, such as psychosis or schizophrenia, that they would remain ill for ever. The seminal definition of recovery put forward by Anthony (1993) has stood the test of time and has been repeatedly used, highlighting both the personal nature of recovery and the onus on the individual to accept personal change. It has become a mantra for the recovery colleges where the emphasis is on sharing and learning together (Perkins *et al.*, 2012). The definition is thus:

*'... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.'* (Anthony, 1993)

While the notion of developing a life of new meaning and purpose despite long-term mental health needs seems reasonable, recovery is not without its critics. While such personal stories may be uplifting and inspirational for some, others may find the 'gratuitous self-exploration' which forms the basis of 'acceptable stories' disempowering and humiliating (Hughes, 2015) (p1). The critics feel that recovery has been taken over by and dominated by professionals and policy writers, that capitalist western governments are masking the needs

of those unable to recover, blaming the individual rather than looking at social policy or challenging the medical model of illness. Recovery has also been blamed for the closure and rebranding of services, forcing people to return to unacceptable working arrangements (Field and Reed, 2016, Hughes, 2015, (Harper, Speed 2012). Some critics also believe that rebranding services as 'recovery services' does little more than reduce services and fail patients generally.

One of the main criticisms of recovery is the focus on individualism and places the onus on the individual to develop resilience. This negates the fact that humans are social beings who rely on social contacts and relationships to define ourselves. Given that people need social contact, recovery cannot be achieved within a social vacuum without the right support from others (Price-Robertson, Obradovic and Morgan, 2017, Harper & Speed 2012). The right support is of course subjective, and this makes recovery difficult to clearly define and understand as different people require a different things.

However, despite the criticism, principles of recovery have predominated and evolved and have been conceptualised into the five main areas: 'connectedness, hope, identity, meaningfulness and empowerment' (Leamy *et al.*, 2011). These five broad areas recognise the diversity of recovery, while at the same time appreciating that a framework is required from which recovery based services can be established and measured (Newman-Taylor *et al.*, 2017).

The five areas are also in line with good mental health practice (College of Occupational Therapists, 2006) and have a focus on social recovery as opposed to clinical recovery (South London and Maudsley, 2010). Clinical recovery aims for the person to be symptom free, where as social recovery has a core belief that people can and do live fulfilling lives, even with symptoms, if they have social support and other networks around them.

Within a rehabilitation setting the challenge for each individual practitioner is to ensure they hold true to each of the five principles outlined above (Leamy *et al.*, 2011). This is to ensure that they do not allow service demands to take precedence over personalised approaches, guarding against a 'one size' fits all approach. It has been suggested that recovery focused practitioners face a challenge in how to safeguard against recovery being used as a euphemism for service cuts or untimely discharge arrangements (Rose, 2014; Slade *et al.*, 2014). Rehabilitation services in particular have been subject to change and scrutiny as a result of the recovery movement (Perkins, Slade 2012, Department of Health 2001).

## **1.3 Rehabilitation through time: the impact of recovery on rehabilitation**

### **1.3.1 Rehabilitation in the institutions**

Prior to the formation of the NHS in 1948 there was no national framework or governing body for psychiatric care. Care was a moral obligation (Anthony and Liberman, 1986) and took place in workhouses across the country, where care was provided with a punitive approach in impoverished conditions (Bell, 2005). The rehabilitation that took place in these institutions was limited, with a model of care which assumed patients were incapable of making any significant progress and would remain ill for life (Wing and Morris, 1981). Where rehabilitation did occur, it was viewed as a process that a person went through, where key skills were taught, practised and eventually learnt almost by rote. A team of professionals was key to this learning, offering compensatory and education techniques to achieve a '*reasonable quality of life*' (Hume and Pullen, 1993) (p6). For the more able, rehabilitation took the form of a job. Such jobs were hospital based, for example in the laundry or on the farm, others attended where available occupational or industrial therapy (Wing and Morris, 1981). The main purpose of these activities was occupation – providing a structure to the day and the shaping the preferred behaviours by the use of, for example, a ward-based token economy system (Baker, 1988).

### **1.3.2 Rehabilitation during deinstitutionalisation**

Deinstitutionalisation was first articulated by the then Minister for Health, Enoch Powell, via his now infamous 'Water Tower' speech (Powell, 1961), in which he pledged to close all the old style institutions and reduce the number of psychiatric beds by half. Mental health care had already started to change at this time with the introduction of the 1959 Mental Health Act (Holkar, 1972) and innovative pharmacological advancements, most notably the discovery of chlorpromazine in 1952, both of which enabled people to be treated more effectively in hospital and in the community, thereby reducing the need for hospital admission (Boardman, 1985). The number of psychiatric beds reduced from approximately 100,000 in 1972 to 69,000 in 1983 (House of Commons, 1985).

As institutions across the UK prepared to close, rehabilitation became a widespread intervention to help prepare the patients to move and to equip them with the necessary personal, social and domestic skills necessary to live in the community (Kavanagh, Nkire and Lavelle, 2009; Lelliott, Wing and Clifford, 1994; DHSS, 1971). At its peak, during the mid-1970s and early 1980s, the function of rehabilitation was to bridge the gap between institutional care and community living (Wing and Morris, 1981).

One target population for rehabilitation was the 'old long stay' (OLS) (Mann, 1976). These were people over 65 years of age, of whom over 30% had been in hospital for over 20 years (DHSS, 1971). They were living with few acute psychiatric symptoms, but equally few social and practical skills, experiencing increasing physical frailty (Meeks *et al.*, 1990). Another target population was the 'new long stay' (NLS) - those under 65 years of age but still with hospital admissions in excess of 5 years. They were fewer in number, younger, and subject to frequent hospital admissions and regular detention under the Mental Health Act (Lelliott, Wing and Clifford, 1994).

The NLS had proportionally more challenging behaviour than the OLS, and discharging them to the community proved more troublesome (King, Singh and Shepherd, 2000). Similar to the OLS, they had either lost or not developed the skills required to live independently (Mann, 1976) and were described as having a certain level of preserved personality without the chronicity usually associated with long-term institutional care (Dick, 1990).

Quite unusually, the hospital closure and deinstitutionalisation programmes were subject to large scale evaluation via the Team for the Assessment of Psychiatric Services (TAPS). TAPS was established in May 1985 and in over 30 internationally recognised publications evaluated the impact of the hospital closure policy and the subsequent move of patients into the community (Leff *et al.*, 2000; O'Driscoll and Leff, 1993). In essence it was an evaluation of the rehabilitation provided at the time, which was identified overall to have been a success. Patients increased their level of domestic, social and community living skills, and reported an enhancement in their quality of life (Leff and Trieman, 2000). The combination of hospital closure and rehabilitation programmes had provided relatively stable homes for the majority of patients (Trieman *et al.*, 1998) with most people feeling happy in their new environments (Anderson *et al.*, 1993).

However despite the provision of intensive, multi-professional rehabilitation (Bridges, Huxley and Oliver, 1994; Holkar, 1972) to reduce the impact of disability caused by years of mental illness and institutionalisation (Anthony and Liberman, 1986), some patients remained difficult to place (Trieman and Leff, 1996), a high proportion requiring continued 'asylum' from everyday life (Norman and Parker, 1990).

Other patients reported problems with loneliness, difficulty in maintaining relationships, not feeling functionally able or mentally better (Pejlert, Asplund and Norberg, 1999). In addition to this, there was a failure to consider the readmission needs of previous long stay patients (Leff *et al.*, 2000) with 178 out of 615 patients being readmitted to hospital during the first year

of a community placement (Gooch and Leff, 1996). Interestingly, those who were readmitted were predominately from the NLS population, with a higher risk profile and a greater element of challenging behaviour (Gooch and Leff, 1996; Lelliott, Wing and Clifford, 1994; Mann, 1976).

Despite these problems, deinstitutionalisation continued - institutions closed and the provision of rehabilitation moved the hospital ward to a 'ward in a house' (Shepherd, 1995). This was essentially a large house in which a number of ex-hospital patients lived together. Four such units were set up in the NHS Trust which is sponsoring this research. The staff worked with the residents to create a therapeutic milieu and used social therapies to overcome the disabilities and social disadvantages associated with institutional care (Cope et al., 2004). As the institutions closed and population of long stay patients naturally reduced (Bell, 2005), an assumption was made that rehabilitation was no longer required. It fell out of favour with policymakers and became a redundant concept (Holloway, 2005), failing to appreciate the complex needs of a growing new population of clients struggling to live in the community.

### 1.3.3 Rehabilitation at the turn of the millennium

The latter part of the 1990's and the early part of the 2000's was a difficult time for mental health services both within the UK and internationally due to the overarching cost saving policial agendas to move services out into the community (Field and Reed, 2016). In England and Wales there was a sense that care in the community had failed (Leff, 2001) and that the legislation put into place was ineffective in managing the risks (Rugkåsa and Burns, 2009; Schneider, Carpenter and Brandon, 1999). As a result people were fearful of those with a psychotic illness - prevention of homicide became a motivating factor for care, despite the fact there had been no actual increase in homicide rates for nearly 40 years (Taylor and Gunn, 1999).

The much awaited National Service Framework (NSF) for Mental Health (DOH, 1999) brought with it the promise of restructure and positive reorganisation. It saw the introduction of early intervention in psychosis (EIP) teams, with an emphasis on advocacy and preventative work. EIP services were a welcome addition to existing services, and have since been positively evaluated (Nordentoft *et al.*, 2014), particularly for addressing fundamental recovery issues such as employment and education (Bond, Drake and Luciano, 2015).

However, despite the rehabilitative function of EIP teams, rehabilitation for those with longer-term needs was overlooked and omitted from any strategic level documentation (Killaspy et al., 2005). Rehabilitation was seen to be a poor fit with modern thinking, associated with long

hospital stays, poor treatment response rates, and a characteristically slow pace of work (Holloway, 2010). As a consequence, rehabilitation services were unattractive to commissioners and subject to closure - and this is exactly what happened within the geographical area of this study.

In order to continue to meet the high level needs of a small group of patients, Assertive Outreach Teams (AOT) (Holloway, 2010) were the only option available under the NSF for Mental Health (DOH, 1999). The remit of AOT was to maintain engagement with traditionally difficult to engage and 'non-compliant clients' (Ritchie, 1994; Cold, 1994) to reduce risk and identify when hospital admission was required, and to prevent people falling through the net and failing to receive treatment when acutely unwell.

While the prevalence of psychotic illnesses, aggressive and impulsive behaviour and comorbidity is common in both AOT and rehabilitation populations (Killaspy *et al.*, 2009; Kavanagh, Nkire and Lavelle, 2009), the rehabilitation population are more likely to have recurrent hospital admissions (Killaspy *et al.*, 2009). As well as support with symptom management, accommodation and finding meaningful activity, rehabilitation clients also need support to overcome the issues associated with regular hospital admissions, in a similar way to the OLS and NLS populations before them (Chopra, Harvey and Herrman, 2011; Killaspy *et al.*, 2009) There is also a greater need of assistance in recovering the social support aspects of their life.

#### 1.3.4 Recovery oriented rehabilitation

Rehabilitation in general terms is now firmly back on the wider National Health Service agenda, particularly in light of the NHS Commissioning Guidance for Rehabilitation (NHS England, 2016a). This guidance positioned mental health needs and rehabilitation, albeit in general terms, alongside rehabilitation for serious physical illness such as coronary heart disease and stroke. Rehabilitation was summarised into seven main areas (see Table 1.1 below), recognising that the process is a lengthy, lifelong process which may include '*habilitation, reablement and recovery*' (NHS England, 2016a, p.37).



Table 1.1: *Seven main areas of rehabilitation*

Seven main areas for rehabilitation
<ul style="list-style-type: none"><li>• develop skills for the first time</li><li>• recover from unexpected illness</li><li>• manage long-term conditions</li><li>• self-manage conditions</li><li>• recover from major trauma</li><li>• maintain skills and independence</li><li>• access advocacy</li></ul>

Adapted from NHS Commissioning Guidance for Rehabilitation (NHS England, 2016a)

Despite the NHS Commissioning Guidance (NHS England, 2016a) offering guidance that is non-specific for people with long term mental health needs, it is important to recognise the interplay between mental health and physical health (HM Government, 2011). Although the impact of the guidance on mental health rehabilitation services is unknown, the seven core principles are applicable and provide a contemporary framework for rehabilitation specialists, including occupational therapists. However, in shaping rehabilitation for the new millennium, the recovery movement has been the most highly influential driving force, forming the basis of a plethora of guidance, policies and recommendations (Shepherd, Boardman and Slade, 2008; Shepherd, Boardman and Burns, 2008; Department of Health, 2001).

Having lived through a period of time where mental health rehabilitation felt undervalued and side-lined from other mental health services, recovery as a concept with a new set of principles (Shepherd, Boardman and Slade, 2008), has offered a fresh template for rehabilitation services (Holloway, 2010a). It has offered a renewed emphasis on a person-centred care (Critten, Bezyak and Fried, 2013; Rebeiro, 2000) and a personalised goal setting approach to interventions (Clarke *et al.*, 2009; Borg *et al.*, 2009; Playford *et al.*, 2000a). This has shifted the focus of rehabilitation from the all-knowing professionals to the person themselves deciding what aspects of personal recovery are important to them (Shepherd, Boardman and Slade, 2008; Repper and Perkins, 2003; Copeland, 2000). While this level of personalisation is necessary and is to be encouraged, it adds to the complexity of rehabilitation, making it challenging to describe and measure because of the numerous variables.

## **1.4 Rehabilitation as a complex intervention**

Recovery oriented rehabilitation is a complex intervention. As rehabilitation has changed and evolved, it has incorporated a wide range of theoretical frameworks and types of intervention (Murugesan *et al.*, 2007), including those based on cognitive and psychological theories. These include cognitive behavioural therapy and remediation (Velligan, Kern and Gold, 2006; Svensson and Hansson, 1999; Spaulding *et al.*, 1999) and neurocognitive and social cognitive therapy (Kurtz, Bronfeld and Rose, 2012; Kurzban, Davis and Brekke, 2010; Bellack, Gold and Buchanan, 1999). These contemporary interventions have been used alongside more traditional approaches such as social skills training (Bellack, 2004), vocational rehabilitation (Beutel *et al.*, 2005) and pharmacological interventions (Szmidla and Leff, 2006).

This array of possible interventions, used under the broad definition of rehabilitation (Corrigan and Mueser, 2012; Pratt *et al.*, 2006) and coming from a wide theory base, can make recovery oriented rehabilitation difficult to define and therefore difficult to measure.

In addition to the range of therapeutic interventions, staff attitude is a key component of recovery adding a further dimension. While all staff in any health care setting are expected to work with care and compassion, staff working in a recovery oriented way are required to have the ability and skill to deliver person-centred care (Borg *et al.*, 2009). Person-centred care treats people individually and according to their needs, and some would argue this requires additional training (Cook *et al.*, 2016).

Such a multifaceted approach to rehabilitation has moved rehabilitation from simple skill acquisition to targeting the day to day functioning of people (Gigantesco and Giuliani, 2011; Kurzban, Davis and Brekke, 2010), taking account of their social circumstances, state of wellness and motivation to change (Velligan, Kern and Gold, 2006). Thus the ultimate aim of recovery oriented mental health rehabilitation today is to develop and maintain skills and promote independence and self-management (NHS England, 2016a). This works to increase occupational engagement (Kielhofner, 2008) and challenge the occupational injustices (Kristensen and Petersen, 2016; Martin, Sadlo and Stew, 2012; Yerxa, 1990) which can lead to stigma and maintain isolation (Jenkins and Carpenter-Song, 2009; Link *et al.*, 2001).

## **1.5 The rehabilitation unit**

This research was undertaken in an NHS trust with four rehabilitation units. Two of the units were designated as *homes for life* for people rehoused when the local psychiatric institution closed, another prioritised clients with challenging behaviours. These three units were

essentially wards in the community, as they were still managed under local hospital policies, and had a greater emphasis on maintaining safety rather than rehabilitation (Shepherd, 1995). The fourth unit had a focus on rehabilitation and described itself as working in a recovery-orientated way (Anthony, 1993). It took referrals from local acute mental health wards, a local challenging behaviour unit, and the trust-wide forensic hospital.

This fourth unit was chosen for the study as it was the only one where rehabilitation was prioritised over just maintaining safety. The unit was still staffed 24 hours a day by registered mental health nurses and each client had a primary nurse responsible for coordinating rehabilitation within the multi disciplinary team (MDT) (McCloughen *et al.*, 2008). The MDT consisted of nursing assistants, a Responsible Medical Officer (consultant psychiatrist), an occupational therapist, and a part time psychologist. The team was managed by a senior nurse and the author of this thesis working as a consultant OT, provided clinical supervision and leadership to the MDT. The author, in the role as the consultant OT did not work directly with the clients.

This unit was a purpose built two storey property divided into three, six-bedroomed houses, surrounded by a small, but well maintained garden. Each bedroom contained a single bed, wardrobe, wash basin and a locked medicine cupboard. Residents were encouraged to personalise their own rooms and keep the doors locked. The main facilities e.g. bathroom, kitchen and lounge were shared between the six residents in each house.

Each resident was given a weekly food budget of £28.00 to purchase the main ingredients for meals, and this could be achieved independently or with staff as part of an individualised recovery programme as required. Other aspects of the recovery programme available at the unit included attendance at weekday occupational therapy sessions, referral to Mindfulness and Cognitive Behavioural Therapy for psychosis, and social events in the evenings and weekends. As people progressed toward discharge, individual sessions were provided to support the transition to new accommodation. The discharge process was tailored to meet individual needs.

By 2014, four years into the study, two of the four units had closed because of service redesign and one was transferred to social care, leaving just the research site open. In addition, the dedicated community rehabilitation team had been absorbed into mainstream services, essentially replicating what other trusts had done 15-20 years previously. Anecdotally, these changes brought considerable uncertainty for the clients and staff, with the fear that their unit would be next to close.

## **1.6 Evolution of the study**

The drive for this research study evolved from tensions observed from within the clinical setting of the fourth rehabilitation unit described above. One tension was in relation to how different rehabilitation is from other streams of mental health care, given that the recovery agenda now influences services across the spectrum of mental health care (Shepherd, Boardman and Slade, 2008; Anthony, 1993). The differences of length of stay and destination on discharge (Killaspy, Harden et al. 2005) between rehabilitation and other forms of mental health care created polarised views on the cost effectiveness and added value of specialist rehabilitation units. Tensions were observed between practitioners and commissioners, with managers finding themselves somewhere in the middle, trying to appease staff, bringing in recovery based practices and challenging the assumption of the commissioners that the rehabilitation unit did nothing but delay client discharge.

This tension was based on a concern that a large proportion of clients coming through the unit were still in need of a high level of care after 9-12 months of rehabilitation. Thus, clinical decisions on a client's discharge destination were routinely questioned and high cost placements were often refused. On the other hand, staff believed they were doing a very good job discharging people back into the community. Their assumption was supported by anecdotal evidence from clients and family, who in the main articulated that rehabilitation was a good thing and that clients benefited from it. Staff believed that the commissioner's perception about poor effectiveness was contributing to the unfair disinvestment in rehabilitation services across the city.

In addition, a number of staff at the unit had worked in rehabilitation for many years, some going back to as far as the start of deinstitutionalisation (Bell, 2005; Wing and Morris, 1981) - the arrival of the recovery agenda (Shepherd, Boardman and Slade, 2008; Anthony, 1993) was viewed with scepticism, and perceived as a new word to describe the work they had been doing, effectively disregarding what they had been doing up to that point (Battersby and Morrow, 2012; Tsai, Salyers and Lobb, 2010). As a consequence the uptake of training and engagement with the Recovery College (Perkins *et al.*, 2012) and other contemporary practices such as Wellness Recovery Action Planning (Copeland, 2000) was anecdotally low.

## **1.7 About the author of this study**

I qualified as an occupational therapist (OT) in 1991, but my first experience of working in mental health rehabilitation was as a first year student in the late 1980's. After completing a

master's degree in 2006, I returned to work in this area as a consultant OT and saw things in a very different light. To enlighten the reader of my own professional interest in rehabilitation, what follows is a narrative reflection on my own rehabilitation journey. This section is thus written in the first person.

My formative experience took place in a large gothic-style hospital, set within an established woodland. The hospital was on the outskirts of a large 'London overspill' town, and to a 19 year-old girl from Cornwall the environment filled me with fear and trepidation. I have very clear memories of bus drivers checking people's feet before he would let them on to the bus: shoes for '*Yes you can travel*', slippers for '*No you can't!*'

For 3 weeks of a 6 week placement I was assigned to work on a male, long-stay rehabilitation ward. In my view the ward failed to stimulate the patients, and staff appeared either bored or frightened. There was an expectation that the men would remain on the ward for life with little hope or prospect of change. My role was to assist the men with their personal care to ensure they were ready on time to start their session of work at the industrial therapy unit housed within the hospital. Reflecting back on this experience, I had no idea what I was supposed to be doing. I can see now that neither I, nor the rest of the staff, or the environment provided the men with the verbal, physical or emotional support they needed to enjoy life, experience mastery or develop hope for the future.

An acute admissions ward was my base for the second half of my placement. Here patients were younger, less physically and cognitively damaged, and somewhat less frightening. In contrast to the previous ward, where patients demonstrated no desire to leave the ward environment, the patients on this ward were always trying to find ways to get out of the hospital. I am sure this was not true for all, but the difference between the two patient populations and the staff in both these environments was startling and memorable. I recall thinking that I would never choose to work in a mental health rehabilitation environment again.

Upon qualifying I took up a post on a mental health acute admissions ward which was part of the large psychiatric hospital where I had worked as a student. However, across the hospital, as elsewhere within the UK, long-stay wards were closing, people were being moved into the community, and community mental health teams (CMHT) were being established. By 1993 the rehabilitation service at the hospital had gone - yet in my role in the CMHT I was working with many deinstitutionalised people who were struggling to cope with living in the community, as they did not have the necessary skills.

Over the next 10-15 years all the old-style psychiatric institutions across the UK closed and rehabilitation was viewed as old fashioned, out of date and no longer a necessary part of the health system (Holloway, 2005) - people were in theory being treated in the community. In reality however many were being placed in hospitals away from their hometowns, often in private hospitals, as the overall number of rehabilitation beds had been reduced (Killaspy and Meier, 2010).

However, some areas managed to retain their rehabilitation beds for longer. The service where I worked from 2006-2014 was in the unique situation of having four NHS-funded rehabilitation units with a total of 54 beds. It was from my work at these units that I started to question the role of rehabilitation, what it contributed to an individual's recovery, their discharge and their ability to live successfully in the community. As an OT I was particularly interested in the skills relating to activities of daily living and in whether rehabilitation impacted on the individual's functional performance.

#### 1.7.1 Occupational Therapy

Occupational Therapy, as a profession, believes fundamentally in the importance of 'knowing and doing' (Hagedorn, 2000) (p4), of achieving time-related activities within certain environments to create a sense of mastery (Meyer, 1977). The relatively recent addition of Occupational Science to the Occupational Therapy theory base brings the science of the human, as an occupational being, from a much wider social and cultural environment into the discourse on the meaning of occupations (Yerxa, 1990). Alongside its humanistic and person-centred approach to therapy (Rogers, 1961), occupational therapy draws on occupational science to underpin a range of scientific, philosophical and theoretical frameworks to understand and provide the clinical rationale for its interventions (Kristensen and Petersen, 2016; Crouch and Alers, 2014).

However, to others outside of the profession OT can be viewed as a simple 'low tech' profession that uses everyday activities in assessment and intervention modalities (Hagedorn, 2000, p3). While the activities which OTs use are indeed everyday activities, their understanding of 'doing and being' (Farnworth, 1998) arises from an awareness that occupational engagement is complex, and engagement in human occupation arises out of personal 'volition, habituation and performance capacity' (Kielhofner, 2008, p12).

In summary, volition is what motivates and drives the person - why they do what they do and when they do it. Habituation is the roles, habits and routines that a person has which create a pattern for day to day doing. Performance capacity is the presence of a person's physical,

psychological and cognitive components (Kielhofner, 2008). The integration of these basic concepts of occupation within the context of the environment is what enables occupational engagement across three broad areas of activity: activities of daily living (self-care and maintenance), play (hobbies, sports and pastimes), and productivity (paid and unpaid work) (Kielhofner, 2008).

Occupational Therapy, from its inception has worked with people whose ability to engage in meaningful activity has been disrupted through physical or mental ill health (Meyer, 1977), resulting in occupational deprivation, occupational imbalance, occupational injustices or occupational alienation (Yerxa, 1990). Through a detailed understanding of the person, the environment and the occupation, occupational therapists are able to work with clients to bring about personal, environmental or occupational changes to enhance occupational engagement (Fisher, 2009; Townsend and A. Wilcock, 2004; Law *et al.*, 1996).

Occupational therapists are recognised as essential staff members within the rehabilitation process (NHS England, 2016a). With their understanding of how people perform occupations within the context of their environment, occupational therapists are well positioned to assess the performance capacity of individuals (Fisher, 2009; Kielhofner, 2008). With their knowledge and skill in the application of occupational analysis, occupational therapists are also well placed to set rehabilitation goals (Richter, Schmid-Ott and Muthny, 2011; Playford *et al.*, 2000b). With an awareness of occupational science, (Yerxa 1990) they fully appreciate that to recovery socially individuals need to engage in meaningful activity and maintain social connections. With an understanding of performance capacity, occupational therapists enable people at their own level to participate in their environment (MacDonald-Wilson and Nemec, 2005), and thereby re-establish roles, habits and routines (Kielhofner, 2008) which add meaning and quality to their life. It is through this occupational lens that rehabilitation is framed throughout this thesis.

## **1.8 Relevance to practice**

With the rising prevalence of mental ill health (Mental Health Foundation, 2016), the increasing awareness of what is required to facilitate recovery (Leamy *et al.*, 2011), and the national focus on rehabilitation generally (NHS England, 2016a), it is timely to investigate a recovery-oriented model of mental health rehabilitation and explore the evaluation to date of contemporary services. Although recovery remains high on the the Government's agenda (Shepherd, Boardman *et al.* 2008), there is a sense amongst clinicians that rehabilitation

continues to be a forgotten need within contemporary mental health services (Holloway, 2005), that the complex needs of a relatively small population requiring extended periods of high level care and rehabilitation (Killaspy, Harden et al. 2005) have been misunderstood by those commissioning services.

In recent years there has been renewed interest in mental health rehabilitation. There is now a small body of contemporary, UK based research from a nationally supported research programme: Rehabilitation Effectiveness for Activities of Life (REAL) (Killaspy *et al.*, 2017), which is both raising the profile of rehabilitation and updating the somewhat outdated body of rehabilitation literature.

The REAL studies have gone some way to highlighting the contribution of rehabilitation within the wider mental health arena, and have brought to the fore some of the current issues faced by rehabilitation service staff and clients in terms of quality (Killaspy *et al.*, 2013a; Killaspy *et al.*, 2011), outcome measurement (Killaspy *et al.*, 2016) and staff training (Cook *et al.*, 2016; Killaspy *et al.*, 2015; Killaspy *et al.*, 2013b). However, the REAL project did not have the service user perspective as a focus, meaning that the views of those using the service continue to be under-represented.

If current mental health rehabilitation services are to fully embrace the principles of recovery, the narratives of those experiencing the service must be heard. In this way services could not be accused of presenting only acceptable narratives (Hughes, 2015) but would get to the core of what service users felt they need. Equally importantly, given the history of rehabilitation, the effectiveness of rehabilitation must be evaluated in a way that is sensitive and representative of its complexity and taking a client-centred approach.

## **1.9 Broad area of research**

The broad area of research within this study will focus on how rehabilitation effectiveness has been evaluated in the past and assess whether the client perspective has been considered, and if so how. This investigation is particularly interested in individual as opposed to group changes over time and if people feel they have been treated in a way which is bespoke to their needs- if recovery principles being upheld in rehabilitation units.

The development and maintenance of skills and the changes towards independence and self-management are still at the forefront of rehabilitation today (NHS England, 2016a). They are therefore considered an essential point of investigation, particularly given the five main



areas of recovery: 'connectedness, hope, identity, meaningfulness and empowerment' (Leamy *et al.*, 2011).

### **1.10 Summary**

The first chapter of this thesis has provided an overview of the recovery movement and summarised current and historical perspectives of rehabilitation. The complexity of rehabilitation and the influence of recovery on rehabilitation practice are acknowledged. The evolution of rehabilitation and the impact that recovery has had on rehabilitation services, nationally and more specifically at the unit where this study took place, have been explored. Key tensions, albeit observed from a single perspective, which suggested a lack of a shared understanding of recovery-oriented rehabilitation within the rehabilitation unit, were highlighted. My own background as a researcher were introduced and details of my background as an occupational therapist given. This included an outline of the core assumptions of occupational therapy in order to provide a basis for the occupational lens taken in this thesis.

This chapter concludes with the identification of the area of research, which brings together a desire to understand what contemporary mental health rehabilitation is, especially in light of the the national recovery agenda, and how it has been previously evaluated. This is the focus of the next chapter: the literature review.

## **Chapter Two**

### **A review of the literature**

#### **2.1 Introduction**

A literature review is a systematic way of collecting, analysing and synthesising recent studies undertaken in a particular field in order to develop a composite or summary of what is already known (Rozas and Klein, 2010). Areas of conflict or agreement are highlighted, gaps in the knowledge base may be identified and research undertaken to further understand a particular theory or phenomenon. There are many ways to review the literature, depending on the philosophical position of the researcher, the subject under investigation, and the purpose of the review (Creswell, 2014; Murray, 2011).

The philosophical position of the researcher is somewhere along a philosophical continuum (Creswell, 2014). At one end of the continuum, a researcher may take a very strong positivist, empirical and quantitative approach to research (Eisenhart, 1998) from an ontological position of there being only one truth. Such a truth can be reached epistemologically only by means of a value free approach to enquiry. This means there must be distance between the researcher and the research itself. Thus in laboratory experiments the impact of a change on a variable is measured to test a hypothesis.

At the other end of the philosophical continuum is an ontological research position accepting many realities and taking an epistemological stance of many ways of knowing (Murray, 2011). Constructionist research methodologies are employed for the building of ideas as they emerge from the data (Creswell, 2014). While these two ends of the continuum may appear diametrically opposed (Creswell, 2014) practice based health care research is increasingly seeking to explore and understand human existence while at the same time seeking evidence that is transferable. Researchers taking this stance are philosophically towards the middle of the continuum, using both quantitative and qualitative methodologies (Creswell, 2014; Gaber and Overacker, 2012; Andrew and Halcomb, 2009; Anaf and Sheppard, 2007).

The style of literature review conducted before a research study commences will depend on the research to be undertaken and the philosophical stance of the researcher. Inductive reviews typically draw on meta-analyses and randomised controlled trials with a view to confirming what is already known and reaching scientifically robust conclusions generalisable to a large population. Such reviews constitute much of the research undertaken to date within the medical and biomedical fields. On the other hand, a narrative literature review will challenge and re-examine what is taken for granted and explores

alternative ways of understanding the world and human experience, appreciating that human action varies depending on the context and situation (Eisenhart, 1998). Such a review seeks to 'theory build' as opposed to 'theory test' by drawing together narratives for the purpose of reinterpretation and in order to gain new insights into the human experience (Baumeister and Leary, 1997).

The focus of this literature review, which takes a narrative approach, is to explore how recovery focused inpatient mental health rehabilitation has been previously evaluated. This is with a view to exploring any commonalities and gaps in the literature from both a recovery (Anthony, 1999) and occupational therapy (COT 2010) perspective. Since the introduction of the National Service Framework (NSF) for Mental Health (DoH 1999), a survey conducted in 2007 reported that 54% of mental health services had seen a reduction in their rehabilitation services, with 18% reporting a unit or ward closure, with a further 18% reporting proposed closures or reduction in provision in the near future (Mountain, Killaspy et al. 2009). With this level of reduction, and the influence of recovery on rehabilitation, coupled with the tensions discussed in Chapter 1, it is judicious to reassess how effectively contemporary rehabilitation services are being measured. This is particularly relevant given the top four functions of a rehabilitation unit have been identified as: improving quality of life, maximizing skills, promoting recovery and facilitating greater independence for service users (Killaspy et al., 2005).

Occupational therapists, with their understanding of occupational science, appreciate the role of engagement in meaningful occupations as a way of combatting occupational deprivation, alienation and injustices frequently experienced by those with long term mental health needs (Yerxa 1990, Kristensen, Petersen 2016). Occupational therapists are experts in understanding the range of skills required to efficiently and effectively engage in activities of daily living (Fisher and Jones, 2014; Fisher and Jones 2012). Occupational therapists in a rehabilitation setting will work with people to improve their skill and level of functioning, which in turn promotes recovery, independence and an overall improvement in quality of life (COT 2010). While occupational therapy is a key health care profession within rehabilitation as a whole (NHS England, 2016a), only 61% of long stay and 78% short stay rehabilitation units in England employ an occupational therapist (Killaspy et al., 2005), which would indicate that looking at rehabilitation through an occupational lens is a unique approach and one that has not previously been explored.

## 2.2 Search strategy

The initial literature search was conducted in December 2013 and updated in April 2017 using CINAHL, MedLine, Psych Info, Scopus and Delphis databases. To give the strategy a framework, the PICOS (P = population, I = intervention, C = comparison, O = outcome(s) and S = study) approach was applied as outlined in Table 2.1 (Costantino, Montano and Casazza, 2015).

Table 2.1: Search parameters using PICOS

Search parameters		Justification of search parameters
Population	People with serious mental illness / schizophrenia Adults aged between 18-65	Most frequent users of inpatient rehabilitation beds  Traditionally the age range imposed by adult mental health services for rehabilitation
Intervention	Mental health / psychosocial rehabilitation	A generic term for a variety of services Excludes specific interventions (e.g. cognitive behaviour therapy) that are narrow in their availability
Comparison	In person, over time	Pre and post measures for individuals and groups
Outcomes	A formal measurement that can be repeated over time	Changes following inpatient psychiatric rehabilitation
Study designs	Any	To include all methodologies, to capture personal experience as well as quantitative data

Papers considered for inclusion were limited to those printed in the English language from 1999 onwards. This was a pertinent time in history for mental health services with the publication of the National Service Framework for Mental Health (Department of Health, 1999), which gave a clear, national structure for mental health services in England. It was also the time that deinstitutionalisation in the UK was nearing completion and the large psychiatric institutions that had dominated care in the past were closing. The use of key words, as summarised in Table 2.2 and the application of Boolean logic was applied to increase search specificity.

Table 2.2: *Search terms used in initial literature search*

psych* or schizo* or mental*	rehab*	model* or goal* or outcome*	“assessment of motor and process skills”
severe or chronic or enduring	“quality of life”	“inpat*” (inpatient)	function*

To ensure specific relevance to the review, each article that was read in full was subject to appraisal against the inclusion/exclusion criteria as detailed in Table 2.3

Table 2.3: *Inclusion and exclusion criteria*

Inclusion	Exclusion
The intervention of multi – disciplinary inpatient, psychosocial rehabilitation	Specific elements of rehabilitation in isolation e.g. cognitive therapy, token economy Specialised rehabilitation settings e.g. secure units
Measure psychosocial rehabilitation across more than one timeframe	Identification of need without measuring how or if the needs are meet
Clients with a psychotic illness, diagnosed post the closure of the institutions	Clients with non-psychotic illnesses, institutionalisation or post-traumatic stress
The use of measures that explore personal change over time for clients	The effects of group work over time The effects of working in rehabilitation from a staff perspective

Combined, the 2013 and 2017 literature searches generated a total of 903 articles for appraisal (Figure 2.1). Having saved each search, the title of each article was read online and a decision made on its relevance, based on the search parameters (Table 2.1) and the inclusion/exclusion criteria (Table 2.3). At this stage, 589 were removed, leaving 314 possible articles for inclusion in the review. Of these 314, each abstract was read on line, reducing the possible number for inclusion in the review to 34. The reason for the removal of 280 articles at this stage included duplications, studies based in the community, or studies with a focus on other forms of rehabilitation e.g. alcohol or drug rehabilitation and rehabilitation for those experiencing a first episode of psychosis. The remaining 34 articles

were printed and read in full to ascertain relevance to the narrative review. This reduced the total number for inclusion in the narrative review to 13, with the other 21 having some relevance elsewhere in the study. A brief summary of the rationale for exclusion is given in Appendix 2.1. Thirteen studies have been included in the narrative review (Figure 2.1) and were subject to critical appraisal using a relevant appraisal tool.

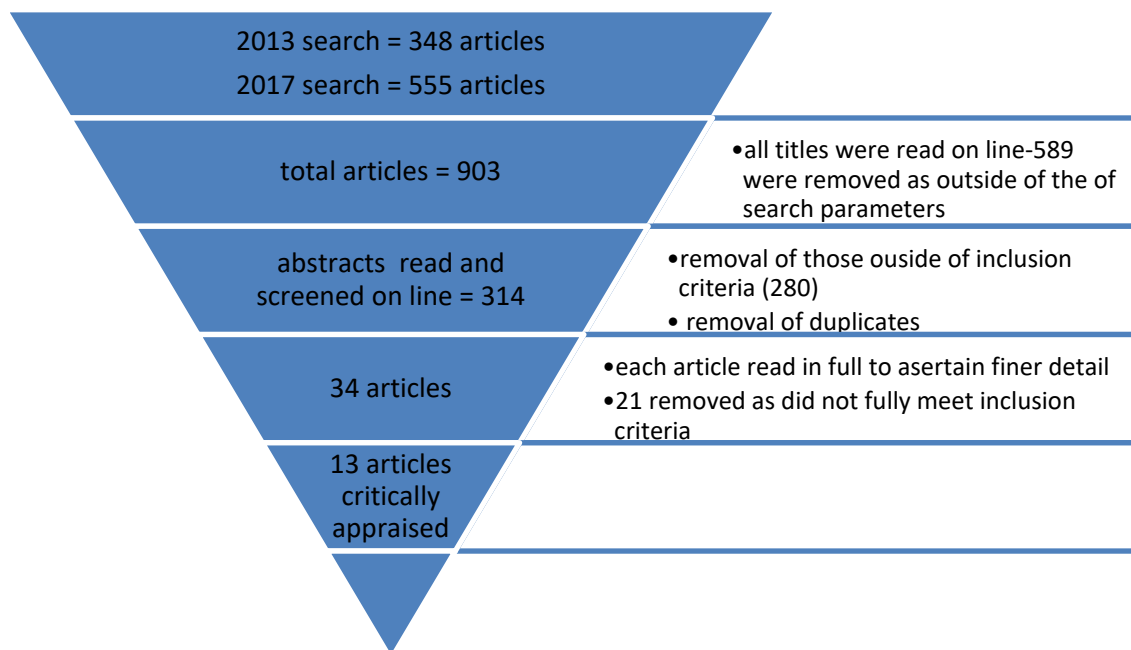


Figure 2.1: Search strategy flow chart

### 2.2.1 The critical appraisal

All 13 papers were critically reviewed with an appropriate quality assessment tool. As the majority of studies in the review were cohort studies, a critical appraisal tool specifically designed for studies without a control group was necessary to give a fair appraisal. Similarly, as comparison across time and a specific intervention (inpatient mental health rehabilitation) were key inclusion criteria, it was essential that these components were considered as part of the critical appraisal. Thus, the American National Heart, Lung and Blood Institute (ANHLBI) Quality Assessment Tool for Before – After (Pre-Post), Studies With No Control Group, was chosen as the main critical appraisal tool (American National Heart, Lung and Blood Institute, 2017).

The tool asks specific questions about the consistency of an intervention, evaluates if measures are taken before and after the intervention, and considers the percentage lost to follow up after baseline. In addition to this, the tool provided an overall quality indicator of the study, of *good* - with the least risk of bias, *fair* - susceptible to bias, or *poor* - indicating a significant risk of bias - which is not something the new CASP Cohort Study appraisal tool is able to do (CASP, 2018a). The ANHLBI do not provide a critical appraisal tool for qualitative studies therefore the CASP appraisal tool for qualitative research was used for the qualitative study (CASP, 2018b). See Appendix 2.2 for a detailed critical appraisal of the individual articles.

### **2.3 Studies included in the narrative review**

All 13 studies measured the effect of inpatient psychosocial rehabilitation across two or more phases. Six studies were from the UK, three from America, two from Australia and one each from Sweden and Canada. Of the studies identified, ten were cohort studies, seven of which were retrospective; two were controlled studies; and one was a qualitative study. The small number of studies identified since 1999 is reflective of the continuing paucity of research into mental health rehabilitation (Holloway, 2010a; Holloway, 2005; Killaspy *et al.*, 2005).

### **2.4 Evaluating the effect of rehabilitation**

It is evident from the review that evaluation of the effectiveness of rehabilitation is undertaken in a variety of ways, utilising different tools. The key fields of inquiry have been collated into the following seven areas of interest: functioning, symptoms, behaviour, clinical costs, patient experience, quality of life and needs. Table 2.4 provides a summary of the measures identified in the review. Due to the high volume of tools identified in the review, only those used in two or more studies are critiqued. Details of all measures identified in the review are provided in Appendix 2.2.

Table 2.4: Summary of the measures used across the studies in the literature review

Area of interest	Measures	Clinician rated	Self-rated	Interview	Computer based
Functioning	Wechsler Adult Intelligence Scale (n=1) Hinting Task (n=1) Rey Auditory Verbal Learning Task (n=1) COGLAB (n=1) Life Skills Profile (n=2) Time use diary (n=1) Global Assessment of Functioning (n=3) Health of the Nation Outcome Score (n=1) Strauss-Carpenter Scale (n=1) Information obtained from clinical notes (n=1)	x X x x X X X			X X X X
Symptoms	Brief Psychiatric Rating Scale (n=4) Kessler 10 (n=1) Colorado Client Assessment Record (n=1) Comprehensive Psychopathological Rating Scale (n=1) Becks Depression Inventory (n=1) Hopkin's Symptom Check List - 90 (n=1) Scale for the Assessment of Negative symptoms (n=1) AIMS (n=1)	X X X X X	X X	X X X	
Behaviour	Special Problems Rating Scale (n=3) Clinicians Alcohol and Drug Use Scales (n=2) Nurses Observation for Inpatient Evaluation (n=2) Social Behaviour Scale (n=1) Behaviour and Everyday Living Skills Schedule (n=1)	X X X X X			
Clinical cost	Occupied bed days (n=4) Community living and working (n=4) Change in medication use (n=2) Use of the Mental Health Act (n=1)	X X X X			
Patient experience	One to one interviews using photo-elicitation (n=1) Target complaints (n=1) Client Satisfaction Survey (n=1) The information Questionnaire (n=1)		X X <sup>1</sup> X <sup>2</sup>	X	
Health status / QoL	SF-36 (n=1) Kajandi (n=1) Quality of Life Scale (n=1)		X	X X	
Needs	Camberwell Assessment of Needs (n=1)	X			

<sup>1</sup> This has been assumed as no details in the paper

<sup>2</sup> This has been assumed as no details in the paper



## 2.5 Functioning as a measure of change

*Functioning*: This is the ability of an individual to perform cognitively and socially, integrating a range of skills to engage in activities and to acquire a level of achievement required to live life as they wish. This was the most frequently measured construct, using measures to examine cognitive skills and higher executive functioning, such as those required to plan, problem solve and evaluate outcomes, and to examine social functioning, including specific life skills as well as global functioning. In total, 10 different measures of functioning were used across nine different studies, making functioning the most commonly measured construct in the review (Bunyan et al., 2016; Killaspy *et al.*, 2016; Killaspy and Zis, 2013; Gonda, Deane and Murugesan, 2012; Liu et al., 2011; Peer and Spaulding, 2007; Vandevooren, Miller and O'Reilly, 2007; Leff and Szmidla, 2002; Svensson, Hansson and Nyman, 2000). The measures were a combination of self-reported scales, interviews, objective observations and computer based assessments (Table 2.4) and have been further sub-categorised into global, social and cognitive functioning measures.

### 2.5.1 Global Functioning

Data on global functioning was gathered in five studies: four studies using specific measures (Killaspy *et al.*, 2016; Gonda, Deane and Murugesan, 2012; Vandevooren, Miller and O'Reilly, 2007; Svensson, Hansson and Nyman, 2000), and one study gathering information informally from client notes (Bunyan *et al.*, 2016). Of these five studies, one was prospective (Killaspy *et al.*, 2016), one was a case controlled study (Svensson *et al.*, 2000), the rest used retrospective data. The data collection period ranged from 7 years prior to rehabilitation to 1 year post rehabilitation. Data was gathered from standardised measures recorded in clinical records and staff accounts via interview. The staff accounts due to the passage of time were subject to validity issues.

Both the Gonda *et al.* (2012) and the Svensson *et al.* (2000) studies were rated good, with the others being rated good to fair (Killaspy *et al.*, 2016) fair (Bunyan *et al.*, 2016) and poor (Vandevooren, Miller and O'Reilly, 2007) (Appendix 2.2).

The Vandevooren *et al.* study (2007), a retrospective study (n=25), was rated poor due to the overall paucity of information, including no details on participants' gender, age or diagnosis. There were also errors with reporting the results percentages (page 217). While the study collected data from two measures (the Global Assessment of Functioning (GAF) (see 2.5.3 below) and Colorado Client Assessment Record (see Section 2.11) little to no information is given about the tools or the level of detail they collect. However a higher level of functioning

was recorded on the GAF post treatment, but the details of the interventions available were not explored in depth. The main focus of this study was accommodation after discharge and an increase in independent living following discharge based on the client's choice of living environment was seen, although no direct link can be made.

In comparison, the study by Gonda et al (2012) was rated good, due to its detailed method and comprehensive results sections. Wide ranging information is provided in relation to the rehabilitation programme, the study setting and the staffing. The admission criteria and the breakdown of the participants demographics (n=337, 170 men and 167 women) is clear. 95% of the population had a schizophrenic type illness, including schizoaffective disorder, with the mean age of admission being 33.7 years for the male and 33.4 years for the female participants, with an average length of stay being 109 days and 113 days respectively.

Similarly, the Svensson et al study (2000), a case-controlled study comparing retrospective psycho-social rehabilitation (data collected 1982-1991) with a current cohort of people receiving cognitive based rehabilitation (data collected 1990-1994), was rated good. This Swedish study was rated good as the aims were clearly stated with the study setting, the skills of the therapists and the details of the matched control group clearly described. However, despite the health system in Sweden being largely similar to that of the NHS (Anell, 2008), the average age of the study population (24.6 years) was notably younger than in the other articles in the review. In addition to this the timeframe between the two cohorts is substantial, as is the average length of intervention - 54.5 weeks for the psycho-social group compared to 72 weeks for the cognitive based group. This may be influential in reaching the study conclusion that cognitive based rehabilitation was more effective than conventional rehabilitation at facilitating community living.

Despite this, the Svensson et al study was considered to be the most comprehensive study in the review in terms of measuring across the whole spectrum of rehabilitation, covering four of the areas of interest detailed in Section 2.4 (functioning, symptoms, patient experience and quality of life). However the outcomes of rehabilitation in this study focused on use of services, medication, bed occupancy and accommodation after discharge, rather than how effectively either group were at living independently in the community or their quality of functioning.

The Bunyan et al (2016) study (n=22) was rated fair due to a lack of clarity in the selection criteria and limited participation information (no gender breakdown). While data was retrospective, referrals came from participants in acute and forensic settings and it is unclear if this is where they were at the time of the retrospective data analysis or the route from which they came to the rehabilitation service. All data was collected from the Trusts

electronic record system or from paper notes when the timeframe predated the electronic system. While there is an expectation that information recorded in the clients' notes should be an objective and accurate reflection of events, there is always the potential for subjectivity. In the case of the Bunyan et al study (2016) where researchers were relying on previous staff accounts, interpretation of the written account, along with poor selection criteria may impact on validity of the findings. The Killaspy et al. study (2016) is reviewed the next section 2.5.2.

In total three objective measures were used to collect data on global functioning:

- Global Assessment of Functioning (GAF) (Jones et al., 1995)
- Strauss-Carpenter Scale (S-CS) (Strauss and Carpenter, 1977; Strauss and Carpenter, 1972)
- Health of the Nation Outcome Scale (HoNOS) (Wing, Curtis and Beevor, 1996)

The GAF was the most commonly used measure of global function used in three separate studies (Killaspy *et al.*, 2016; Vandevooren *et al.*, 2007; Svensson *et al.*, 2000). Both the S-CS and HoNOS were used in just one study and further information on these measures can be found in Appendix 2.2.

The GAF provides a numerical score between 100 – 1 (high to low functioning) of a person's ability to address and cope with everyday life events. It is widely used within mental health services, and is reported to have good reliability (Schwartz, 2007; Jones *et al.*, 1995). However, the inter-rater reliability of the scale has been questioned due to its brief administration instructions and a lack of clarity on how to score it (Aas, 2011). It is an objective assessment of a client's functioning, as opposed to his or her own perception of their functional ability, and has been found to be too symptom biased (Samara *et al.*, 2014). A more recent study found the GAF to be consistent with other tools, for example the Positive and Negative Syndrome Scale (Andreasen, 1982) and the Brief Psychiatric Rating Scale (Köhler *et al.*, 2016), but these are both measures of symptoms and not functioning. Details of these measures can also be read in Appendix 2.2.

### 2.5.2 Social functioning

Social functioning was measured in two UK studies (Killaspy *et al.*, 2016; Killaspy and Zis, 2013). The first study was part of the National Institute for Health Research (NIHR) funded programme, Rehabilitation Effectiveness for Activities of Life (REAL) (Killaspy *et al.*, 2017).

This was a four phase programme of research which first surveyed and scoped rehabilitation provision across England before developing a quality indicator and training programme for staff. The study included in this review gathered data from 50 rehabilitation units across England which had been previously rated above the mean for quality of care on the quality indicator (Killaspy *et al.*, 2011). This was a prospective study (n=329) with 12 month follow up exploring longitudinal outcomes and costs. The study is rated good to fair due to its robust representation of the population and follow up strategies. However, data was collected from staff interviews and a review of case note and not from the service users themselves.

The second study (Killaspy and Zis, 2013) used retrospective data (n=141) collected over 5 years from one NHS Trust, and included rehabilitation units and community supported accommodation. It was not possible to identify which participants were in rehabilitation and which were in supported accommodation in the community. This study was also rated good to fair, based on possible recall bias and issues with retrospective data collection, given that the study stated that any gaps in the information were completed by a key informant.

Both studies used the Life Skills Profile (LSP) (Rosen, Hadzi-Pavlovic and Parker, 1989), while the Time Use Diary (TUD) (Jolley *et al.*, 2006) was used only in the Killaspy *et al.* study (2016) to measure activity levels at four time periods during the day from a staff perspective (see Appendix 2.2).

While the LSP was developed as a measure of social functioning generally aimed at people with schizophrenia, inter-rater reliability has been found to be low, and disparities appear to be linked to how well the staff member completing the tool knows the patient (Trauer, Duckmanton and Chiu, 1995). Similar to the TUD, the LSP is an observational tool completed by staff based on what they are observing. Neither tool considers the context in which the patient is attempting to engage, or how this might translate into other social contexts.

### 2.5.3 Cognitive functioning

Cognitive functioning was measured in two American studies (Liu *et al.*, 2011; Peer and Spaulding, 2007) (n=180 and n=162 respectively) using measures designed for use with the general public, rather than those with long term mental health needs. More detail on the cognitive functioning measures used within this review (Table 2.4) can be read in Appendix 2.2.

Both studies used retrospective clinical data, with no follow up data available to evaluate the long-term transferability of the intervention. While the two studies highlight that cognitive functioning for people in rehabilitation is variable and can improve with the right environment

and time, Peer and Spaulding (2007) identify that the '*rehabilitation milieu*' was particularly important for a group of lower cognitively functioning participants. While higher executive functioning is essential to perform day to day activities, neither study considered or measured the person's ability or efficiency with performing day to day activities. Both studies used the Nurses' Observation Scale for Inpatient Evaluation (NOSIE), and the Liu et al study (2011) utilised the Brief Psychiatric Rating Scale (BPRS), recognising the limited value of measuring cognitive functioning in isolation.

#### 2.5.4 Summary of measures of functioning

Functioning was by far the most frequent area of interest measured by the studies examined in this literature review. This is unsurprising given the requirement of humans to function within their environment and the role of rehabilitation in facilitating effective day to day functioning. While cognitive functioning is essential for day to day functioning, what is important, is the application of cognition or otherwise and the ability of a person to be effective in their environment. This link was not made in the studies, which miss the application of cognition to an understanding of 'doing, being, becoming, and belonging' (Hitch, Pépin et al. 2014). Similarly, the measures of social and global functioning did not measure change in the participant's actual ability to perform day to day activities as they relied on subjective staff accounts which were frequently based on retrospective data. The gap within the data is the measure of how an individual performs the day to day activities that they want and need to do to live the life they desire, and so become and belong.

#### **2.6 Symptoms as a measure of change**

*Symptoms:* There are a wide range of psychiatric symptoms including low mood, increased anxiety, hallucinations, obsessional or unusual behaviour. Measures of symptoms, in terms of existence or severity, are frequently used as a diagnostic tool. Symptom measurement can also be self-rated giving the client's perspective, or clinician rated providing an objective view. Symptoms of schizophrenia and of other mental health conditions can be distressing and can impact a person's life in a multitude of areas. The reduction of symptoms is often a main aim of treatment, therefore it would seem reasonable to include symptom reduction as a positive outcome of rehabilitation and as a domain to be measured. In this review, symptoms of mental distress were measured in 6 of the 13 studies (Gonda, Deane and Murugesan, 2012; Liu *et al.*, 2011; Vandevoreen, Miller and O'Reilly, 2007; Arfken, Wilson and Hegedus, 2002; Svensson, Hansson and Nyman, 2000; Bruseker and O'Halloran, 1999), using eight different measures as detailed in Table 2.4.

Of these six studies, four have been critiqued above (Gonda, Deane and Murugesan, 2012; Liu *et al.*, 2011; Vandevooren, Miller and O'Reilly, 2007; Svensson, Hansson and Nyman, 2000), leaving two studies (Arfken, Wilson and Hegedus, 2002; Bruseker and O'Halloran, 1999) to be reviewed at this point before the measures themselves are considered. While both these studies fall within the timeframe of the review, the data collection periods were 1992-1997 and 1993-1995 respectively. This brings into question how new, such 'new' interventions are in the context of the emergence of the recovery movement.

Using prospective sampling, the Arfken study (2002) evaluated the outcomes of people with serious mental illness resident in an inpatient rehabilitation centre in rural America (n=114). The initial aim of the study was to comprehensively evaluate the outcomes of a residential programme using face to face patient and relative interviews, medical card reviews (clozapine national register) and a review of clinical notes. However, the original study was subject to a poor response rate with an abbreviated telephone interview being offered to address this. In addition to interviews the study used four measures (Brief Psychiatric Rating Scale, Beck Depression Inventory, Abnormal Involuntary Movement Scale and the SF-36, a perceived health status). The study concluded that those with a planned discharge were more likely to be living independently than those discharged without a plan. While comparative results are presented, there is paucity of detail and lack of clarity on data to substantiate the comparative results presented. It is for this reason despite transparency around methodological changes that this study is rated fair.

The Australian study by Bruseker and O'Halloran (1999) aimed to determine the effectiveness of a new psychosocial, rehabilitation programme for residents (n=76) at a rehabilitation unit with 20 beds, and 30 day clients who acted as the comparison group. This paper focuses on the residential clients (male=53, female=23) of which 82% had schizophrenia or related diagnoses, having an average age of 33 years. This study is rated poor because its selection process is unclear, with no defined inclusion and exclusion criteria, and no details about how comparative the two cohorts were. Moreover, while the measures used in the study (Brief Psychiatric Rating Scale, Scale for the Assessment of Positive and Negative Symptoms and the Quality of Life Scale) were all conducted with the clients via semi structured interviews, the fact that these interviews were conducted by the study's first author brings in an element of bias, particularly as the study was about evaluating a new service where presumably positive outcomes would be favoured. The client satisfaction scale is not referenced and would appear to be an unvalidated tool. The attrition rate of this study was 50% which was attributed to different stages in the clients' assessment processes, or where they have simply been lost to follow up after discharge. While there are

known issues with participant retention with this client group, (Arfken, Wilson and Hegedus, 2002) this rate is remarkably high.

This section of the review has identified eight tools used across the studies to measure symptoms:

- Brief Psychiatric Rating Scale (Lukoff, Liberman and Nuechterlein, 1986)
- Kessler 10 (Kessler *et al.*, 2002)
- Colorado Client Assessment Record
- Comprehensive Psychopathological Rating Scale (CPRS) (Åsberg *et al.*, 1978)
- Becks Depression Inventory (BDI) (Beck *et al.*, 1961)
- Hopkins symptom check list (Derogatis and Cleary, 1977)
- Scale for the Assessment of Negative Symptoms (Andreasen, 1982)
- Abnormal Involuntary Movement Scale (AIMS) (Lane *et al.*, 1985)

Of these eight tools, only the Brief Psychiatric Rating Scale (BPRS) (Lukoff, Liberman and Nuechterlein, 1986) was used in more than one study (Gonda, Deane and Murugesan, 2012; Liu *et al.*, 2011; Arfken, Wilson and Hegedus, 2002; Bruseker and O'Halloran, 1999). The other seven measures were used in just one study each - further information on these can be read in Appendix 3.2. It is interesting to note that three measures, the Comprehensive psychopathological Rating Scale (CPRS), the Becks Depression Inventory (BDI) and the Hopkins symptom check list, are predominately measure symptoms of depression. This is an issue for people with long term mental health needs, particularly psychotic illnesses where negative symptoms may either overshadow symptoms of depression or result in mis-diagnosis (Andreasen, 1982). While people with psychotic illness such as schizophrenia can experience depression, this is rarely a reason for admission to a rehabilitation unit in isolation - people are more frequently likely to be exhibiting negative symptoms of schizophrenia, which has a very different pathological cause (Andreasen, 1982)

The BPRS is a well-recognised and established tool which has been found to have good cross cultural inter-rater reliability, except for the dimension of disorientation (Dingemans *et al.*, 1983). It is frequently used as a benchmark measure from which the reliability and validity of other measures may be compared. However, it has been found to be less sensitive at picking up the negative symptoms of schizophrenia, such as avolition, and a more sensitive tool is recommended (Bell *et al.*, 1992). This is particularly relevant for the rehabilitation population who typically demonstrate fewer positive symptoms (e.g. hallucinations, hostility and suspiciousness) but generally more negative symptoms (e.g. avolition, apathy and

anhedonia) (Andreasen, 1982). Improvement rates were between 35.8% and 32.4% depending on how the cut off was calculated (Gonda, Deane and Murugesan, 2012).

### 2.6.1 Summary of measures of symptoms

The measurement of symptoms is often used to evaluate rehabilitation and, as demonstrated in this review, a wide variety of tools have been used to do this. The most frequently used was the BPRS - used in four studies - with a strong desire amongst the other studies to measure depressive symptoms. Only one study (Bruseker and O'Halloran, 1999) appreciated the difference between depression and negative symptoms of schizophrenia. Although this study was rated poor in quality, the essence of what it was attempting to measure was reflected in the appropriateness of its tools, which included a quality of life measure. However, proponents of recovery have long identified (Harding *et al.*, 1987; Anthony, 1999) and continue to identify the difference between clinical and social recovery (Repper and Perkins, 2003), and that people can still experience an element of recovery, even with ongoing symptoms.

## 2.7 Behaviour as a measure of change

*Behaviour:* People with mental illnesses are known to have difficulties managing their behaviour. This is part of any illness, from a short period of exacerbated anxiety where people may avoid stressful situations, to more serious and long-term illnesses such as schizophrenia where people may display unusual, challenging or life threatening behaviour. Such extreme behaviour can have an impact on a person's ability to live amongst others and make it challenging to find the right environment in which to live. Given that the purpose of rehabilitation is to equip people with skills to manage their behaviour, change in a person's behaviour over time is a pragmatic measure to use. Behaviour was measured in five studies (Killaspy *et al.*, 2016; Killaspy and Zis, 2013; Liu *et al.*, 2011; Peer and Spaulding, 2007; Leff and Szmidla, 2002) using 5 different tools as detailed in Table 2.4.

Four of these studies have been critiqued above, leaving only the Leff and Szmidla study (2002) to be critiqued before going on to consider the five measures of behaviour identified in this review.

The main aim of the Leff and Szmidla study (2002) was to evaluate an experimental rehabilitation programme that had been developed towards the end of deinstitutionalisation specifically for patients deemed difficult to place (Leff and Szmidla, 2002). The participants of the experimental group (n=22) were selected without formal criteria, but on the basis that the



researchers knew them from involvement in previous studies. This group were titrated to modern antipsychotic medication, worked with staff who had specific training, and were subject to care plans developed on the basis of cognitive behaviour therapy. The control group (n=60) were not afforded any of these modern treatments and were provided with the usual treatment. The fair to poor rating for this study is based predominately on the loose inclusion criteria and the potential for bias based on the authors' involvement in training the staff for the experimental group, and the provision of the medication for the control group by the drug company. This study was strongly focused on behaviour, and used three of a total of five tools to measure behaviour:

- Special Problems Rating Scale (SPRS)
- Clinician's Alcohol and Drug Use Scale (CADUS)
- Nurses Observation for Inpatient Evaluation Scale (NOIES)
- Social Behaviour Scale (SBS)
- Behaviour and Everyday Living Skills Schedule (BELS)

Of these five measures, three were used in two or more studies. The Special Problems Rating Scale (SPRS) was the most frequently used tool to measure behaviour change, being used in three studies (Killaspy *et al.*, 2016; Killaspy and Zis, 2013; Leff and Szmidla, 2002). The SPRS was designed to focus on challenging behaviours, for example, aggressiveness and sexually inappropriate behaviours which could make it difficult for a person to be discharged from hospital into the community (Trieman and Leff, 1996). While the Leff and Szmidla study (2002) reported a reduction in aggressive behaviour for their experimental group of *difficult-to-place*, the population for whom this tool was designed, Killaspy and Zis (2013) identified the most positive changes in behaviour in the older generation concordant with medication. Killaspy *et al* (2016) noted a reduction in contact time, and subsequently cost, for people who at baseline had reported self-harm and suicidal risk.

The data for the BELS was collected via a staff interview on a client's behaviour over a week. While it has been found to have high inter-rater reliability (Trieman and Leff, 2002), the potentially subjective nature of this tool allows for a judgemental interpretation of behaviour based solely on observation without an appreciation of the context or function of the behaviour. Such an understanding is important when working in a recovery oriented way in order to avoid stigmatisation or the removal of hope.

Of the remaining tools to measure behaviour, the Clinicians Alcohol and Drug Use Scale (CADUS) (Drake, Mueser and McHugo, 1996) and the Nurses' Observation Scale for Inpatient

Evaluation (NOSIE) (Honigfeld, Gillis and Klett, 1966) were each used in two separate studies. The use of the CADUS in two of the most recent studies (Killaspy *et al.*, 2016; Killaspy and Zis, 2013), demonstrates that despite an association between schizophrenia, substance misuse and mortality (Hjorthøj *et al.*, 2015), the problematic use of alcohol and drugs was uncommon (7% and 4% respectively) (Killaspy *et al.*, 2016), and where present there was no statistically significant difference between those who progressed, remained stable or relapsed (Killaspy and Zis, 2013).

The Nurses' Observation Scale for Inpatient Evaluation (NOSIE) (Honigfeld, Gillis and Klett, 1966) was used in two studies (Liu *et al.*, 2011; Peer and Spaulding, 2007). The NOSIE is a 30-item scale designed to provide a behavioural and observational rating of psychiatric inpatients based on nurse observations of the previous 72 hours. Similar to the CADUS and the SPRS there is no opportunity for the client to add context to their behaviour. While the NOSIE has good reliability for people with long term schizophrenia, namely to evaluate the effects of medication on acute psychosis in an acute ward setting (Lyall, Hawley and Scott, 2004), most clients in a rehabilitation setting do not display a high, sustained level of acuity before being transferred back to hospital (NHS England, 2016b).

### 2.7.1 Summary of measures of behaviour

In this review it has become evident that while behaviour has been measured in a variety of ways in the appraised studies, the focus has been on abnormal behaviour that was either socially unacceptable or put the client or others at risk. All tools rely on staff rating the behaviour observed without necessarily an understanding of the reasons for the behaviour. While the emphasis on reducing such behaviours is understandable, what has been routinely missed is an evaluation of the development or maintenance of new skills that may facilitate successful community living and reduce the likelihood of relapse. Acquisition of skills has been identified as one of the core functions of a rehabilitation unit (Killaspy, Harden *et al.* 2005) therefore a failure to investigate positive behavioural changes misrepresents not only the interventions within a rehabilitation unit, but is also arguably not recovery oriented.

## **2.8 The costs and benefits of rehabilitation**

*Costs and benefits:* Being in hospital is expensive - in 2012/2013 it was reported that the NHS spent £2.0 billion on services for people with psychosis, with 54% of this on inpatient care (Knapp *et al.*, 2014). This is an estimated 25-50% of the total budget allocation for mental

health services (Killaspy *et al.*, 2016). In addition to financial cost, there is also a personal cost to being in hospital in terms of roles, relationships and occupations (Anthony, 1993). The following seven studies consider the short- to medium-term cost effectiveness of rehabilitation: Bunyan *et al.*, 2016; Killaspy *et al.*, 2016; Killaspy and Zis, 2013; Petrie and Mountain, 2009; Vandevooren, Miller and O'Reilly, 2007; Arfken, Wilson and Hegedus, 2002; Svensson, Hansson and Nyman, 2000. There are two main areas of interest:

- number of occupied bed days and readmission rates
- destination on discharge

Of these studies, all but one (Petrie and Mountain, 2009) have been critiqued above. Petrie and Mountain (2009) was a retrospective study (n=35; 24 males and 11 females) with an average age of 36.26 years, spanning 7 years, which examined the impact of rehabilitation on hospital readmission. Data was taken for 2 years pre and 2 years post rehabilitation on number of admissions, total days in hospital, and the use of the Mental Health Act. While the aim is clear and simple, it is unclear if the sample population came from one or more rehabilitation unit, and the participant selection process is not clearly stated. For this reason the study is rated fair.

#### 2.8.1 Occupied bed days and readmission rates

Four studies evaluated the effect on hospital re-admissions and the number of occupied bed days in an acute psychiatric bed before and after rehabilitation. Of these studies, one was a case controlled study (Svensson *et al* 2000) and three used retrospective data (Bunyan *et al* 2016, Petrie & Mountain 2009 and Vandevooren *et al* 2007). While retrospective data is relatively easy to collect and can provide a range of factual information required by those with a financial interest in the effectiveness of the service, it often means that patients are not interviewed as part of the process. Where additional information is required this may be sought from staff, who may or may not have an accurate recall (Killaspy and Zis 2013).

Overall, the findings on whether rehabilitation is effective in reducing hospital stays are mixed. One study concluded that there was no significant difference in the number of hospital admissions pre and post rehabilitation (Vandevooren *et al* 2007). However, this study evaluated data 6 years preceding rehabilitation and one year after rehabilitation, which does not provide equal amounts of data and fails to capture any longer term effect of rehabilitation.

The other three studies compared data 2 years pre and 2 years post rehabilitation (Bunyan *et al.*, 2016; Petrie and Mountain, 2009; Svensson, Hansson and Nyman, 2000) which is a more equitable and realistic timeframe, given how long recovery can take. Of these studies one identified a reduction in readmission rates (Petrie and Mountain, 2009) from 2.51 to 1.17 ( $p < 0.01$ ) with the actual number of occupied bed days falling from 478.34 days to 115.86 days ( $p < 0.001$ ) and a 75% ( $p < 0.001$ ) reduction in the use of the Mental Health Act. Similarly the results of the Bunyan *et al* study (2016) demonstrate a statistically significant reduction in the use of beds post rehabilitation ( $p = 0.006$ ). However the Svensson *et al* study (2000) reports an increase in bed usage by an average of 79.2 days ( $p = 0.01$ ) and an increase in overall bed usage of 1664 days (63%).

It is accepted that in the current financial climate services must be cost effective, and occupied bed days is relatively simple type of data to collect with which to make comparisons. However, as the results of these studies demonstrate, there is inconclusive data around the cost effectiveness of rehabilitation in terms of bed usage alone. While variation in data could be attributed to the operation of the rehabilitation unit, to local health, housing and support facilities as well as individual circumstances (Killaspy *et al* 2016), this method of measurement is seen to be unreliable as a measure of rehabilitation effectiveness.

### 2.8.2 Destination and care needs on discharge

In addition to bed usage, independent living after rehabilitation appears to be a frequent measure of the effectiveness of rehabilitation. Five studies explored various aspects related to discharge arrangements, discharge destination and the use of medication on discharge (Killaspy *et al.*, 2016; Killaspy and Zis, 2013; Vandevoreen, Miller and O'Reilly, 2007; Arfken, Wilson and Hegedus, 2002; Svensson, Hansson and Nyman, 2000).

Starting with the discharge planning process, it has been identified that those with a planned discharge are more likely to be living independently compared to those with an unforeseen discharge, with 77% of those having a planned discharge living in the community at follow up (Arfken, Wilson and Hegedus, 2002). At one year post rehabilitation 64% of participants were living independently, 32% were living in rented houses with unrelated individuals and 32% were living in supervised group settings (Vandevoreen, Miller and O'Reilly, 2007) (NB - these figures are taken directly from the article but do not add up to 100%). Similarly, within a year of admission to rehabilitation, 56% were successfully discharged and 14% were ready for discharge, awaiting accommodation (Killaspy *et al.*, 2016). At 5 year follow-up from discharge, 40% ( $n = 19$ ) of the population of one study (Killaspy and Zis, 2013) were living in the community

with no readmissions or accommodation breakdown. Of the 19 participants, 11 achieved independent living.

When traditional rehabilitation was compared to cognitive based rehabilitation (Svensson, Hansson and Nyman, 2000) 10/21 and 16/21 respectively were living in their own homes, one and four people respectively were not on medication - this was deemed medically the right decision for them. Six of the traditional rehabilitation population and eight of the cognitive based population were in full time work, education or training. Similarly 53% were in employment in the Arfkan et al study (2002) at follow up, but no details of this were provided.

### 2.8.3 Summary of the costs and benefits of rehabilitation

While the evidence in this review suggests that rehabilitation can help prepare people to be discharged from hospital, live independently, and in some cases engage in meaningful occupations in the community, they do not tell us how people have changed in terms of their ability to do so successfully and why this is not the case for all. While discharge destination is an important measure, and independent living is considered the best outcome of all, we must be mindful not to make the assumption that independent living is a totally positive result without understanding the actual experience of living independently.

## **2.9 Patient experience as a measure of satisfaction**

*Patient experience:* A good patient experience has been linked to safe and effective care (Doyle, Lennox and Bell, 2013). It has been a driver for service development since the mid 1990's (Thornicroft and Tansella, 2005), and yet the involvement of patients in planning clinical care is still not mainstream (Grundy *et al.*, 2016). While user involvement has been recognised to strengthen the validity of research in mental health (Veseth *et al.*, 2017; Mjøsund *et al.*, 2017) this review highlights how infrequently service users have actually had their say in the research. Three studies however sought participant inclusion (Notley *et al.*, 2012; Svensson, Hansson and Nyman, 2000; Bruseker and O'Halloran, 1999) using four different approaches as outlined in Table 2.4. The Notley et al study (2012) is the last study to be critiqued below.

The Notley et al study (2012) is the only qualitative study in this review and the only one to have made an in depth exploration of clients' experience of rehabilitation. In the study (n=10), 6 men and 4 women discharged the previous year were interviewed regarding their rehabilitation experience. The researchers used photo elicitation and semi structured

interviews to capture the participants' thoughts, feelings and perceptions on what influenced their rehabilitation journey. They were encouraged to talk about their experiences in detail, from arriving at the unit to life in the community.

This study has been judged to be of good quality, and sets out the service user experience of rehabilitation. The findings highlight that, with reflection, clients recognised a need for rehabilitation following a period of transition due to health instability or social issues. The study found that establishing a daily routine and having the time and space to work to individual goals was a key part of the rehabilitation process. The approach of the staff was identified as a key component. A year or so post discharge from the unit, participants identified how they were able to reconnect to their community and how rehabilitation had affected their roles, routines and identities. While this study is relatively small and limited to one unit only, it does offer insights into what people value about rehabilitation and how they felt it helped prepare them to live in the community.

The Svensson et al study (2000) critiqued above explored individual target complaints (problems) and aims of treatment. They sought the participant's view on the severity of a complaint and re-evaluated this again at follow-up. While such a conversation adopts a person centred approach, there were no details in the paper about the range of complaints or how people felt life had changed.

A client satisfaction survey and an information questionnaire were used as part of a service evaluation (Bruseker & O'Halloran 1999). Unfortunately in the paper there was no reference for either of these measures so very little is known about them. However 85% of the study population reported high satisfaction with the service and 94% demonstrated an increased knowledge of their illness. Satisfaction scales may be subject to bias as the participants feel they should provide a positive result, even if they disagree (Mazor *et al.*, 2002).

### 2.9.1 Summary of measures of patient experience

Of 13 studies included in this review, only three have attempted to seek the participant's perspective on their own rehabilitation experience. The Notley et al study (2012) has taken the most transparent approach to this by engaging with the client's own memory of their stay in the unit. While a year had passed from discharge, the use of pictures to elicit memories was a non-biased way of simulating a narrative. While Bruseker & Halloran and Svensson et al (2000) have attempted to involve the participant perspective in the research design, both have prioritised a service evaluation element over personal experience.

## **2.10 General health and quality of life as a measure of change**

*Health and Quality of Life:* The importance of recognising and measuring health and quality of life has long been recognised within health care audit, evaluation and clinical trials (Fitzpatrick *et al.*, 1992). Subjective and objective quality of life, which encompass physical health, have been assessed in mental health services for many decades (Oliver *et al.*, 1997), particularly at the time of deinstitutionalisation as it was one way of evaluating the move to community living from the institutions (Leff and Trieman, 2000; Leff, Trieman and Gooch, 1996; Lehman, 1988; Baker and Intagliata, 1982).

In this review, one health questionnaire SF-36 (Ware Jr and Sherbourne, 1992), and two quality of life measures the Quality of Life (QoL) Scale (Heinrichs, Hanlon and Carpenter Jr, 1984) and the Kajandi (Kajandi, 1994) were used in three studies (Arfken, Wilson and Hegedus, 2002; Svensson, Hansson and Nyman, 2000; Bruseker and O'Halloran, 1999). Details of these measures can be read in Appendix 2.3.

### **2.10.1 Summary of measures of general health and quality of life**

Although general health and quality of life measures have been identified in this review, the attention and detail they have been given alongside other measures used in the studies is limited. This suggests the importance of health and quality of life as a measure of rehabilitation is not valued as highly as other domains such as functioning, symptoms or cost.

## **2.11 Needs as a measure of change**

*Needs:* The personal needs of the clients are vast and depend on a multitude of variables. Often people are admitted into a psychiatric hospital in a poor state of physical and psychological health with multiple needs. A common starting place to understand the spectrum of human needs tends to be Maslow's hierarchy of needs (Maslow, 1943) moving from physiological needs to self-actualisation. Often people move into a rehabilitation unit needing to address their safety and belonging before being able to address the higher needs of esteem and self-actualisation. The measure of need that was identified in this review was the Camberwell Assessment of Needs Short Appraisal Scale (CANSAS) (Slade *et al.*, 1999), adapted from the Camberwell Assessment of Needs (Phelan *et al.*, 1995). It was utilised in the Killaspy and Zis (2013) study alongside tools that measured behaviour, social functioning and substance misuse. Details of the scale can be read in Appendix 2.3.

Killaspy and Zis (2013) used the CANSAS to compare the needs of patients who progressed, remained stable or relapsed. Those who progressed or remained stable reported more met needs and fewer unmet needs than the relapsed group, suggesting that identification of need is paramount in the rehabilitation process. Needs of whatever sort are personal and subjective, and given the client centred focus of rehabilitation it is surprising that just one out of 13 studies explored what the participants felt they needed from rehabilitation. It is not surprising that unmet needs have been linked to relapse.

## **2.12 Summary of the review**

In summary, this review identified 13 studies published between 1999 and 2017. Six studies were rated good, or good to fair, and all studies measured change across two or more timeframes (Appendix 2.2). For the most part the studies were cohort studies (n=10) using retrospective data from routine clinical data (n=7). A cohort study by its very nature is not designed to evaluate personal change. This means the individual nature of personal change has not been a primary focus in contemporary research when evaluating the effectiveness of rehabilitation. This is arguably an oversight in the era of person centred, recovery focused mental health care.

Instead it would appear that researchers to date have been more interested in evaluating the participants' symptoms, 'abnormal' behaviour as rated by a clinician, or the clinical cost of rehabilitation in terms of occupied bed days and readmission rates, as opposed to individualised change in skill, which enables a person to achieve the day to day occupations they need and desire.

The use of retrospective studies is understandable given the challenges of engaging with participants with long term mental health needs in longitudinal studies (Arfken *et al.*, 2002). Where current or prospective cohorts were used in the reviewed studies, attrition rates reached 50% (Arfken *et al.*, 2002; Bruseker and O'Halloran., 1999). While retrospective data may be considered a more accessible option, particularly for the novice or clinically based researcher, it is not without its drawbacks. Such drawbacks include recorder error and retrieval bias. Due to the reflective nature of retrospective data there is no option to actively engage with the participants - which is not reflective of current recovery oriented practice and rehabilitation services (Wright 2017).

This review found that rehabilitation has been evaluated using 35 different measures across the 13 studies, with all studies using two or more measures. The approach to evaluation was categorised into one of seven areas of interest (Table 2.4). Measures that were used twice



or more were critiqued, with a view to assessing their suitability as a measure in this thesis. Functioning was the most commonly measured area of interest, yet no study considered functioning through an occupational therapy lens. An occupational therapy lens appreciates the importance of 'doing, being, becoming, and belonging' (Hitch, Pépin et al. 2014) through involvement in meaningful occupations. Rehabilitation through an occupational therapy lens would therefore be interested in measuring particular skills, which are known through research to affect functioning in the activities of daily living and have relevance to the individual (Fisher and Jones, 2014; Fisher and Jones 2012). This is a significant gap within the current literature, as is the exploration of how changes in functioning are translated into day to day functioning in the community, as well as the impact which rehabilitation has on recovery, skill acquisition, quality of life and independence (Killaspy et al., 2005).

While a reduction in troublesome symptoms and 'socially unacceptable' behaviour are considered as indicators of effectiveness of rehabilitation, this sits uncomfortably if rehabilitation units are being asked to fully embrace principles of recovery, and to work in a recovery oriented way (Wright, 2017; Boardman *et al*, 2010; Department of Health, 2001) as we know people can live successful and fulfilling lives even with symptoms (Anthony, 1993). Of the eight different measures of symptoms of mental illness, only one tool was specifically designed to measure a change in negative symptoms of psychosis, more common amongst the rehabilitation population than acute psychotic symptoms of anxiety or depression (Appendix 2.3). In addition to this, all the measures of behaviour were completed from the staff perspective, often from case notes or memory, without involving the participants in order to gain an understanding of the reason for their behaviour. Interestingly, no measure of functioning, symptoms or behaviour evaluated the acquisition of new skill or positive behaviours as a response to a reduction in 'socially unacceptable' behaviours or improvement in symptoms. The removal of a negative behaviour evokes a different response to the acquisition of a new positive behaviour. If we are to promote hope, agency and opportunity within the rehabilitation unit (Newman-Taylor, Garner et al. 2017, Shepherd, Boardman et al. 2008, Shepherd, Boardman et al. 2008) to prepare people to live more independent lives and look after themselves in the community (Notley, Pell et al. 2012), it would make sense to measure positive behaviour and skill acquisition rather than just a reduction in unwanted symptoms or behaviours.

As less than half the studies in this review were prospective (n=6) the opportunity to hear the participant voice is limited. Indeed, only four of the six studies gathered data via interview or self-report from the participants, the other two relied on clinician rated assessments or measures. Of these four studies, three collected data on subjective health status and quality

of life (Arfken., *et al* 2002; Svensson *et al.*, 2000; Bruskeker and O'Halloran, 1999), however the critique of each tool showed that the measures used either lacked suitability, due to a mismatch between the measure and the target group, or the validity of the tool was poor. There was also very little narrative of change over time or any exploration of the links between quality of life and any of the other measures. This is a further gap in the literature, given the connection already made between quality of life, skill acquisition, independence and recovery (Killaspy *et al.*, 2005).

In conclusion, this review has identified four main evaluation shortfalls within the literature. Firstly there is a paucity of prospective research, involving people with mental health rehabilitation needs and their experiences of their journey through rehabilitation. With this absence, and a predominance of cohort studies considering group changes, there has been limited opportunity to explore individual change. This is inconsistent with the recovery paradigm and person-centred occupational therapy principles aiming to address occupational injustices, resulting from mental ill health. Furthermore, there is a lack of recognition of the need for the evaluation of skill development, as opposed to the removal of unhelpful behaviour patterns, culminating in a noticeable omission of evaluation of skill acquisition over time. Finally, the impact of rehabilitation on quality of life has rarely been considered since deinstitutionalisation, and given the influence of the recovery agenda on rehabilitation practices this appears to be a sizable omission. This literature review has led to the following research question:

***What is the effect of inpatient mental health rehabilitation on an individual's functional performance and do changes have an impact on quality of life?***

The next chapter outlines, discusses and justifies the research methodology, the design of the study and the methods of data collection, including the various processes of analysis required to answer a question of such complexity.

## **Chapter Three**

### **Methodology**

#### **3.1 Introduction**

This chapter presents the methodology used in this research study. It provides an overview of a range of philosophical assumptions and their impact on healthcare research. The researcher's own philosophical stance is presented which has led to the choice of the pragmatic methodological approach underpinning this study. Within the design section there is a description of the data collection tools, including justification for the change in the Quality of Life Tool following the pilot phase. This chapter concludes by reporting on the recruitment and selection methods, administration of the tools and the specific analytical processes employed.

#### **3.2 Methodology**

##### **3.2.1 The philosophical spectrum**

The way we view the world and what we believe to be true are based on a set of propositions and assumptions. For many hundreds of years philosophers have attempted to reach a consensus on what is philosophically true about the world in which we live (Gaarder, 1994). Kuhn (1970) advocates breaking down the complexity of the real world into paradigms, different perspectives or viewpoints as a way of attempting to unravel and understand the complexity. As scientific knowledge develops, and thus challenges existing knowledge, a 'scientific revolution' or 'paradigm shift' occurs which results in a change in how the world is viewed (Kuhn, 1970). A researcher's methodological approach to exploring and understanding a problem is underpinned by their own paradigm, or world view. Traditionally it is accepted that there are major very different ways in which to view the world: positivism and constructivism. Positivism and constructivism are viewed as being either end of a spectrum, with post-positivism and pragmatism positioned between the two opposing ends. Post-positivism shares many similarities with positivism, while at the same time recognising the place of qualitative methods. Pragmatism however, rejects the '*either-or*' assumptions of both positivism and constructivism preferring to decide which method is most suitable to address a particular research question, rather than giving allegiance to one particular paradigm (Tashakkori and Teddlie, 1998,p.22). Table 3.1 provides a summary and comparison of the main philosophical paradigms.

Table 3.1: *Comparison of positivism/post positivism, constructivism and the pragmatic approach to research*

	<b>Positivism / post positivism</b>	<b>Pragmatism</b>	<b>Constructivism</b>
Methods	Quantitative	Quantitative and qualitative	Qualitative
Logic	Deductive	Deductive and inductive	Inductive
Ontology	Believes there is a single reality	Accept external reality. Seek explanations for best outcome	Multiple, constructed realities
Epistemology	The knower and the known are independent - objective point of view	Both objective and subjective points of view	The knower and the known are inseparable, subjective point of view
Axiology	Inquiry is value free	Values play a role in interpretation of results	Inquiry is value bound
Generalisations	Time and context-free generalisations are possible	Some generalisation may be possible	Time and context-free generalisations are not possible
Causal Linkages	Real causes that are temporally precedent to or simultaneous with effects	Causal relationships may be present, but not able to be pinned down	Impossible to distinguish cause from effect, all entities shape each other

### 3.2.2 A positivist and post-positivist approach to research in health care

A positivist and post-positivist approach emphasises the importance of predictions, cause and effect, and value-free evidence. Positivists and post-positivists take an ontological stance, believing that there can only be one truth or reality which can be found if sufficiently looked for. Positivists and post-positivists take an epistemological stance - that the researcher is independent and totally objective from the observed, enabling the research to be value free, allowing time- and context-free generalisations to be made. A positivist and post-positivist approach uses quantitative data collection methods, for example numerical scales, standardised questionnaires or observation schedules, to measure and quantify differences and or similarities (Creswell, 2014; Denzin and Lincoln, 2013; Parahoo, 1997). A post-positivist paradigm differs from the positivist paradigm by acknowledging that values are present, but that they can be controlled, and that findings are probably true (Tashakkori and Teddlie 1998, Crotty 2012).

Within health care generally there is a dominance of medical research with a natural leaning towards a positivist and post-positivist approach. This is not surprising given the scientific basis of the profession, with the desire to establish cause and effect of illnesses and to test the effectiveness of treatment interventions. In medical research, randomised control trials have become accepted by the majority as the gold standard (Hyde, 2004). For example, there are very many large-scale studies using randomised controlled trials conducted to evaluate

specific treatments (Sensky *et al.*, 2000) followed by meta reviews of such trials (Srisurapanont *et al.*, 2015) to appraise the generality of the findings of a number of similar studies.

Nevertheless, generalisations made from such large scale positivist or post-positivist research studies have the potential, through the application of logic, to reduce the human experience into empirical data. In doing so, there is a risk of losing the human element, bringing into question the credibility of the research and its application to individuals, particularly to those with a severe mental illness (Andresen, Oades and Caputi, 2011; Tashakkori and Teddlie, 2010a; Repper and Perkins, 2006). The widespread assumption within medical care that large-scale, positivist and post-positivist research provides the best evidence has led to such evidence being the main source of evidence integrated into clinical and best practice guidelines as a principle of good care for the general population, with little acknowledgement of individual variations (Hinojosa, 2013; Hyde, 2004).

### 3.2.3 A constructionist approach to research in health care

In contrast to a positivist and post-positivist approach, a constructionist approach to research emphasises the importance of understanding the world in which the person lives by seeking out personal viewpoints and experiences, and engaging with and interpreting the world (Crotty, 2012). A constructionist framework aims to understand that world through interpretation of the lived experience and seeks to generate theory from the data (inductive) as opposed to allowing the analysis of the data to be shaped by existing theory (deductive) (Braun and Clarke, 2013). It takes the stance that the reality is a result of knowledge generated by history, culture and society (Burr, 2015). Thus constructionist researchers hold an ontological position of many realities and multiple truths and an epistemological position of many ways of knowing. A constructionist approach to research utilises qualitative data collection methods, such as open-ended questions, participant observation and questionnaires, to gain a rich and detailed picture of an individual's experience (Tashakkori and Teddlie, 1998).

A constructionist approach by necessity tends to focus on small-scale research studies in order to gain a depth of understanding into individuality and the lived experience of participants (Creswell, 2014). The growing acceptance of a constructionist approach means there are greater opportunities to apply meta-analysis principles, in a similar way to those used in quantitative data collection (Kaite *et al.*, 2015). This not only adds rigour and validity in a way that can be understood by all researchers, but challenges the notion that the quality and relevance of qualitative research is inferior (Hinojosa, 2013; Andrew and Halcomb, 2009a;

Hyde, 2004), thereby raising the credibility of a constructionist approach to research in health care.

This has meant that for example research aimed at understanding the lived experience of schizophrenia and the associated stigma (Jenkins and Carpenter-Song, 2009) or the impact the illness has had on an individual's life (Gould, DeSouza and Rebeiro-Gruhl, 2005) are starting to be viewed as important, relevant and credible alongside RCT medical trials, positioning qualitative alongside quantitative research.

#### 3.2.4 A pragmatist approach to research in health care

While postivist, post-positivist and constructionist research methods are recognised as bringing opposing viewpoints to a research question, there has been an ongoing academic debate or 'paradigm war' (Tashakkori and Teddlie, 1998, p3) in which the purists at each end of the philosophical spectrum have attempted to displace the other on epistemological and ontological grounds (Andrew and Halcomb, 2009). The constructionists were critical of the reductionist approach within the positivism paradigm, and the positivists were critical of an inability to separate the value-bound closeness of the researcher to the research object in the constructivism paradigm (Creswell, 2013; Tashakkori and Teddlie, 1998; Gage, 1989).

This debate not only recognised the strengths and limitations of each polarised position, but traced the roots of pragmatism to American scholars such as William James (1842-1910) and John Dewey (1859-1952) who put forward the notion of a third methodological paradigm (Creswell, 2014; Creswell, 2013; Tashakkori and Teddlie, 2010b) long before pragmatism was recognised as a research paradigm in its own right. With its flexibility and its regained and growing popularity in complex multi-faceted health care settings (Grey, 2014, Ellis and Levy, 2008; Ivankova, Creswell and Stick, 2006), pragmatism enables the clinical researcher to engage with the methodological approach best suited to the research question. With a pragmatic approach, clinical researchers are able to do this without the limitations of either a pure constructionist or positivist approach, or the limitations of their associated methods. The pragmatic approach is said to bridge the gap between developing a science base and overcoming barriers to implementation in practice amongst clinically based researchers (Palinkas *et al.*, 2011). This fits well with occupational therapy which has its foundations in both art and science (Hinojosa, 2013, Kielhofner 2006), balancing the testing of established theory (deductive) with developing new theory (inductive) relevant to an evolving professional theory base.

A pragmatic approach to research is commonly referred to as a mixed methods approach, however caution is required to understand with clarity what is actually being mixed (Gray, 2014). Tashakkori and Teddlie (1998) developed a taxonomy of the evolution of methodological approaches illustrating a difference between monomethods, mixed methods and mixed model studies, and showing how each of these methods might be conducted sequentially or simultaneously, with or without a dominant method. Consequently there are many possible variations for a study design. In its broadest sense, a mixed methods approach could combine two qualitative methods of data collection without a quantitative method, and vice versa. It could also also mean mixing qualitative and quantitative methods in one study, with or without triangulating the data.

While this clearly increases the flexibility of research, it also means that the researcher needs to be proficient in a greater number of data collection and analysis methods. The researcher is also required to be clear on the purpose of the mixed methods approach to ensure the design of the study meets the study aims and answers the research question. Greene et al (1989) identified five main purposes of a mixed methods approach: to seek convergence of results (triangulation), to examine differences (complementarity), to discover fresh perspectives (initiation), the use of one method to inform the next (development) or to add breadth (expansion). The aims of discovering fresh perspectives and of convergence of results sit comfortably within the purpose of this study and the researcher's own philosophical stance.

### 3.2.5 Researcher's philosophical stance

The philosophical stance I have adopted for this research study is embedded within a number of beliefs, assumptions and experiences. My professional position, as outlined in Chapter 1, is that of an occupational therapist, with over 20 years' experience of working with people with serious mental illness. I strongly believe that given the right environment, the skills and time to practise occupations that are both meaningful and necessary, a person can change and move towards an engaging and productive lifestyle. This is not to say people can be cured of their symptoms or are able to live without a significant amount of support and assistance, but I believe with the right intervention, approach and engagement strategies people can change, become more independent and have an improved quality of life.

Within healthcare, including mental health, there is a clear dichotomy between viewing people as individual and unique with their own personal experiences and needs, and viewing

people as essentially the same with generalisations and an assumption that what works for one will work for another. This tension between personalisation and generalisation is evident when considering the philosophical viewpoint of this study. As an occupational therapist with an epistemological stance of many truths and an ontological position of many realities, I want to hear the person's experience of rehabilitation. Yet working in the National Health Service, with commissioners and senior managers who require empirical evidence of an intervention's effectiveness, there is a need to provide acceptable evidence.

The tension for me as a researcher is in acknowledging my own philosophical stance and the benefits it brings to research methodology, while at the same time recognising and acknowledging how other philosophical viewpoints can contribute to and enhance the research methodology. For this reason, I have chosen a mixed methods approach embedded within a pragmatic paradigm using both qualitative and quantitative data collection tools.

### 3.2.6 Validity and reliability

The concepts of validity and reliability are embedded within a positivist perspective to test the quality of the research, thus ensuring results can be replicated and that the research measures what it actually set out to measure. However, when using qualitative methods of investigation there is '*a shift from measurement to understanding*' (Harper and Thompson, 2011, p219), with an emphasis on '*trustworthiness and authenticity*' (Denzin and Lincoln, 2013, p205) in assessing the rigour of the study.

Such credibility is afforded to research which demonstrates a rigorous approach to study design, application of the data collection methods, interpretation of the results, and generalisations of the findings (Denzin and Lincoln, 2013; Harper and Thompson, 2011; Smith, 2008). When qualitative methods are used, researcher reflexivity - the ability to separate oneself from any invested interest in the topic, to be open and transparent about feelings, values and judgements, and to demonstrate the ability to stand back and be objective - is essential to increase the trustworthiness and authenticity of the research (Finlay, 2011).

In this study, validity, reliability, trustworthiness and authenticity were attended to throughout. This is addressed in more detail in regard to the specific tools used in Section 3.3 below.

## **3.3 Design of the study**

The overall design chosen was mixed methods in a longitudinal study with three data collection phases, where both qualitative and quantitative data were collected. This design



was informed by the gaps identified in the literature review, where there was a paucity of prospective, qualitative research investigating the client's perspective, and limited or no prospective quantitative research investigating positive behaviour change. The three phase design was also informed by the literature review as a 3 month follow up allowed for the review of any maintenance of change.

- Phase 1 - at admission to the unit (typically within one month)
- Phase 2 - once a discharge date is agreed (typically following a case review, approximately 9 months after admission)
- Phase 3 - approximately three months post discharge

Within a mixed method study there are a number of possible designs (Creswell, 2013; Creswell and Plano Clark, 2011), but for this research study a concurrent, convergent design was chosen, where both qualitative and quantitative data were collected at approximately the same time (Creswell and Plano Clark, 2011). This concurrent triangulation design is probably the most familiar of the mixed methodology approaches (Creswell, 2014; Tashakkori and Teddlie, 1998), and fits well for exploring the experience of community based rehabilitation for people with psychosis (Roy *et al.*, 2016). However large amounts of data are generated and the comparability of data using two or more methods of analysis may not be straightforward (Tashakkori and Teddlie, 1998) Thus, Ivankova *et al* (2006) strongly recommend that the researcher use a visual diagram to illustrate how the two data collection methods are used together. Figure 3.1 highlights how the data collection methods converge to give an understanding of the individuals experience of rehabilitation.

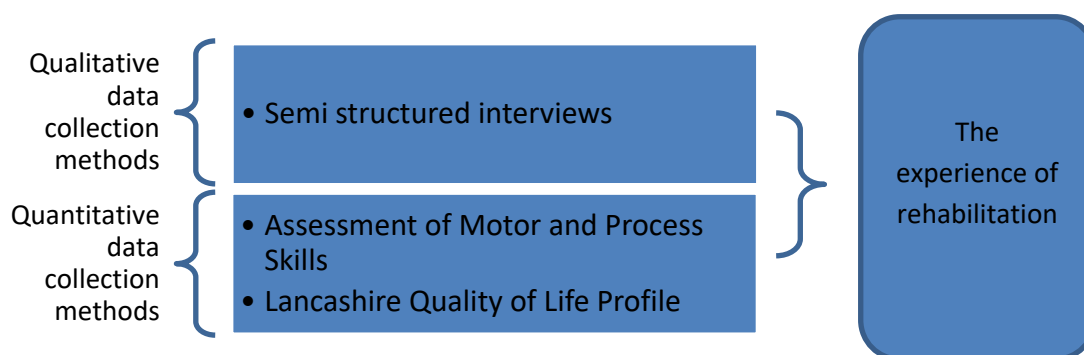


Figure 3.1: The concurrent, convergent, mixed methods design

One of the strengths of a concurrent, convergent mixed methods design is that it does not give priority weighting to any one method (Palinkas *et al.*, 2011; Ivankova, Creswell and Stick, 2006) allowing participants freedom to decide on the order in which they wish to complete the tools without this affecting the outcome (Creswell and Plano Clark, 2011). Once the data is collected, it is analysed separately and then brought together or triangulated to help develop a fuller picture of understanding of a phenomenon (Creswell and Plano Clark, 2011). Triangulation, a concept originally identified by Denzin (1978), aims to address the weaknesses in one method by combining it with another, and as a consequence will draw on both deductive and inductive logic to interpret the data (Creswell, 2014; Creswell, 2013; Tashakkori and Teddlie, 1998). In this study individual experiences captured over the three phases via the semi-structured interviews will be triangulated with the results of the Assessment of Motor and Process Skills and the results of the Quality of Life Profile to gain a fuller picture of the participants' experience of rehabilitation. Inductive logic gained from analysis of the interviews will be triangulated with deductive logic gained from the quantitative measures equally to gain a more comprehensive understanding of the participants experience of rehabilitation.

### 3.3.1 Data collection tools

Three data collection tools were used in this study:

- Semi-structured interviews (Braun and Clarke, 2013)
- Assessment of Motor and Process Skills (Fisher and Bray Jones, 2012)
- Lancashire Quality of Life Profile (European Version) (Oliver *et al.*, 1997)

In the following sections each tool will be discussed in terms of its relevance to the study, why it was chosen, and its reliability and validity in relation to people with long-term schizophrenia.

### 3.3.2 Semi-structured qualitative interviews

Qualitative research methods are used when there is an issue or problem to be explored and understood (Creswell, 2013; Harper and Thompson, 2011). There are many ways in which data can be collected including questionnaires, one to one interviews, focus groups and diaries, in which the individual is able to tell their story as they wish (Gray, 2014; Creswell, 2014; Harper and Thompson, 2011; Kumar, 2005). One to one interviews which seek to gain an

understanding of personal experiences, feelings or attitudes (Gray, 2014) can take many forms. They may utilise an unstructured open-ended approach; a semi structured interview using a set of questions as a guide; or a closed approach, such as an online questionnaire or survey (Creswell, 2013). The purpose of an interview is to gather rich and detailed information regarding a lived experience, to find commonalities and differences in that experience, which when interpreted, gives meaning to that experience (Creswell, 2013).

For this study a semi-structured approach was chosen. Such an approach allows time for the interviewer to build a rapport with the participant while keeping the interview balanced between a framework of topics to explore but having the flexibility to move into new areas (Smith, 2008). Conducting a semi-structured interview is a skilful task, requiring empathy, reflection and the careful use of prompts (Smith, 2008), the purpose being to facilitate an ethical exploration of a personal topic. Such awareness and sensitivity is particularly important for people experiencing mental health problems (Harper and Thompson, 2011). Due to the nature of a semi-structured interview, skilful and sensitive probing and clarification can elicit rich and detailed personalised data based on the individual's own experiences, values and attitudes (Gray, 2014).

#### 3.3.2.1 Trustworthiness and authenticity

The trustworthiness and authenticity of the qualitative interviews was considered at the design stage, with the choice of pre-set, peer reviewed schedules for each of the three phases. The schedules were developed following conversations with previous and existing residents at the unit, who were not at any point participants in the study. The schedules were informed by the literature, subject to the academic supervisory process, and reviewed by a clinical psychologist with experience of working in mental health. This process ensured the topic areas were wide enough and the follow-up questions sufficiently open-ended to facilitate an open conversation (Appendices 3.6-3.8).

The interviews were guided by a pre-set schedule. This was to ensure no topic areas for discussion were forgotten, rather than using pre-set questions. The delivery of the questions was not pre-set, apart from the first question to get the interview underway. The interview followed the principles of an unstructured interview, with open-ended questions, returning only to the schedule if the participant required a prompt (Kumar, 2005).

Each interview was conducted by the same researcher, with the permission of the participant was audio-recorded to ensure nothing was lost, and transcribed verbatim. This enabled the researcher to check and double check the whole content of the interview against the

transcript. A further layer of credibility was added by giving participants the opportunity to review their transcribed interview. The rationale for this was both ethical and practical, to improve accuracy and credibility and allow the participant the opportunity to change or remove content. Despite every attempt by the researcher to find somewhere quiet to meet, there were frequently outside disruptions and participants often spoke quietly. This made it difficult for an inexperienced audio transcriber to capture everything that was being said. Although a transcript of each interview was sent to participants, none were returned with amendments. A possible reason for this might be participant burden as the transcripts were written to emulate a script, which is not a usual printed reading format.

In addition to this, throughout the data collection phase the researcher kept a reflective log of feelings and experiences in relation to the process. The log was mainly used as a secure place to make brief notes of things that occurred in the early stages of the research process, but was primarily in relation to data collection and data analysis. For example, reflections were written about the interviewing technique and how research interviewing differs from clinical assessment interviewing, and feelings and thoughts that arose during transcription to be used at a later date to ensure transparency in the analytical process (Creswell, 2013).

### 3.3.3 Assessment of Motor and Process Skills

The Assessment of Motor and Process Skills (AMPS) (Fisher and Bray Jones, 2014) is a standardised, observational tool designed to enable an occupational therapist to evaluate *'the quality of a person's performance of activities of daily living in natural, task-relevant environments'* (Fisher and Bray Jones, 2012). It has been widely used in the area of mental health (Rojo-Mota *et al.*, 2014; Merritt, Gahagan and Kottorp, 2013; McNulty and Fisher, 2001; Girard *et al.*, 1999; Magalhães *et al.*, 1996; Pan and Fisher, 1994), including those with schizophrenia as a work indicator (Haslam *et al.*, 2010) and in a rehabilitation setting (Ayres and Panickacheril John, 2015). It was chosen for this study as the residents of the unit were familiar with its use, as it was routinely used by the OT who worked in the unit. Therefore, the completion of this tool as part of the research did not increase participant burden.

As employment, education and occupational activities have been identified within clinical guidelines as a priority area for intervention for people with psychosis (National Institute for Clinical Excellence, 2014), it is important that such needs are identified and measured in terms of a functional assessment (Brown, 2009): where a person is assessed engaging in a desired occupation within a natural environment (Christiansen, Baum and Bass-Haugen, 2005). Functional assessments are an obvious choice within a rehabilitation setting, given that the

aims of rehabilitation include gaining or re-gaining independence, skill development and self-management (NHS England, 2016).

Occupational therapists are experts in functional or occupational performance and understand the occupational skills required to effectively and effortlessly engage in day to day activities, and understand the impact the environment has on functioning (Fisher, 2009). The Assessment of Motor and Process Skills (Fisher and Bray Jones, 2014; Fisher and Bray Jones, 2012) is the only standardised assessment to reliably measure occupational performance and can only be administered by a fully trained and calibrated occupational therapist registered with the Centre for Innovative OT Solutions (CIOTS). The calibration process requires each therapist to successfully complete 10 assessments via the CIOTS website within three months of the intensive five day training programme.

An assessment consists of the calibrated OT observing a person carrying out two familiar tasks of their choice from over 100 standardised activities. The tasks are organised in a hierarchy of difficulty, and this is expressed in logits, the easiest tasks rated as 0.7 logits, average tasks rated at 0.0 logits, and the hardest tasks being rated as -0.7.

The evaluation of the person's occupational performance focuses on 16 motor and 20 process skill items, which are observed while the persons carries out the tasks. The OT observes each task, rating each of the motor and process skill items on a 4-point scale. Each skill item is marked from 1 – 4 as follows

- 4 = competent
- 3 = questionable
- 2 = ineffective
- 1 = deficit

During the evaluation the OT conducts a performance analysis (evaluation of each action, in a chain of actions to perform the desired activity) and a task analysis (evaluation of the task in relation to environmental and personal factors) to assess the person's occupational performance (ability to carry out daily activities) in terms of effort, efficiency, safety and independence (Fisher and Bray Jones, 2014). The OT also rates on a scale of 1 (no problem) to 6 (inordinate problem), the overall quality of each task based on the amount of effort required, the efficiency of the task, how safe the person was, and the amount of assistance required. The OT then makes an assessment of the person's overall ability to lived in the

community, be this independently, with minimal assistance, or with moderate to maximum assistance (Fisher and Bray Jones, 2014).

Once this is completed for each task, the raw scores are entered into the Occupational Therapy Assessment Package (OTAP) software, where a special application of Rasch analysis, converts raw, ordinal scores into hierarchical or interval data (Fischl and Fisher, 2007). Scoring of the AMPS is criterion-referenced (Fisher and Bray Jones, 2012) and expressed as logits to give an ability measure (both motor and process) relative to the competence cut off measure (Motor = 2, Process =1). The scores are also expressed as standardised Z scores, which position a persons occupational performance relative to an age-matched normative sample.

The results of the two tasks for each evaluation are combined and presented as two computer generated graphs, one for motor skill and one for process skill. The OTAP software allows for two evaluations to be displayed on the graphs, allowing for comparison of occupational performance over time. An example of the graphs can be seen in Section 3.6 (Figures 3.2 & 3.3).

#### 3.3.3.1 Validity and reliability

The AMPS has demonstrated good validity and reliability across a number of cultures worldwide, including the UK (Gantschnig, Page and Fisher, 2012; Goldman and Fisher, 1997; Fisher *et al.*, 1992). It has been shown to be an effective assessment to use with people with a wide range of illnesses from addictions (Rojo-Mota *et al.*, 2014) HIV (Merritt, Gahagan and Kottorp, 2013) and mental illness (Merritt, Gahagan and Kottorp, 2013; McNulty and Fisher, 2001; Girard *et al.*, 1999; Magalhães *et al.*, 1996; Pan and Fisher, 1994). It is a suitable tool to use with people with schizophrenia in a rehabilitation setting (Ayres and Panickacheril John, 2015; Haslam *et al.*, 2010).

In addition to this, the necessity of a 5 day international calibration training course ensures a high level of rigour and fidelity, with administration of the assessment in accordance with the AMPS administration manual (Fisher and Bray Jones, 2012).

#### 3.3.4. Quality of Life

Quality of Life (QoL) is a dynamic concept that changes in relation to many variables including, for example, living environment, financial status, housing, occupation and health. The search to understand it, measure it and attain it has been around since the time of the

early Greek philosophers (Oliver *et al.*, 1997) and there still continues to be no single, universally accepted definition of QoL or a definitive collection of elements to measure (Skevington, Lotfy and O'Connell, 2004). However, it is agreed that QoL is a '*multi-dimensional phenomenon*' bigger and infinitely more complex than individual variables that any tool attempts to measure (Priebe *et al.*, 1999b, p2-3 ) and that it is an all-encompassing concept related to a person's functioning - their behaviour and attitudes, their roles and relationships, and their pleasures and expectations all within the context of their current living conditions (Oliver *et al.*, 1997). This view of QoL moves away from a narrow view of symptoms and pathology of mental illness to focus on the whole person, giving a holistic perspective of the person (Baker and Intagliata, 1982). The World Health Organisation described QoL as an individual's -

*'perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment'* (WHO, 1997)

The complexity underpinning the concept of QoL has led to the development of many different measures. There are specific Health Related Quality of Life (HRQoL) tools capturing global health related data with objective and subjective perspectives (Skevington, Lotfy and O'Connell, 2004) and disease or illness specific QoL measures, with a focus on the severity of symptoms and the impact on functioning (Schmidt, Garratt and Fitzpatrick, 2000). While it can be useful to have a range of tools to choose from, it poses challenges when incorporating quality of life measures into a scientific study as it can be problematic to choose the right one for the right purpose (Skevington, Lotfy and O'Connell, 2004; Schmidt, Garratt and Fitzpatrick, 2000).

#### 3.3.4.1 Quality of life and mental illness

Quality of life measures have been used in mental health research for a number of years and were a significant aspect of the evaluation of deinstitutionalisation (Leff and Trieman, 2000; Leff, Trieman and Gooch, 1996). There are a number of tools specifically designed for use in psychiatry (Gigantesco and Giuliani, 2011), including those experiencing a first episode of psychosis (Chan *et al.*, 2016) and those who are homeless (Van *et al.*, 2012). Quality of life measures have also been used as a method to evaluate the impact of a patient education programme (Pitkänen *et al.*, 2012), the impact of perceived stigma (Sook Hee and Hyun Jeong,

2012) and the effect of community based rehabilitation programmes (Van Busschbach and Wiersma, 2002; Browne, 1999). Quality of life, as an indicator of change, is supported by current recovery based thinking (SLAM/SWLSTG, 2010; Shepherd, Boardman and Slade, 2008). At the time of writing, work is being undertaken to develop a tool entitled Recovery Quality of Life (Keetharuth *et al.*, 2017; Brazier *et al.*, 2016), highlighting a continued interest in the quality of life of those who experience a mental illness.

For this study, the World Health Organisation Quality of Life (WHOQOL) BREF 26 (Skevington, 1999) was originally chosen. The rationale for this was its level of international recognition for use in health care research and its ease of administration, asking just 26 short questions across four domains (physical, psychological, social relationships and environment) (Skevington and McCrate, 2012). However, it was felt to be neither specific nor sensitive enough to pick up change in a client group where change is often little and slow. Given this, a small pilot study was conducted to evaluate the usability of a longer, more specific tool designed for people with long term mental health needs, the Lancashire Quality of Life Profile, European Version (Thornicroft and *et al.*, 2006; Oliver *et al.*, 1997).

#### 3.3.4.2 Pilot study

In January 2011 a small pilot study was conducted to assess the feasibility of using the LQoLP-EV (Thornicroft and *et al.*, 2006), given that it was specifically designed for people with long term mental illness compared to the generality of the WHOQOL-BREF-26 (Skevington, Lotfy and O'Connell, 2004). The LQoLP-EV has a total of a 105 elements as opposed to just 26 questions on the WHOQOL-BREF-26, so participant burden was a concern.

The LQoLP-EV questionnaire was completed with one, randomly selected new admission client to the unit on the 18<sup>th</sup> January 2011. It took 25 minutes to complete, which was less than the mean time of 33 minutes as described in the handbook (Thornicroft and *et al.*, 2006). The client's feedback relating to the tool was that it was nice to talk about herself and she enjoyed the opportunity to think about her life. She felt it was time well spent. This concurs with what we know about engagement and acceptance, and how talking about oneself is known to be intrinsically therapeutic and empowering (Oliver *et al.*, 1997, p17). Although the pilot study was one person, the feedback from the client was extremely positive and the questionnaire did not feel onerous to the participant or the researcher. This person did not



form part of the study. Following ethical approval for a substantive change, the QoL instrument was changed (Appendix 3.1b).

#### 3.3.4.3 Lancashire Quality of Life Profile – European Version

The Lancashire Quality of Life Profile - European Version (LQoLP-EV) measures the health and welfare for people with long-standing and complex mental health needs (Thornicroft and et al, 2006). It was developed as part of a European Commission Study, the European Psychiatric Services: Inputs Linked to Outcome Domains and Needs (EPSILON). It is one of five standardised and translated instruments to measure key domains in mental health care across European countries (Thornicroft and et al, 2006). The questionnaire is completed via a semi-structured interview, which has a total of in excess of 100 different items and includes a professional assessment of quality of life based on observation of the person. The questionnaire gathers both subjective and objective data.

#### 3.3.4.4 Validity and reliability of the Lancashire Quality of Life Profile

Validity and reliability tests were conducted as part of the EPSILON study and revealed that internal consistency was mixed, being lowest for the work and leisure domains and most stable for the self-esteem domain. On test-retest reliability, the pooled LLS scores were stronger than the individual LLS scores, with an overall validity and reliability rating of good (Thornicroft and et al, 2006; Gaité *et al.*, 2000).

### **3.4 Ethical approval**

This research was conducted with full National Health Service (REC Reference: 10/H0502/47) and University ethical approvals. University ethical approval was originally sought from University College Cork, Ireland (where this PhD was first registered) and subsequently transferred to Brunel University London where the PhD was re-registered following a change in the supervision team. The ethics committee at University College Cork and the National Research Ethics Committee, Southern Health Research and Development Committee were both attended in person by the author/researcher. A request for an amendment to include the Lancashire Quality of Life Tool was granted in January 2011. This request was granted without further attendance at any of the Research Ethics Committees. (Appendix 3.1a and 3.1b)

### 3.5 Method

This section describes the processes used to ensure that data collection was robust and transparent. In doing so it recounts the recruitment and selection process, including informed consent and ethical practice. It also details each data collection method for each of the three data collection tools: qualitative interviews, Assessment of Motor and Process Skills and the Quality of Life questionnaire.

#### 3.5.1 Recruitment and selection

Recruitment took place from one south coast rehabilitation unit between April 2011 and April 2013. All new admissions to the unit were informed of the study by letter (Appendix 3.2) and were provided with a verbal summary of the study by their key nurse. If interested, the key nurse asked the participant to sign a declaration of interest form (Appendix 3.3) and state how they would like the researcher to contact them.

The initial meeting between the researcher and participant was at a mutually agreed place and time (usually within the lounge of the unit). The purpose of this first meeting was to ensure recruits to the study met the inclusion criteria (see Table 3.2). If the criteria were successfully met, more detail of the study was provided via the patient information sheet (Appendix 3.4) with the opportunity to ask questions.

Table 3.2: *Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"><li>• Serious mental illness as diagnosed by a responsible medical officer</li><li>• Admitted to the unit in the last month</li><li>• Aged 18 years or above</li></ul>	<ul style="list-style-type: none"><li>• Admission for a clozapine restart only</li><li>• Admission temporary while awaiting accommodation</li><li>• Co-existing physical or terminal illness that results in physical frailty or fatigue that would prevent full participation in the rehabilitation programme</li><li>• Lack of ability to give informed consent</li></ul>

### 3.5.2 Informed consent and ethical practice

At the initial meeting with a potential participant it was made clear that participation in the study was entirely voluntary, and that any care received at the unit would not be affected whether they participated in the research or not. It was also emphasised that individuals could withdraw from the study at any time without giving a reason. Once the participant was fully aware of the expectations of them and the structure of the research they were asked to give written informed consent (Appendix 3.5).

Once written consent was given, the researcher established which of the three measures the participant would like to undertake first and whether they would like to do so in one or two further meetings. Mutually agreed times were identified for data collection.

At the end of data collection the participant was verbally invited to meet with the researcher again, this time prior to discharge. As the researcher was not involved in the individual's care, reliance was placed on the nursing staff on the unit to inform the researcher when a discharge date was arranged for each individual participant. This required keeping in contact with the unit on a regular basis to ensure the opportunity to invite people to participate in phase 2 was not missed. On verbal invitation, consent at phase 2 was implicit by engagement.

Once the second phase of data collection was completed, the researcher asked the participant's permission to obtain their forwarding address so that an appointment could be made approximately three months post discharge to complete the measures for the third and final time. With individual participant agreement, approximately eight weeks after discharge, a letter was sent to them offering an appointment to meet with the research again. A telephone number was provided so that a mutually convenient time and place could be agreed. Consent was implicit by engagement in phase 3.

### 3.5.3 Data collection processes

Data collection commenced once consent was given. The data collection tools were completed in the order requested by the participant and generally this took place in two meetings, approximately one week apart. Demographic information such as gender, age, number of years in contact with the service, diagnosis and Mental Health Act status was gathered at the first of the two data collection meetings.

Three data collection tools were employed in this study, each with different requirements in terms of materials, environment and set-up. Each one will be considered in turn, starting with the qualitative interview. However it must be stressed that no tool carries more weighting

than another. The participant was free to choose the order of completion at each phase without this affecting the results.

### 3.5.3.1 Qualitative interviews

The qualitative, semi-structured interviews in this study required some advance preparation including:

- securing a quiet environment, with minimum chance of disruption (a 'do not disturb' notice was put on the door)
- ensuring that the audio equipment was in working order with spare batteries
- ensuring the correct interview schedule for the correct data collection phase was available for each participant

At the start of each interview, verbal consent was gained from the participant to audio record the interview. They were also reminded that should they wish they could see a copy of the transcript.

All the interviews in this study were conducted with reference to an interview schedule. The schedule for each of the three phases was adapted to reflect where in their rehabilitation journey the participant was and contained five or six discussion topics rather than direct questions. This open approach to interviewing allowed the researcher to adapt the interview according to where the participant wished to take it.

- **Phase 1 interview** schedule allowed for the participant to talk in detail about their experiences before rehabilitation, for example what had led them to being in rehabilitation and how they felt about being in the unit. It also encouraged conversations about the future and what the participant hoped to achieve (Appendix 3.6).
- **Phase 2 interview** schedule had a reflective element and facilitated discussion about the experience of rehabilitation. This schedule also encouraged the participants to talk about their imminent transition from rehabilitation to living in different accommodation (Appendix 3.7).
- **Phase 3 interview** schedule again had a reflective element, but also stimulated conversations about the participants understanding of rehabilitation and the role it had played for them in their current situation (Appendix 3.8).

After each interview, the information was saved to a secure password protected memory stick. All 33 interviews were transcribed as soon as possible after the interview, with the researcher transcribing 10 interviews, the remainder transcribed professionally to save time.

A transcript of each interview was either given to the participant by hand or posted to their preferred address. As outlined in Section 3.3.2.1 above, no transcripts were returned requesting amendments. The transcripts were collated into the three separate phases for data analysis. Analysis did not commence until all data had been collected.

#### 3.5.3.2 Assessment of Motor and Process Skills

The first stage of the data collection process was to carry out an occupational therapy assessment to elicit which of the standardised ADL tasks the participant wanted to complete (Fisher and Bray Jones, 2012). Once this was agreed, a suitable time and place was negotiated appropriate to the activity. Activities took place in a range of locations throughout the rehabilitation unit for phase 1 and 2, including the kitchen, garden, lounge, bathroom and the participant's own bedroom. In phase 3 activities took place in the most suitable location in the participant's home.

If resources were required, either the researcher provided them or the participant used their own items, depending on the task. For example, one participant chose to clean his shoes - he did not have polish or cleaning cloths so these items were provided by the researcher. Another chose to iron some items of clothing - he used his own clothes and the unit's iron and ironing board. The set-up of the environment was task specific and dictated by the Task Descriptions in Volume 2: User Manual (Fisher and Bray Jones, 2014).

Once the order of the two tasks was agreed and the environment set up as required, the participant was read the following statement devised by the researcher to ensure each participant was given the same instructions: *'We are ready to go, you can start now. Please let me know when you are finished. I will be here, but try to work as if you are alone'*. Once the tasks had been completed it was rated on a copy of the AMPS Score form before being transferred to the Occupational Therapy Assessment Package (OTAP) software for analysis.

#### 3.5.3.3 The Lancashire Quality of Life Profile – European Version

To conduct the LQoLP-EV a quiet environment with a small table was required. For phases 1 and 2 this was the quiet room or lounge within the rehabilitation unit. For phase 3 this was a quiet place at the participant's home, usually their bedroom.

On each occasion the LQoLP-EV was introduced to the participants with an explanation of the marking format and the different sorts of answers explained in detail. Some questions required a 'yes' , 'no' or 'don't know' response, while others required the participant to identify where on a life satisfaction scale (LSS) of 1-7 they rated different aspects of their life. The participants were given a laminated copy of the 1-7 LSS to refer to, which clearly

identified the two different ends of the scale from 1 – ‘could not be worse’ to 7 - ‘could not be better’.

Each question was read out in turn and the participant was given time to respond. If the participant required the question to be read again, it was, with their attention drawn to the marking grid again, for example ‘*Where on this scale of 1 – 7 would you say you are?*’

Some people preferred to read the questions themselves after the initial reading by the researcher. The researcher completed the questionnaire in front of the participant. The process of familiarising the participant with the layout of the questionnaire and the marking format was repeated for each participant in each phase.

On completion of the questionnaire, the raw data was transferred onto a specifically prepared data spreadsheet, using Version 21 of the Predicative Analytical Software (PASW), a statistical software package designed for statistical analysis of quantitative data (Griffith, 2010). The design of the spreadsheet reflected all the questions for each participant in each of the phases.

### **3.6 Processes of Analysis**

Three methods of data analysis were employed to analyse the data in this study, each one appropriate to the data. The qualitative interviews were analysed using Thematic Analysis (TA) (Braun and Clarke, 2013), the AMPS via Rasch Analysis, on computer-scoring software located on the CIOTS website, and the QoL using Minimal Detectable Change (MDC) (Donoghue and Stokes, 2009).

#### **3.6.1 Thematic analysis of the interviews**

Analysis of all the interviews followed and was based on the stages of TA as described by Braun and Clarke (2013, p202-203). After transcription of each interview, which occurred as soon as possible after the interview, the stages of analysis were applied to each phase in turn to allow for complete immersion in the data for that phase.

*Stage 1: Reading and re-reading of the data.* The scripts for each phase were initially read in their entirety to gain a sense of the contents of each set of data and an overall familiarity with the data. They were then read again and this time preliminary codes were assigned by highlighting the script and making a separate note of the code, its location in the script and a brief description in a preliminary coding frame.

*Stage 2: Initial coding of data.* Complete coding (Ibid, p206) was undertaken using a manual coding approach (colour coding, cutting and pasting slips of paper) which elicited a large number of open codes for each phase: (phase 1 = 95, phase 2 = 49, phase 3 = 40). These largely manifest codes were further reduced and combined through deductive analysis, into both manifest and latent codes (phase 1 = 54, phase 2 = 40, phase 3 = 34).

*Stage 3: Combining codes into overarching themes.* Once all features were coded, the codes were combined into potential themes, with both sub-themes and overarching themes. At this stage three additional processes were employed: reflexivity, bracketing and the development of a pictorial representation of the overarching themes, identifying hierarchical and linear connections between the themes. Reflexivity, a process whereby the researcher continues to develop a sense of self-awareness (Finlay and Gough, 2003), and bracketing (the putting aside of preconceptions) (Tufford and Newman, 2012), are essential elements of TA so that the stages of analysis are transparent and the values and judgements of the researcher are acknowledged (Appendix 3.9).

*Stage 4: Coherence of themes.* This stage, as the previous stage, is a cyclical process of reviewing and refining the themes, combining some themes to strengthen them, ensuring the latent themes are a fair representation of the participant experiences and reviewing the connections between them. The pictorial representation of the themes was a useful way to conceptualise the relationships within and between themes.

*Stage 5: Defining the meaning of each theme.* This stage was also a cyclical process and resulted in the final naming of the themes to give an overall picture of the content of each of them. For each of the main overarching themes, in each of the three phases, the title of the theme was deduced from the raw data to provide an interpretation of that particular phenomenon.

*Stage 6: reporting the findings.* This final stage of presenting the results of the analysis was again cyclical. The order in which the themes and sub-themes were presented needed to reflect the frequency of the codes and the importance of the theme. Similarly, the connections within and between the themes was way of capturing the themes as a whole, and therefore recognising the depth of relationship between themes for the participants. Pictorial representations were useful in this regard.

### 3.6.2 Assessment of Motor and Process Skills and Rasch analysis

Once both tasks for each assessment were completed, the raw, ordinal ADL motor and ADL process scores were recorded manually before being input into computer-scoring software held on the Centre for Innovative OT Solutions (CIOTS) website, from which the AMPS graphic reports were generated (Fisher and Bray Jones, 2012).

The computer-scoring software uses Many-Faceted Rasch (MFR) Analysis to convert the ordinal ADL motor and ADL process skill item scores into linear ADL motor and ADL process ability measures, or logits, that can be used for statistical analysis and evaluating change (Fisher and Bray Jones, 2012, Fisher, 1993). MFR Analysis is required to take account of the complexity of converting ordinal scores from two or more ADL tasks into ability measures with the challenge of the task (e.g easier than average, average or harder than average) and the severity of the calibrated assessor (Fisher and Bray Jones, 2012).

#### 3.6.2.1 Interpreting the AMPS results

AMPS scores are interpreted from a criterion-referenced perspective and a norm-referenced perspective. Criterion referenced results are expressed in logits on both the ADL Motor Scale and the ADL Process Scale. The logits represent a level of competence as assessed in terms of effort, efficiency, safety and independence. The level of competence cut-off of the ADL Motor Scale is 2 and on the ADL Process Scale is 1. A person scoring below the cut-off on the motor scale will demonstrate some clumsiness and/or increased physical effort. Below the cut-off on the process scale a person will demonstrate some inefficient use of time, space and objects and/or may demonstrate some safety risk.

The norm-referenced perspective is the person's ADL motor and ADL process ability measures (logits) as compared to a normative sample (a well aged-matched sample). The norm-referenced results are expressed as a Z score, with the Z score representing the number of standard deviations a person is from the normative mean where the mean is set at zero (0.0 SD).

The norm-referenced perspective can be seen as the bar to the left of the ADL Motor and ADL Process scales, with the black dot in the centre representing the mean for the age-matched normative sample and the normal range extending up and down by 2SD ( $\pm 2SD$ ). In practice this means 68% of the population will be within one standard deviation (-1SD to +1SD) of the mean of an age-matched normative sample, whereas 95% of the population will be within two standard deviations of an age-matched normative sample. It is common practice to consider scores between  $-2SD$  to  $+2SD$  to be '*within normal limits*' - anything



outside of that range is considered outside of normal range. The data for the age-matched norms can be found in the AMPS Manual (Fisher and Bray Jones, 2012) (Table 15-9, p15-43)

In the example illustrated in Figures 3.2 and 3.3, the ADL Motor and ADL Process Scales show two different assessments (time 1 and time 2). In this example the person remains below the ADL Motor competency cut off and outside of the age-matched norm on both occasions and moves from within the risk zone to below the competency cut off, and yet is just within *normal limits* for their age. The narrative to the right of the scales indicates the quality of the person's occupational performance.

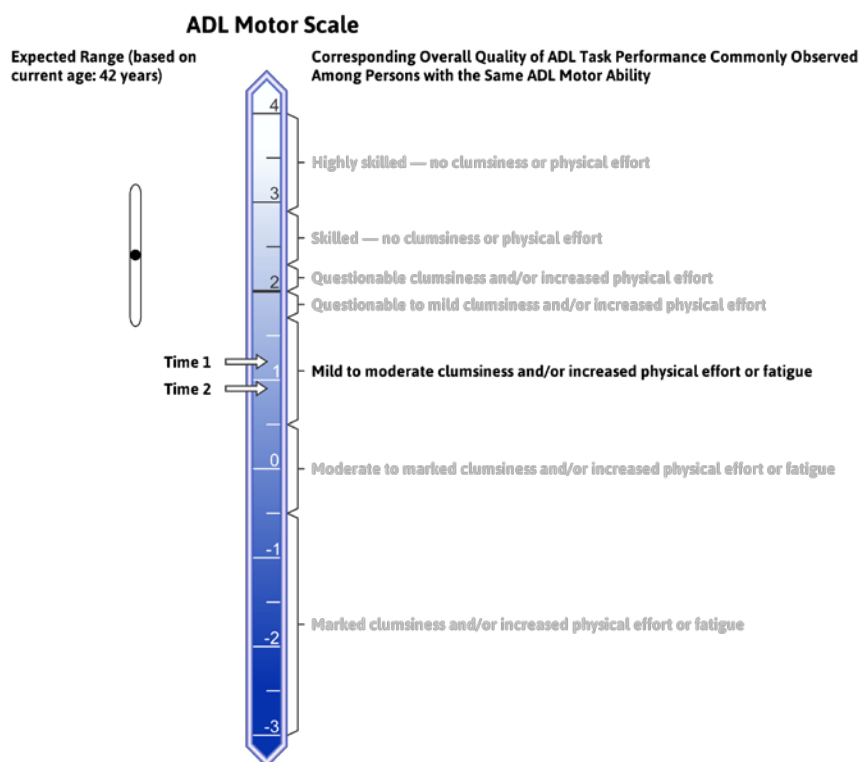


Figure 3.2: ADL motor scale, highlighting two different assessments (time 1 and time 2)

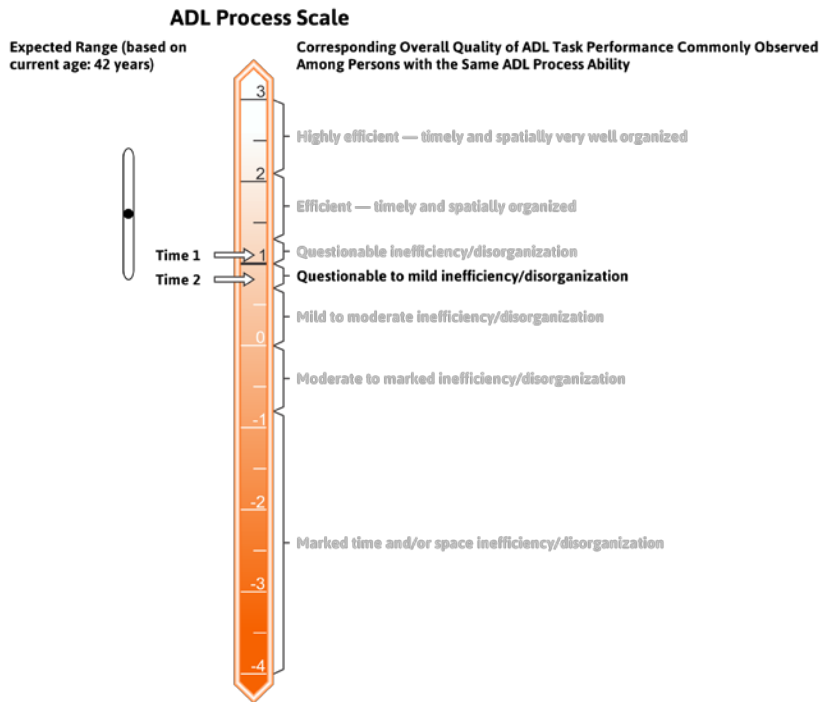


Figure 3.3: ADL process scale, highlighting two different assessments (time 1 and time 2)

### 3.6.3. Quality of Life: data inputting and cleansing

A PASW spreadsheet was designed to allow each participant to have a separate row across the variables for each phase where they completed the LQoL-EV. The independent variables were the three phases and the dependant variables included demographic data and answers for each of the individual questions of the questionnaire, totalling 155 dependant variables. Inputting of data occurred as soon as possible after completion of the questionnaire. It was independently checked by someone not involved in the research for accuracy, by cross-referencing the raw data on the questionnaire with the information entered into PASW. Once all data was entered it was cleansed, and a decision made regarding missing data before analysis commenced (see Table 3.3).

Missing data in the form of unanswered questions cause problems in research, and establishing the reason for its omission is a key part of the data cleansing process (Gray, 2014). The cleansing process in this study commenced with identifying all gaps in the PASW spreadsheet, recording these and revisiting the raw data on the original questionnaires to ensure no data had been missed in error. After this initial step, gaps in the data were identified. The next step of the cleansing process was to establish the reason for each gap. According to) There are three reasons for gaps in data (Humphries, 2013; Sterne *et al.* 2009):

- Missing completely at random – no systematic link between missing values and observed values. For example, weight measurements may be missing because of breakdown of the scales.
- Missing at random – a systematic difference between missing values and observed values can be explained. For example, weight measurements may be lower for girls than boys, due to girls being more likely to have missed being weighed.
- Missing not at random – even after differences have been considered systematic differences remain. For example, girls are less likely to get weighed as they are busy exercising.

As part of this cleansing process, gaps in the data were identified in domains: work/education, family relations, finances and religion, as detailed in Table 3.4. The LSS scores were calculated according and in line with the manual (Thorncroft and et al, 2006) to remain as true to the data as possible (see Table 3.3). At this point in the analysis perceived quality of life, psychological wellbeing and self-esteem were considered, as the manual was inconsistent with the tool as regards general and global wellbeing.

Table 3.3: *Summary of missing Quality of Life data*

Domain	Proportion of missing data	Missing at random/ not random	Management of missing data in line with recommendations in the manual (Thorncroft and et al, 2006)	Impact on LSS
Work/education	High number of participants unable to answer Q.3.5 & Q.3.6	Not at random	Data relating to these two questions was deleted as participants were not in employment or education	The LSS score for work/education, across all three phases was calculated using only the data for Q.3.7
Family relations	High Q.9.7 relating to marriage not relevant	Not at random	Data relating to this question was deleted as only one participant was married	The LSS score for family relations, across all three phases was calculated using Q.9.5 & Q.9.6
Finances	Medium Three participants wished to keep some details private (Q. 6.1 & Q. 6.4)	Not at random	The LSS scores were calculated without this element of data.	This data did not affect the LSS scores
Religion	Low One participant at phase 1 only choose not to answer Q5.3	Not at random	The LSS score for phase 1 was calculated with one element of missing data	The LSS score for religion at phases 2 and 3 and three was calculated using a complete set of data

### 3.6.3.1 Quality of Life and statistical analysis

The data generated from the Lancashire Quality of Life Profile (Oliver *et al.*, 1997) was analysed with the support of Version 21 of the PASW (Griffith, 2010). Initially the data was analysed to establish the descriptive statistics and these were explored to identify measures of central tendency (mean, median and mode) and measures of variability (standard deviation) (Parahoo, 1997).

Normative data was then collated from a reliability and internal consistency study of the Lancashire Quality of Life Profile – European Version (Gaitte *et al.*, 2000) and using the manual (Thornicroft and *et al.*, 2006) the standard error of measurement (SEM) was established for each of the LSS scores, general well-being and global well-being. The SEM was used to calculate the Minimal Detectable Change (MDC) value (Donoghue and Stokes, 2009): an '*estimation of the smallest change*' based on the standard error of measurement (SEM) '*that can be detected objectively for a client*' (Donoghue and Stokes, 2009, p344). With a confidence value of 95% the MDC is able to report on small changes of effectiveness resulting from day to day clinical interventions and is frequently used in therapy based research where quality of life is an outcome measure (Lin *et al.*, 2010).

Given that individual change as opposed to group change was being sought, non-parametric tests, such as the Friedman Test and Wilcoxon signed rank tests, were eliminated in favour of establishing clinically meaningful change on a case by case basis.

## **3.7 Summary of methodology: design, method and process of analysis**

This chapter has provided an overview of the philosophical basis of this research study. It has set out why a pragmatic mixed method design was chosen and provided details of how the design was executed, being sensitive to the different ontological and epistemological stances at either end of the philosophical spectrum. The three data collection tools: qualitative interviews, Assessment of Motor and Process Skills and the Lancashire Quality of Life Profile have been described and their use in the study substantiated. The method of data collection, different for each tool, has been recounted to demonstrate transparency and replicability. This chapter draws to a close by detailing the data analysis method employed for the different data extracted by each of the tools. The next three chapters present the results of the research, commencing with the themes emerging from the thematic analysis of the qualitative interviews.

## **Chapter Four – Findings (1)**

### **Understanding the participants – thematic analysis of phase 1**

#### **4.1 Introduction**

This is the first of three chapters in which the findings of this research study are presented. This chapter is divided into two sections: Section 1 provides a short vignette of each participant as an individual together with a vignette of the unit to contextualise the daily routines there (Braun and Clarke, 2013). Section 2 presents the results of the thematic analysis of the interviews that were conducted at phase 1. The results of the thematic analysis for phase 2 and 3 interviews are presented in Chapter Five, and Chapter Six presents the findings of the Assessment of Motor and Process Skills (AMPS) (Fisher 2010), and the Lancashire Quality of Life Profile (QoL) (Oliver, Huxley et al. 1997) as well as demography.

#### **4.2 Section 1 - Participant and unit overview**

24 people were admitted into the unit during the data collection period (April 2011 – April 2013). 21 of the 24 people meet eligibility criteria (Table 3.2). Of the 21, one participant withdrew before data collection commenced and another participant became too unwell to take part. Thus the total number of participants included in the study at the start was 19: 6 women and 13 men (Table 4.1). The total number of participants completing three phases of data collection was 5 (Table 4.2). The reasons for participant dropout during the data collection period may be viewed in Appendix 4.1.

To familiarise the reader with each participant and know them as individuals rather than a blended cohort of participants, a vignette is provided for each of 17 participants where there is at least onset of complete data. Two of the 19 participants, while agreeing to take part in the study, dropped out before all three sets of data were collected at phase 1 (Table 4.2). A vignette aims to give sufficient contextual and relevant information that the individual can be appreciated, while at the same time balancing individuality with anonymity (Braun and Clarke, 2013).

Table 4.1 Overview of study participants (all names are pseudonyms)

Name	Sex	Age	Marital status	Years in MH service	Previous Rehab	Diagnosis
Marco	M	49	Divorced	10	Yes <sup>3</sup>	Schizophrenia
Frank	M	53	Single	2	No	Psychotic depression
Jason	M	33	Civil partner	14	No	Schizophrenia
Nigel	M	47	Single	18	Yes <sup>4</sup>	Schizophrenia
Mabel	F	57	Single	4	No	Bipolar disorder
Mark	M	40	Single	15	No	Psychotic depression/OCD
Rita	F	51	Divorced	20	No	Schizophrenia/alcohol dependency
Susan	F	41	Divorced	18	No	Schizo-affective
Steve	M	22	Single	6	No	Psychosis/drug dependency
Mohammad	M	53	Divorced	13	No	Bipolar disorder
Jan	F	25	Single	15	No	Schizophrenia/drug dependency
Warren	M	27	Single	4	No	Psychosis/drug dependency
Mick	M	24	Single	6	No	Psychosis
Richard	M	55	Divorced	25	No	Schizophrenia
Pete	M	42	Single	25	Yes <sup>5</sup>	Schizophrenia
Maria	F	39	Married	8	No	Schizophrenia
William	M	27	Single	0.5	No	Psychosis
Michelle	F	41	Single	22	No	Schizophrenia
Dave	M	39	Single	10	No	Severe anxiety

Table 4.2 Overview of participant data completion

	Phase 1			Phase 2			Phase 3		
	IV	AMPS	QOL	IV	AMPS	QOL	IV	AMPS	QOL
<b>Marco</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>
<b>Frank</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>
<b>Jason</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>
<b>Nigel</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>
<b>Mabel</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>	<b>x</b>
Mark	x	x	x	x	x	x			x
Rita	x	x	x	x	x	x			x
Susan	x	x	x	x	x	x	x		x
Steve	x	x	x	x	x	x			
Mohammad	x	x	x	x	x	x			
Jan	x	x	x						
Warren	x	x	x						
Mick	x	x	x						
Richard	x	x	x						
Pete	x	x	x						
Maria	x	x	x						
William	x	x	x						
Michelle		x	x						
Dave			x						

### 4.3 Participants vignettes

In total 17 vignettes are presented, starting with the participants who completed all three phases of data collection (n=5): Marco, Frank, Jason, Nigel and Mabel. Next are vignettes of

<sup>3</sup> Admitted to same unit about 6 years ago

<sup>4</sup> Been on a rehab ward in a secure hospital, under Section 37/41 Of the MHA with Home Office restrictions

<sup>5</sup> Been on a rehab ward in a secure hospital, under Section 37/41 Of the MHA with Home Office restrictions

participants who completed all three data collection tools at phases 1 and 2, and some elements of the data collection tools at phase 3 (n=3): Mark, Rita, Susan. Next are those who completed all three data collection tools at phase 1 and 2 (n=2), but due to treatment not being completed did not have the opportunity to enter phase 3 of the data collection process: Steve and Mohammad. The last set of vignettes represent the participants who completed phase 1 (n=7): Jan, Warren, Mick, Richard, Pete, Maria and William. Vignettes are not provided for Michelle or Dave as neither completed an interview from which the majority of this information was elicited.

#### 4.3.1 Participants who completed all three phases

##### Marco

Marco was the only participant to have been in rehabilitation before - he was in the same unit approximately 6 years previously. English is a second language for Marco, and although he speaks it well and has a university education from his homeland he struggled to get a professional job in the UK. For many years he worked in large city and coastal locations undertaking various manual jobs. On becoming unwell on this occasion Marco experienced a psychotic breakdown. He was eventually evicted from his flat and was living in his car for a number of weeks before the police took him to a place of safety. He had no contact with his two teenage children and this caused him a great deal of distress. On discharge Marco moved to live independently in a housing association flat. He had minimal support from mental health services.

##### Frank

Prior to coming into the service, Frank was living independently, driving his own car and working locally as a skilled labourer. He was born, educated and had lived in the same city all his life. His home had been left to him by his parents when they died. When Frank lost his job, which he attributed to the recession, he re-mortgaged, but things did not go to plan and eventually his home was repossessed. He was transferred to the unit after a few months in the local psychiatric hospital. He did not like being in the unit and spent much of his time in town. The desire to 'get his house back' remained strong during his time in the unit. On discharge Frank moved into a newly refurbished housing association flat where he received weekly support from the community mental health team.

##### Jason

Over the years Jason had had numerous admissions to hospital under the Mental Health Act. However, this was his first time in rehabilitation - it was an agreed and voluntary

admission. Prior to his admission Jason was living in a privately rented flat with his elderly companion. His companion undertook most of the household tasks and generally took care of Jason. However as his companion was becoming increasingly frail, the burden of caring for Jason was becoming too great - Jason was admitted to the unit to develop his skills so that household tasks could be more equally distributed. In addition to his mental health needs Jason was diagnosed HIV positive, but at the time of his admission was asymptomatic. He returned home to his flat and to his companion.

### Nigel

Before moving to the rehabilitation unit Nigel spent four years in a forensic, medium secure hospital. He had committed an index offence<sup>6</sup> of actual bodily harm and was therefore subject to Home Office restrictions under Sections 37/41 of the Mental Health Act. During his time in the secure hospital he progressed from the locked ward to the rehabilitation ward within the hospital, which afforded slightly more freedom. Nigel was pleased to be at the rehabilitation unit, engaged fully with all that was on offer, and reportedly enjoyed being on the unit. He was discharged to live in 24 hour supported accommodation, but hoped to move to an independent flat in the future.

### Mabel

Prior to her move to the rehabilitation unit, Mabel lived in a residential home with her elderly mother. Apparently they were both struggling to live in their own home, and it was deemed Mabel could not cope on her own. After her mother's death Mabel remained living in the residential home for another year or so, keeping herself busy helping with the tea trolley and with small amounts of kitchen work, e.g. emptying the dishwasher. On discharge Mabel moved to a one bedroomed warden controlled flat - this was her first experience of independent living. She was supported in her flat by the community mental health team and received extra physical assistance around the home because of her reduced strength and stamina as a secondary consequence of a spinal scoliosis.

#### 4.3.2 Participants who completed phase 1 and phase 2 and parts of phase 3

### Mark

Mark who was educated to degree level became unwell after a number of years working full time and living independently. The symptoms of his illness made it increasingly difficult for him to sustain his level of independent functioning, and prior to admission hospital under the Mental Health Act he had been living with his parents for 4-5 years. Throughout his time in

---

<sup>6</sup> A criminal offence committed while psychiatrically unwell



rehabilitation he felt nothing could be done to help him and he engaged minimally with staff and other residents, he did however retain a good relationship with his parents. He was discharged to a room within a male hostel where he received twice daily care to prompt with medication and personal care. Mark completed the AMPS and the interview at phase 1 and 2 and the QOL across all three test phases. He was readmitted into hospital during phase 3 of testing so was unable to complete the remaining measures.

### Rita

Rita had numerous admissions to hospital over a period of 20 years or more, but this was her first time in rehabilitation. Her most recent admission to hospital was under the Mental Health Act as her rented home had become uninhabitable due to neglect. Rita had a brother who occasionally helped with large household chores and would on occasion assist her financially. She also had two good friends who lived close by, and had six children with whom she had little to no contact. On discharge Rita returned to live alone, but with intensive support from the outreach team and informal support from her friends. However she continued to drink to excess and remained vulnerable. She completed the QOL questionnaire at all three phases of testing and the interview and AMPS at phase 1 and 2. Rita was not at home at the scheduled time to complete the outstanding measures.

### Susan

Susan was educated to degree level and used to work as a primary school teacher. She became ill fairly early on in her career, and in recent years had used her skills and mental health experience to work as a peer support worker for a Mental Health Trust, helping fellow clients to develop Wellness Recovery Action Plans<sup>7</sup>. Prior to admission to the rehabilitation unit she was living in a shared house, but her life skills were deteriorating and her ability to maintain independent living was causing concern to health care staff. Following rehabilitation Susan moved into 24 hour sheltered accommodation. Susan was readmitted to hospital during phase 3 of testing, having not completed the AMPS.

#### 4.3.3 Participants who completed phase 1 and phase 2

### Steve

Since the age of 16 or 17 Steve had been in receipt of intermittent care from mental health services, both community and hospital based. This was his first time in rehabilitation, having being transferred from an acute hospital. Prior to his admission to hospital Steve was living

---

<sup>7</sup> Wellness Recovery Action Plan (Copeland 2000) - a self-management tool to assist with mental health recovery

independently in a housing association bedsit. However because of his drug dependency, the friends he kept, and the symptoms of his illness it was impossible for him to maintain the agreement of his tenancy - he lost his tenancy during his hospital admission, rendering him homeless. On discharge from rehabilitation, Steve moved into an independent flat in a supported accommodation complex. He was attending college and working 3 hours a week in a voluntary cleaning job. He did not return calls to take part in phase 3.

### Mohammad

Mohammad was transferred to rehabilitation following an extended stay in an acute ward. He came from a large, close-knit community where his extended family provide both practical and financial help to both Mohammad and his elderly mother. Mohammad was divorced with no children and had lived with his mother for a number of years as his illness had commenced approximately 13 years ago. While he was encouraged to attend to his domestic chores in the unit, he would frequently go home so that his mother could cook and do his washing for him. On discharge from the unit he returned home to live with his mother, he stopped his medication and was re-admitted into hospital under Section 3 of the Mental Health Act with an exacerbation of his psychosis. He was therefore unable to continue to participate in the study.

#### 4.3.4 Participants who completed phase 1

### Jan

Jan had been in and out of mental health services since the age of 15 years old, yet had not lost the hope of one day being a dancer. Over the years she has lived in variety of supported accommodation, including a hostel and group homes. Alongside support for her mental health needs, Jan was also in receipt of help for issues relating to gambling, drinking and illicit drugs. This was her first time in a rehabilitation unit. She was very reluctant to stay as her boyfriend, while being able to visit during the day, was not allowed to stay overnight. While at the unit her symptoms increased and she became increasingly distressed, which resulted in an attack on a member of staff. This necessitated a move to a more secure environment.

### Warren

Warren was admitted informally to the local psychiatric hospital following a psychotic breakdown and physically threatening behaviour towards his elderly parents, with whom he lived. Prior to this, he had been supported by the community mental health team for a number of years and had a history of substance misuse. He was ambivalent about being in

rehabilitation and rarely engaged with staff or fellow residents, preferring to isolate himself and use illicit substances while residing at the unit. Warren was unavailable for phase 2, as against medical advice he self-discharged from the unit and returned to live with his elderly parents.

### Mick

Mick left school at 13 and had been in mental health services since the age of 18. He had a below knee amputation as a result of serious self-harm and walked with a limp with a prosthetic and reported being in constant pain. Prior to his admission to rehabilitation, he spent a number of years in a challenging behaviour unit, and the move to the rehabilitation was a clear and transparent part of a journey towards greater independence. While Mick was very positive about the move to rehabilitation, on a day's home leave he threatened to kill his parents with a knife. He was subsequently held on remand in prison and therefore unavailable for phase 2.

### Richard

Richard had been living in a long-term residential institution prior to his move to rehabilitation. The move was necessitated by the closing of the home. He spent a lot of time in his room or seeking time with staff. As there were no plans to discharge him at the end of the data collection period (April 2013) Richard did not meet the criteria to be included in phase 2.

### Pete

Pete was transferred to the rehabilitation unit from a medium secure hospital and continued to be on Section 37/41 of the Mental Health Act with Home Office restrictions at the end of the data collection period (April 2013). Therefore he was not included in phase 2. However, despite occasional lapses with alcohol and drugs Pete was looking after himself very well, spending time on Skype to his girlfriend, shopping and playing his guitar.

### Maria

Maria used to work in a bank but lost her job as she became too unwell to do what was required. She was separated from her husband, had a strained relationship with her own parents and had very limited supervised contact with her 8 year old child. Maria did not meet the criteria for phase 2 as there were no plans to discharge her at the end of the data collection period (April 2013).

## William

William was brought to the attention of mental health services by the police - he had been living in a tent in the woods and scavenging for food. Apparently he had been living like this for approximately 6 years, as a result of being unable to pay his rent when his work as a builder dried up. William found the rehabilitation unit claustrophobic and struggled to verbally communicate with people. He was discharged to supported accommodation, although it is understood he returned to live on the streets and was subsequently readmitted to hospital. William completed all three measures at phase 1 of testing. He declined to take part in phase 2.

### **4.4 Vignette of the unit**

As outlined in Chapter One, the unit where this research took place was an 18 bed NHS-funded rehabilitation unit, staffed 24 hours a day. Each resident had his or her own bedroom, which they could personalise and were encouraged to keep locked during the day. During the day residents were expected to be up, dressed and willing to take part in a range of therapeutic and or social activities, both on and off the unit. One or two friends were allowed on the unit at any one time but no overnight guests were permitted.

After approximately a 4 week assessment and settling-in period, therapeutic interventions included support with medication concordance, management of side effects, and techniques to manage intrusive thought patterns, for example CBT for psychosis (Lecomte, Leclerc and Wykes. 2016). In addition, residents were offered support with structuring their day to attend to self-care and domestic activities (meal preparation) of daily living, accessing community facilities or addressing sleep and rest patterns, as appropriate. Socially the unit provided a shared lounge and shared kitchen in each of the three houses. In addition to this, there were three outside smoking areas and a separate group room, where art and craft activities could be enjoyed under the supervision of the occupational therapist. Social events included the occasional pamper or film evenings and trips in the minibus to out of town supermarkets.

All therapeutic and social interventions were offered either on an individual or group basis and may have involved one or more members of the multi-disciplinary team. The aim of involvement was to increase levels of confidence, independence and self-determination. Unfortunately, the unit's only occupational therapist was off work for a substantial time during the data collection period, and this was felt by some participants to negatively impact their ability to engage in the rehabilitation and recovery process.

## 4.5 Summary of Section 1

This section of Chapter Four, the first of three findings chapters, has presented vignettes for 17 of the 19 participants recruited onto the study, as well as an overview of the interventions offered at the unit. This is to help familiarise the reader with the participants as individuals, appreciate their reasons for being in rehabilitation, and become familiar with the routine on the unit. This offers an opportunity to understand participants' personal narratives and their journeys through rehabilitation.

## 4.6 Section 2 - Phase 1 interviews

Phase 1 interviews were conducted during the participants' first month of admission to the rehabilitation unit. There were 17 completed interviews, each of which were recorded and transcribed as detailed in the methodology chapter (Section 3.6.1). The interviews ranged from around 10 to 40 minutes in length. Four main themes emerged from the data analysis, each with corresponding sub-themes. Figure 4.1 details the links between the themes and the sub-themes (Braun, Clarke 2013). The order in which the themes are presented reflects the experience of the participants and the importance of the message they are sharing. There is a sense of the participants moving from naming the losses they have experienced to establishing a balance of power and control, though to working out what rehabilitation can offer them and where they fit within the rehabilitation unit.

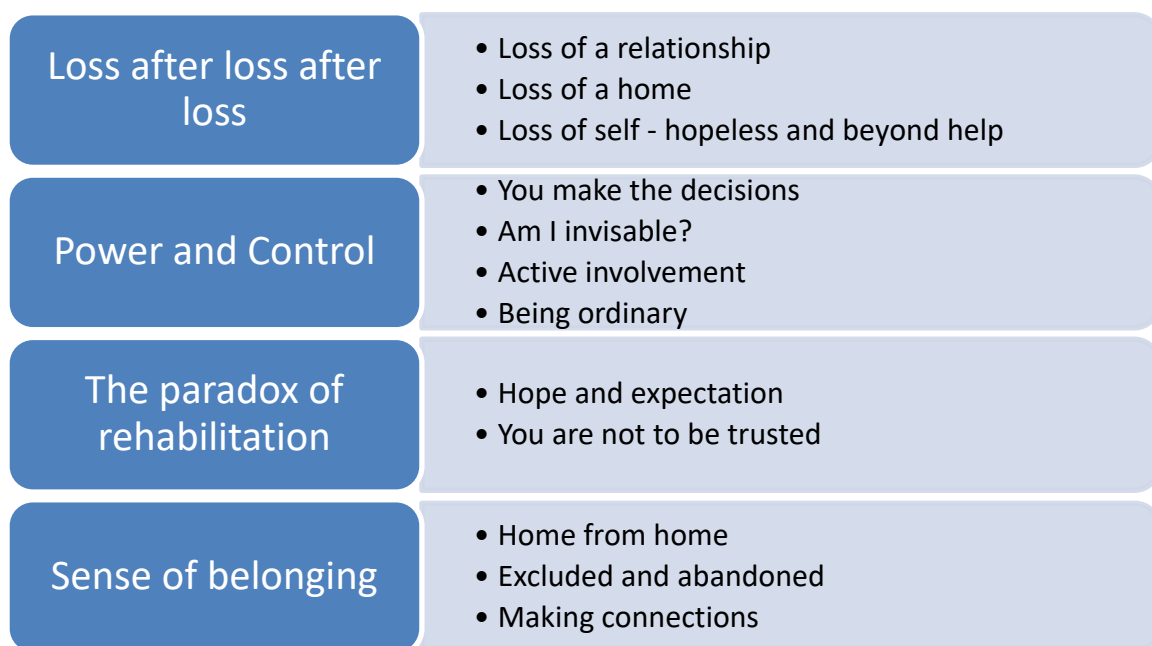


Figure 4.1: Themes that emerged from Phase 1 interviews

#### 4.6.1 Loss after loss, after loss

This overarching theme emerged from the multitude of losses which people had experienced prior to their move to the unit. This is presented first, as it creates a powerful image of the participants' lives before rehabilitation. It also points to the breadth and range of help people may require to support them in rebuilding their lives after a lengthy period of mental ill health. Frequently individuals spoke about a series of losses and the impact these had on their lifestyle. This overarching theme has three themes a) loss of a relationship, b) loss of a home, and c) loss of self - hopeless and beyond help, as detailed in Figure 4.2 below.

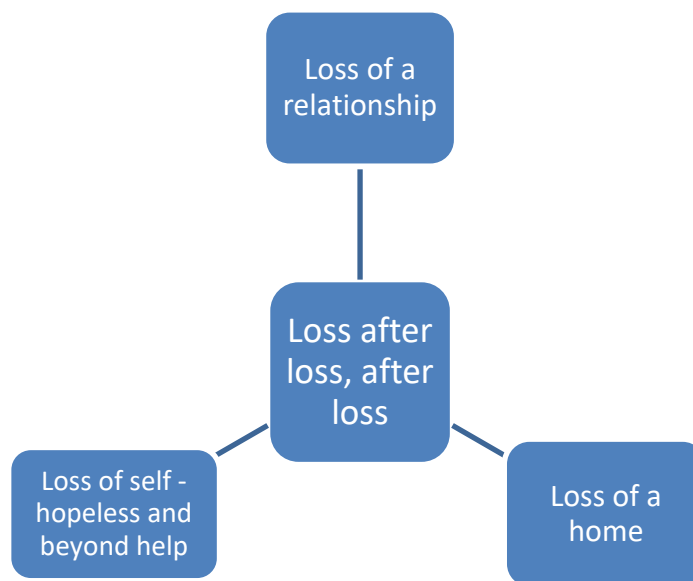


Figure 4.2: Loss after loss, after loss

##### a) Loss of a relationship

Perhaps the most life changing loss experienced for the participants was the loss of a stable relationship, above all other losses. As Marco describes, the break-up of his marriage was influential in the loss of his job and ultimately the loss of his lifestyle.

*'I was once a driver and a furniture fitter in London in 2000-2001. Then my ex-wife claimed for divorce so we had a bad moment at home and then it caused the end – I was sacked in my job and I went back to [home country] for two to two and a half years.'* (Marco)

Similar to Marco, Maria's marriage broke down, leading to further significant, life-defining losses

*'I'd just separated with my husband. I worked in a bank. I lost my job in the bank. I lost custody of my son and I think that was one of my trigger points that set off the breakdown.'* (Maria)

While Marco and Maria experienced losses as a consequence of marriage breakups, other participants experienced the loss of a relationship due to the death of loved ones, as Frank explains:

*'Things have changed a lot as my best friend is dead now, my parents are dead and I don't know if I said this to you before but I am the only one left now ... but that's no good remembering that now, you know, we are in 2011.'* (Frank)

The loss of a loved one, through marriage breakup or death can be a trigger for other losses. As we have seen however participants experienced similar losses without the loss of a significant relationship.

#### *b) Loss of a home*

The loss of a home is a dramatic loss, for which there are many reasons and contributing factors, as was the case above with Marco. Similarly, William describes how his loss of employment lead to him living in a tent:

*'I lost my job and I ran out of money [when asked why he was living in a tent]... I was a labourer on a building site - they just ran out of work... (I used to live) on my own, it was a shared house. I then lived in a tent – I used a gas cooker for cooking and just stay warm.'* (William)

Rita still had her house, but due to a relapse in her mental health her home had become completely inhabitable and everything was replaced, taking with it meanings or memories attached to her belongings. While Rita still had a house, she had lost her home, as she explains:

*'My home was completely gutted out and everything was chucked away because the place was so untidy cos ... the whole place was refurbished, I got two new sofas, a fire surround, new bed, new cooker, new fridge, everything from my past life had gone.'* (Rita)

These multitude of losses, that of a relationship, a job and a home appear to also bring with them a loss of purpose and meaning to life. These losses combine to produce a sense of all hope being lost.

### c) Loss of self - hopeless and beyond help

In this third sub-theme Richard, Mark and Jan speak about a loss of personal hope and a sense of being beyond help. They all identify a sense of isolation and of being stuck, hopeless and beyond help. Richard provided a visual image of how he saw himself:

*'I can't explain it, my body feels empty sometimes, like an eggshell, I'm stuck with a shell, but the yolk is gone.'* (Richard)

Mark and Jan described feeling hopeless and being beyond help, despite offers of help:

*'I don't know, I can't, I can't, there is nothing I can do, I can't ... it's a nightmare. ... I will just be like this forever, till whenever, I don't know what to do... I can't do anything, I can't ... I drop things, I can't ... I went shopping yesterday ... I can hardly open food containers, you know, you have to get rid of packaging, I can hardly open them, horrible.'* (Mark)

*'I talk to the staff about how I feel and that and they are very helpful, but on the other hand I feel like leaving because I feel like I have let myself down and everybody else down. Like I feel I am going backwards.'* (Jan)

The sense of sadness portrayed by Richard, Mark and Jan speaks for itself - they are unable to see the future being any different for them which creates a strong sense of hopelessness.

#### 4.6.1.1 Summary of Loss after loss, after loss

This theme focused on the multitude of losses participants experienced prior to moving into the unit. Three sub-themes identified the most common areas of loss experienced by the participants: the loss of a relationship; loss of a home; and eventually the loss of hope and a sense of being beyond help. While no direct link is made between losses and participants' mental health, what emerges from the themes is a sense that the losses are a heavy burden to carry, and change at times feels impossible.

Hope is required to enable change - people can feel hopeless if they feel out of control with no power to regain control in their lives. The following theme considers the challenges which emerged for the participants in relation to power and control.



#### 4.6.2 Power and control

This second theme is represented as a set of scales - there is a feeling of a balancing act between too much and too little power and control and where it sits (Figure 4.3). The scales signify the challenges about who is perceived as holding the power, and how problematic it can be for participants when they feel disempowered to the point of feeling invisible to staff. On the other side of the scales, the balance is addressed by active involvement, to a level which matches the participants' needs. Examples are given where participants are facilitated to regain personal control. The four sub-themes are a) you make the decisions, b) am I invisible? c) being ordinary and d) active involvement:

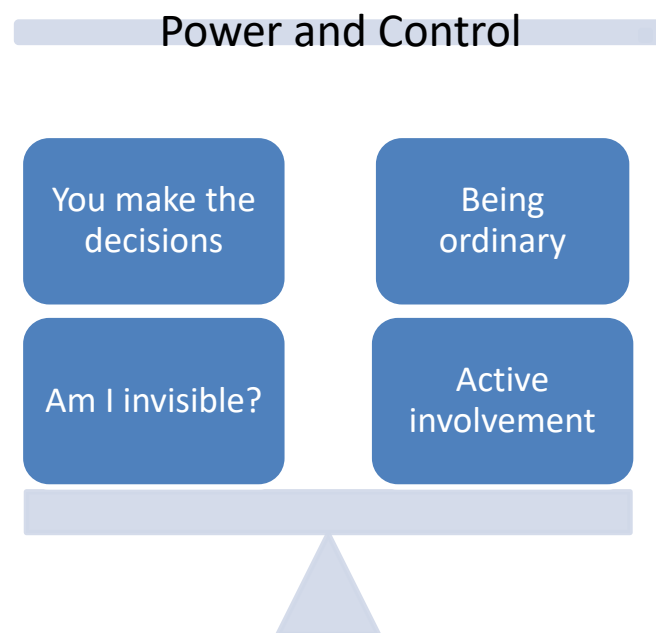


Figure 4.3 Power and Control

a) *You make the decisions*

This theme draws together two key areas where the participants felt others to be more powerful than themselves in their own lives, controlling decisions and making choices for them. The first area is related to moving into the rehabilitation unit, the second is how the participants are able to structure their own day.

i) *Moving day*

As regards moving into the unit, Richard, Warren and William spoke about having no choice about their move to rehabilitation, and worse still, Warren and William describe feeling as if they were being threatened by staff:

*'The doctor said I had to come here, I had no choice'. (Richard)*

*'They said if I didn't come they would section me [under the Mental Health Act], I came round.'* (Warren)

*'I was forced to come here – [were you involved in the process?] no, no they don't tell you anything, they just move you around.'* (William)

While these participants felt they had no choice in moving to the rehabilitation unit, Jan and Mabel despite expecting to move, describe the actual moving event being completely out of their control, resulting in them feeling unsettled by the suddenness and abruptness of it.

*'It was a bit manic really. They were needing the bed in [acute hospital]. I was supposed to come for an overnight stay and then go back to [acute hospital]. But basically I was told, "Pack your stuff, you're going in a couple of hours' time," which was a bit of a shock really. So I had to quickly round everything up, and I even had to remove washing from the machine'* (Jan)

*'On the Wednesday he said, "Up and out of it Mabel," so he said, "I'll be back to take you out," he said, "at 14:00 and that," and it was after 14:00 he come on the Wednesday and the lady had to get like the carers to come in to help me pack up and that and I left on the Wednesday and I've been here ever since'. (Mabel)*

ii) *Structuring my day*

The other area where participants felt unable to make their own decisions was in relation to how they structured their day. There was a perception that routines and expectations were inflexible, paternalistic and not open to individualisation. William and Frank experienced been treated like children in relation to maintaining their personal hygiene, and not being able to decide for themselves when to wash.

*'The staff are too, too, they treat us like children. They tell us when to wash and what to wear and that. I don't like that at all, that way of life.'* (William)

*'Like when you get up one morning and not have a shower sort of thing, and they say no you gotta have a shower you know, you gotta go up and have shower you know, even though you have 3 or 4 showers a week sort of thing you know, still ... not always enough for them'. (Frank)*

Similarly, the power and control tensions are very clear in what Frank says about the attitude he experienced from staff about his medication and in Mick's experience of having a drink:

*'They are so sort of strong minded you know ... you can't just wander off out and not ... not take your medication ... they are very strict on that. I know that cos one of the staff told me ... they said you just as might go back to the [psychiatric hospital] whatever he means by that ... if you can't get your medication sorted out, one of them actually told me that one day ... so I wandered out of the building ... (Frank)*

*'I can come back drunk and that can be no problem, know what I mean, but Dr X could turn round and section [Mental Health Act] me saying because I am drinking, taking alcohol, a drug, that I am endangering my mental health, too much power, watching me too much...' (Mick)*

While there is an appreciation that medication concordance and the use of alcohol are both examples of long-standing contentious issues within a psychiatric setting, it sounds as if Frank and Mick were treated in a paternalistic way, with staff exerting their power rather than working collaboratively with Frank and Mick to develop a joint solution.

*b) Am I invisible?*

This second sub-theme draws together the times when participants felt interactions with staff left them feeling unnoticed and lacking in individuality with little interest in them. Frank and Mick describe interactions with staff which made them feel unimportant. This is a subtle way of staff remaining in control and holding onto the power.

*'Sometimes the staff don't have time for you. I don't think that is helpful, I think they should have more time for the residents, cos sometimes they say sorry, I am busy, I've got to do something, you know.' (Frank)*

*'I have been eating out, everywhere I've been I've been offered food, but they haven't noticed, you know what I mean. Today I had to kick up a bit of a fuss for them to take me shopping cos they didn't really want to do it, but I said I hadn't been shopping for ages so they said yeah'. (Mick)*

On occasions when staff did interact with the participants it felt as if it was to the staff's agenda, without truly acknowledging the participants' needs and wishes, as described by William and Susan. This again is a subtle, but powerful way of disempowering other people.

*'They [the staff] don't see you very much, they don't say anything ... they ask me a lot of questions but they seem to have the answers before I do, so I don't know why they ask me the questions ... it's them that ask the questions, they don't tell me anything.' (William)*

*'It [care plan] was done for me, and I really wanted someone ... I really wanted to be there to help draw it up, and I was disappointed when it was just presented to me and I had to sign it. I was disappointed not to have had input.' (Susan)*

Feeling so disempowered can have a negative impact on a person's ability to start to regain some power and control - in the worst case it can be paramount to neglect and abuse. While there is no suggestion of that here, there is certainly a perceived imbalance of power. To balance this, the next sub-theme considers where the staff are perceived to have got it right.

c) *Active Involvement*

This third sub-theme is represented in Figure 4.3 is diametrically opposed to the sub-theme 'you make the decisions'. In comparison to 'you make the decisions' this sub-theme highlights a participant experience that feels inclusive, positive and individualised.

i) *The time is right*

Nigel and Steve recount a positive perception of the unit, they felt it was the right step for them and saw their admission to the unit as a way forward and something to which they had agreed. They were actively involved in the decision making process.

*'Well [this unit] is the next step for me you see, you know previously I have been at [the secure hospital] on [the rehabilitation] ward, been up in the flat ... my MDT team plus the manager of the ward they all turned round and said that I had proved I could look after myself when I came down from the flat, it was just a few months and then I came here.'* (Nigel)

*'I knew about it when I was in the acute unit cos I got told about it and I knew I was moving from [challenging behaviour unit] to here. I needed to come here because it is the next step of getting out there.'* (Steve)

It is interesting to note that Nigel and Steve both moved to the rehabilitation unit from a long-term placement in a secure setting. They were involved in the conversations relating to the move, increasing their awareness of personal power in making the decision.

ii) *You understand me*

Other examples of being involved include the staff 'knowing' how much support to give, when to step in and when to step back, making the participants feel understood, as Susan, Steve and Maria illustrate:

*'I get prompted every day and, you know, I get a lot of support here, a lot of help. If I'm left to myself at the moment I won't do things. As it is I need, sort of a real kick up the backside, proverbial, because you know, I am still quite ... I have been quite depressed and on and off still suffer from depression. And because I've got support, I'm more able to get out of that depressive state more quickly.'* (Susan)

*'It's when I am feeling a little bit ill they help me to come here, I get one to ones ... they have a chat with me about it and make me feel calm and relaxed and it's really helpful. Showing me how to cook, keeping me tidy and making sure I have a bath and stuff like that. They're helping me get a job, getting me to do multitasking, doing loads of different little jobs ... they are helping me with my schizophrenia and stuff, making sure I am well before I get out there.'* (Steve)

*'They have arranged for Quitters<sup>8</sup> to give me a call, so I've got an appointment next week. So they are helping me on that. One of them said they would help me bid for a flat as well. I haven't got a clue what I'm supposed to be doing with that though.'*  
(Maria)

The participants have described a wide variation of interaction and support, which from their perspective was right for them at the time. The level of interaction, which is facilitative of empowerment, is difficult to predict, as each participant had very individual requirements, but when it is right, people feel noticed and valued and they start to reclaim control for themselves.

#### *d) Being ordinary*

This final sub-theme draws together the participants' early identification of the desire to regain control in their lives and to be ordinary. There are two key areas: a description of what ordinary looks like for the participants, and the role personal responsibility plays in being ordinary.

#### *i) I want just ordinary things*

With being ordinary, Mick, Nigel and Richard spoke about wanting very ordinary things:

*'I want a flat, independence.'* (Mick)

*'I would like my own flat, a job and a girlfriend.'* (Nigel).

*'...to go and live in my own house. I can quite manage on my own. I lived in a bedsit for nearly ten years. I did my own washing, my own cooking and cleaning.'* (Richard)

Mabel wanted a '*bit of life*' where she can start to put down roots: *'I feel as if I have been a nomad all these years. Well I think I was too young to be living in a nursing home'*.

Mabel's desire to establish herself within her new community was also expressed by Pete, Marco and Jan in terms of earning their own money and developing meaningful relationships as opposed to destructive one, as a way of regaining personal control.

---

<sup>8</sup> Quitters – government funded programme to assist with giving up smoking

*'I'm motivated, I'm just like anyone else really, you know. I mean most people have got a family or a house or a car that they've got to pay, you know, money ... they need money to live. Everyone needs money. You know, I don't like taking the charity or the benefit money. I'd rather be earning my own money and obviously I'd like to be earning money that's alright money really eventually, you know.'* (Pete)

*'I am getting back to my prior mental health life, I have a normal, normal quiet life here, cooking, clean myself, clean my clothes, buying food, shopping ... so my problems are not related to my illness, mainly with a lack of company, with friends, a partner, my daughters mainly.'* (Marco)

*'Whoever I was with weren't my friends after all they just, just wanted my money and wanted me to do drugs ... so I have actually left them now ... I actually said to him, why are you calling me, don't call me again, you are not my friend, and I just put the phone down, umm and I haven't heard from him since, so I keep away from the people that do drugs really.'* (Jan)

ii) *The responsibility of ordinariness*

There is a recognition that to achieve a sense of ordinariness as opposed to being different and living in a rehabilitation unit is not a given, and requires a certain level of personal responsibility, which is not always easy to achieve. For some, this starts with small aspects of personal responsibility, as described by Maria and Warren:

*'I was thinking about getting things done like quitting smoking, prescription fitness.'*  
(Maria)

*'I am learning how to clean up – I am a very messy person. Every time I have a cup of coffee there are granules everywhere, I don't know how it happens, I try to be careful but it just spills everywhere.'* (Warren)

For Nigel and Pete regaining control and being ordinary is represented in having more freedom to leave the unit. But to get this highly desired commodity, negotiation and an acceptance of personal responsibility are necessary attributes:

*'I am going to ask Dr X if I can have a bit more time out ... I know I have to build that up over a period of time, but you know it's like her having to get to know me and me getting to know her sort of thing. I understand they have got to be careful, which is fair enough. There is a lot more freedom, don't get me wrong, there is a responsibility side to it as well, you can't mess around with that, it's not good if you do try to mess around with it.'* (Nigel)

*'I would like a drink and I think I could drink relatively responsibly. I'm not a great fan of alcohol. I'm not a great fan of getting steaming drunk, you know. I'd like to have a few beers and just leave ... enjoy it, you know. But my doctor said no to alcohol. She said if I drank I would go back to (secure unit) so obviously that's a big no-no.'*  
(Pete)

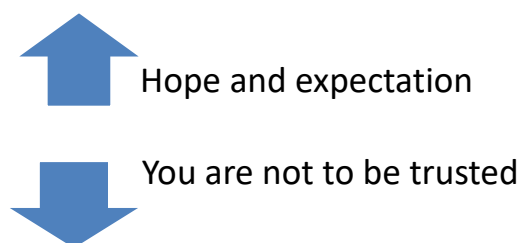
#### 4.6.2.1 Summary of Power and Control

This theme of power and control was represented as a set of scales to signify the balancing act of too much or too little power and control. On one side of the scales, some participants felt completely disempowered, to the point of feeling invisible, particularly in relation to their move to rehabilitation and the threats they received if they did not do as they were told. On the other side of the scales, participants experienced active involvement in their own rehabilitation journey and welcomed the opportunity to try and have ordinary things again and take responsibly for their decisions.

The scales are a metaphor for balance: participants all came from a different starting point and were all at the start of a journey, but at this point in time the direction of travel was unclear. The polarisation of experiences, to some extent can be explained by individual perceptions, however these differences of experiences are further explored in the next theme - the paradox of rehabilitation.

#### 4.6.3 The paradox of rehabilitation

This third theme brings together opposing views identified as a range of expectations and anticipations contrasted with an impression that staff and the function of the unit cannot be trusted. Given the experiences and losses that preceded the participants' admission to the unit, each participant had their own individual expectations of their stay in the unit. The paradox of rehabilitation has two, contrasting sub-themes which capture the contradictory nature of participants' experience of rehabilitation during their first month in the unit. This theme is represented as two elements a) hope and expectation and b) you are not to be trusted - both pulling in opposite directions.



*Figure 4.4* The paradox of rehabilitation

a) *Hope and expectation*

This sub-theme presents a wide range of positive experiences from participants' first month in the unit. Pete Jan and William felt very optimistic about the move to the unit:

*'It's a fresh start for me. It's a turn of the page, you know. It's a fresh start.'* (Pete)

*'I was excited about coming here, I felt really happy about coming here, I thought it was a new way forward, umm I thought I could get the best help here you know.'*  
(Jan)

*'I was on a [x] ward prior to coming here which is a rehab discharge ward and I was fairly alright on there ... fairly stable for quite some time on there, so as a result my doctor gave me a chance to move on ... to come to [rehab unit], this is the next step and I'm going to try and use it for everything I can get out of it.'* (William)

Similarly, Mabel and Mohammad spoke metaphorically about viewing rehabilitation as a fresh start for them with Mabel describing it as *'starting out on a new road'* while Mohammad recognised it was a time to get *'back onto my own two feet again'*.

Despite this sense of optimism and hope that stemmed from being in the unit, there was also some apprehension expressed in terms of the commitment required to make it work, as Susan explains:

*'I was pleased (about coming here) because I knew that it wouldn't be easy coming here, it's not the soft option. But I knew that I wanted rehab and I wanted to get back my life and I wanted to have a structure, and I wanted to learn how to structure and fill my day and also look at going back to work on a WRAP<sup>9</sup> project. So yeah, I felt very optimistic, I still do.'* (Susan)

This identification by Susan of rebuilding a life and a structure was echoed by Jan and Maria who named the skills they wished to develop:

*'I hope to achieve being able to have the confidence to cook, being able to maintain my hygiene for when I move on, being able to budget my money better so that I can get nice things for the flat or group home when I move on, and my mental health to be much better than what it is at the moment'* (Jan)

*'It's getting me used to living in a home environment again, getting used to doing things myself again, whereas before I had everything done for me, cooking and washing-up done for you. All you had to do was your washing and that was it. There was no one there to nag you to do it or keep on top of it.'* (Maria)

Pete noted that he was already doing more for himself, and as this was something of worth to him it had a positive effect on his confidence and hope for the future:

---

<sup>9</sup> WRAP - Wellness Recovery Action Planning



*'Well, this morning I cooked myself a bacon sandwich, I haven't done that for quite a while ... it took quite a while to cook, but it turned out a lot better than I thought it would.'* (Pete)

This idea of doing something of worth was a common one, reinforcing a sense that rehabilitation can be a positive experience that brings optimism. However, there was also a sense of unfocused aspirations that would probably need shaping over time to be meaningful and achievable, as described by Pete, Warren and Mick:

*'Well, I thought of maybe going to college. You know, going ... looking at what's available and what I could do. Maybe a part-time course or maybe some more voluntary work or part-time work or study, or a combination. You know, try and keep busy really.'* (Pete)

*'[I want to] go to college and get a car driving licence – I really want to go to college and then get a job - a job in IT – I am brilliant at IT, I can do spreadsheets and all.'* (Warren)

*'I want to get a voluntary job so I can get back into work, back into a routine, awake and up in the morning, go out to work, voluntary job [so] it doesn't matter if you got a day when you don't want to go in, you don't have to, just until I know I will be strong enough to hold a job down.'* (Mick)

This level of optimism also demonstrated an element of resilience and strength when faced with setbacks and rejections. Frank and Jan demonstrate an element personal strength and determination, which if harnessed correctly could help to bring about achievable and meaningful change:

*'I was looking at [national train service] trains, I mean I have been up there a few times, and up to [town], that's where they are based. I've had no joy out of them and looking for a job in the bank, and tried at that ... but, I've had no luck. I write letters and things but there's been no reply, I've got a letter up there, you know, when you leave me, in a bit I'll be posting a letter make sure, you know, I'll be posting one there.'* (Frank)

*'My aim in life is to be a professional dancer on stage, you know like people doing Fame and that, I wanna be like that, that is my ultimate goal, always has been, I thought I had failed and I would never get it back, my family think I can never be a dancer again, but I can always prove them wrong.'* (Jan)

This strong sense of hope, optimism and excitement is contradicted by a number of elements not being quite as expected, with a number of significant disappointments, which impacted on the level of trust given to the staff.

b) *You are not to be trusted*

The second sub-theme identifies aspects where participants were surprised or disappointed by their early experiences of the unit, creating a sense that rehabilitation was not quite as expected, that staff could be trusted, and where hopes of becoming more independent were dashed by a lack of engagement. Prior to moving to the unit, Maria was initially untrusting of the unit as a whole, simply because the idea was new to her. However, others were more mistrusting based on experience:

*'Something in me just didn't trust the whole set up, I needed to be persuaded to come here. [What swung it for you?] I think after my visit to the place and seeing what it was like. I'd never heard of anything like it before.'* (Maria)

Having spent a number of years in a secure forensic setting, Pete was keen to work out which staff members he felt he could trust and of whom he needed to be wary:

*'There's been one member of staff – a female – I don't feel particularly comfortable around her. Just got a sort of odd feeling about this particular one ... female staff. I don't think she's too clever, but you know ... I'm just trying ... I'm just sussing people out really at the moment. Just trying to remember their names, you know, or try and suss them out a little bit, you know - who you're going to get on with, who's not much cop or ... you know, just sort of sussing people out, you know.'* (Pete)

While this is not specific to rehabilitation, Richard and Pete were not in agreement with their medical diagnoses, adding to a general mistrust about the service. There is also a feeling in what they both say that the opportunity to experience recovery is hampered by having a long-term condition diagnosis which reduces hope for the future:

*'Because the doctor wants me ... he knows ... they say I suffer with schizophrenia: I have to disagree with them. But I think ... now the drink problem is over, I'm alright.'* (Richard)

*'What I don't like is this sort of blanket bombing of diagnosis. You know, once you get labelled schizophrenic that seems to last like the rest of your life. You're going to be schizophrenic, you know, and I don't always agree that ... I think people get ill, but they get well again and I do find that is a big issue that I have a gripe with the system generally.'* (Pete)

There was also a feeling that because Frank and Maria didn't fully trust the staff, they were unable to relax for fear of being discharged with nowhere to go:

*'I mean I don't know when they are planning on you know getting you know rid of me sort of thing, you know. I know for a fact they could give me a letter at any time, you know, that's going to put me in a right panic isn't ... I don't want to end up on the streets, that's my big fear, you know ... I don't want to be on a park bench that the*

*police pick up somewhere like that and ask me loads and loads of questions, you know, come on you're off mate, back to the station to answer some questions, that's what worries me you know.'* (Frank )

*'The fact that I am technically classed as homeless worries me. If this place suddenly closed, where would I end up? My biggest concern is accommodation at the moment. That worries me sometimes.'* (Maria)

This sense of mistrust also extended to feeling that the staff at the unit were testing the participants, and that if 'tests' were failed there would be consequences:

*'I've been told I've got to be here between a year and eighteen months and then obviously I'll probably ... if I can last the course, you know, I'll get my own place.'* (Pete)

Jason on the other hand was looking for some sense of formal recognition for his time in the unit, something to signify he had reached his goals and passed the test:

*'Well, you know, maybe a letter to say that I was here and whatever. Certification that I cook my own meals ... I actually go to bed on time, I go out and about ... have I completed my tasks, kept my goals.'* (Jason)

But lasting the course and keeping to task is challenging when, as Pete, Mick, Rita and Nigel identify, there is very little productive engagement with staff or activities within the unit:

*'I just see it as a little bit sad .... most patients are just sort of drifting from day to day really, you know. I just see it as a bit sad, you know. I see their sadness. I see they're sort of like ... just drifting, you know, pissed off with life and they're not always able to sort of ... to do anything about it. And the staff and doctors don't really help much either, and I do find that a little bit sad, you know.'* (Pete)

*'[it is] boring [here] - there is nothing to do, they don't take you out nowhere, they have got a minibus but they won't take you out, they don't do activities.'* (Mick)

*'I am doing what you would normally do at home, like get up in the morning, have a wash, get dressed - the only problem is I am watching a lot of television, and I haven't got a television at home. So now the summer here I will be out most of the time, going for walks cos I live right by the sea.'* (Rita)

*'I don't know what sort of courses they do here, umm I would like to speak to OT lady to see what is on offer, umm take it from there.'* (Nigel)

While participants do not talk directly of mistrusting staff in relation to lack of things to do, there is a sense of disappointment that results from mistrusting the system and from a lack of meaningful activities or engagement with the staff. This creates distrust in the concept of rehabilitation, as it is not able to provide the help required to enable the participants to achieve their hopes and expectations.

#### 4.6.3.1 Summary of the paradox of rehabilitation

The theme of the paradox of rehabilitation presented two contrasting experiences of being in the unit. On the one hand, despite being a little unsure at the start, for some rehabilitation was seen as fresh start, an opportunity to acquire and practise skills. Some participants saw the opportunity to engage in a range of activities and had an openness to try different things and a level of determination to keep trying following previous disappointments in life.

On the other hand, for some participants the initial experience of rehabilitation was not as expected. In particular, the attitude and behaviour of the staff towards them got in the way of being able to make as much of the opportunity as they had hoped. Participants spoke about not being able to trust the staff, for example not wanting to approach them about developing a collaborative care plan, or feeling unable to have an open discussion about their diagnosis.

There was also a real air of disappointment at not having very much to do on the unit, feeling as if they were just drifting through the day, and on occasion feeling as if they are being tested. While disagreement between staff and people with complex mental health issues is relatively commonplace, the fact that participants do not feel they can trust the staff is diametrically opposed to the creation of a collaborative environment where participants can develop skills and progress. Thus, the final theme elicited from phase 1 considers what is needed for the participants to start to develop a sense of belonging, not only as a way of addressing their multitude of losses but to increase their ability to accept responsibility and find a way forward for themselves.

#### **4.6.4 A sense of belonging**

The fourth and final theme of phase 1 draws together how participants perceived themselves as fitting in, being accepted in the unit and beyond, gaining a sense of where they belong. While the ambience of the unit was recognised as being positively different from other environments by a number of participants, fitting into a new environment could be problematic, particularly if they did not feel understood by others. While some participants felt very at home in the unit, others expressed a different viewpoint, and this created a sense of feeling different to the point of feeling excluded. This exclusion was not just within the unit, but also related to feeling excluded from wider networks, including family. This theme has three sub-themes a) home from home, b) excluded and abandoned and c) making connections. It is represented as flows of energy in the direction of the arrows which either adds or subtracts from participants' overall sense of belonging:

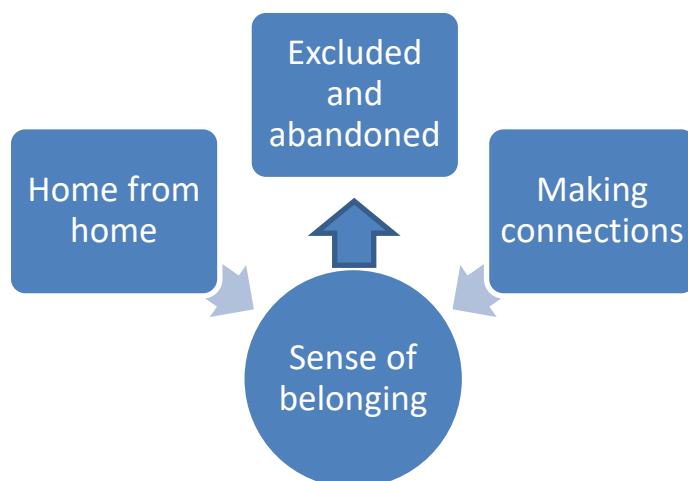


Figure 4.5: Sense of belonging

a) *Home from home*

While the unit tries to distance itself from an acute psychiatric hospital ambience, having fresh flowers on the windowsill and fresh fruit in the fruit bowl in the kitchen, there are some participants who notice and appreciate a different atmosphere and those who don't. According to Susan, Marco and Mohammad the unit felt calm, relaxed and friendly:

*'I think what stood out really is how calm it is here, you know, compared [to] an acute ward.'* (Susan)

*'It's much more relaxing as an environment and the more time I am here, the more relaxing it is.'* (Marco)

*'I like it here very much, you know, it's a lot more quieter and the patients are a lot more ... less hectic or less difficult to get on with or less nasty, you know. And I've made a couple of friends already.'* (Mohammad)

For some participants, the positive ambience of the unit was enhanced by the opportunity to make personal spaces, such as a bedroom, personalised. Susan and Pete felt the unit was different from other places they had been in and appreciated how small things could make a big difference:

*'One of the kindest things they did was let me bring in a small table to do my art work by, and my chest of drawers to put my books in, so they were very accommodating, you know, they were very good.'* (Susan)

*'I mean I spend most of my time either in the kitchen, my room or the smoking area, but I've got a nice room and I'm allowed to have quite a lot of my stuff in there that I wasn't allowed to have in [the secure unit].'* (Pete)

While for a number of participants the unit had a sense of 'home from home', for others it was far from a home, given Mick's description *'It's not a normal environment is it. Would you want to be here?'* And Maria's experience:

*'Getting up in the middle of the night doesn't seem to be accepted. I don't know, it depends what staff's on. Some staff are quite easy going and just say 'hello' and let you get on with it. I've had a lot of bad dreams recently - I just wanted to get up and watch TV for a little while, but I don't feel I can. So it's not home from home really ... it still feels I'm in some sort of institutional set-up.'* (Maria)

What both Mick and Maria are describing is something that feels almost alien and institutionalised - a far cry from a safe, homely environment where they can do as they wish, when they wish.

#### *b) Excluded and abandoned*

This second sub-theme of wanting to create a sense of belonging draws together some strong and painful feelings where Frank, Maria, Mohammad and Mark describe being different, excluded and abandoned by staff and their own family:

*They [the staff] have their own, their own way about doing things you know ... I definitely don't feel like I am one of them you know. It seems like they want it all their own way, their own sort of system you know ... I mean if you ask, apply for a job here or something like that probably, there is no way they would let you in, you know, it ... I would just seem to be sort of separate from them, sort of thing, you know what I mean? I can't ... that's how I mean it seems like inhuman I would have said.'* (Frank)

*'I say goodbye and hello [to the staff] and that's about it. I can't really hold a proper discussion or nothing, they are a bit freaked out by me I think, yeah. They do all right by me, they are perfectly fine, but I don't really, it's the same at the hospital and the same when my mum and dad come in, I don't really talk much.'* (Mark)

The use of the word 'inhuman' by Frank is particularly powerful and is suggestive of something more fundamental than not belonging to the staff group - it suggests being treated with contempt and brutality. Similarly Mark's description of the staff being 'freaked out' is suggestive of staff not knowing what to do, to the point they are scared and move away.

*'My parents supported me the best way they could, but they were more for going out rather than coming round to see me. And I just wanted to be on my own because I was in hospital over Christmas two years ago and didn't get their Christmas card and so I felt a bit estranged from them. And they obviously didn't understand how I was feeling.'* (Maria)

*'It's just my mum needed her independence. She said it was better if I was [independent] I became unwell as well. She couldn't cope with it. She is too old to cope with that.'* (Mohammad)

While Maria and Mohammad talk about a sense of being abandoned by their family, Mabel does have family and friends but there is sadness about it, in that she is not a part of their community as she would like to be:

*[My brother] is able to come once a week or sometimes he might have the chance of calling in during the week and that. He gives me money. I have made you know, one or two [new friends]. I do have a couple of friends in the X area. Would be nice to be able to visit them. I only see one or two of them at church when I go to 10.30 mass on a Sunday morning.'* (Mabel)

These participants have described a sense of exclusion and abandonment that is personal and painful, yet in contrast to this there are examples in the next sub-theme where participants are starting to expand their social connections:

#### *c) Making connections*

This final sub-theme brings together some of the positive aspects which participants identified when they were starting to build or rebuild social connections. This helped to create a feeling of personal identity and give a sense of belonging, as explained by Pete, Nigel and Mohammad:

*'[I know] the young lad who's a grandson of an old friend of the family ... someone I've known all my life, and his grandson unfortunately is paralysed and he's quite miserable really because he's a young lad and obviously he's got this dreadful disability, and I thought I'd try and cheer him up by doing him a nice drawing, you know.'* (Pete)

*'I do a brisk walk there [into town] and a brisk walk back, depends how much time I have, I might pop in for a latte, there is a coffee shop there, I do love my lattes, my favourite is Café Nero's. I haven't found one in the city yet. I sit outside, coffee in one hand, cigarette in the other, watching the world go by.'* (Nigel)

*'I am a member of a working man's club, I go in two weeks, I see my brother once a week and my sister every two weeks.'* (Mohammad)

Each of these three participants identified the importance of connecting with other people, be that watching them go by in the street or being more actively involved with family and friends.

#### 4.6.4.1 Summary of sense of belonging

This final theme of phase 1 demonstrates the complexity of how it feels for the participants in the first month of stay in rehabilitation. This theme focuses on the participants' desire to feel at home and to fit into their community, all with a sense of belonging. For some calmness, quietness and relaxed atmosphere are welcome changes from the acute ward, making the unit feel a safe place. The freedom to personalise their bedrooms was a notable factor in

making the unit feel like home. The opportunity to connect with others outside of the unit added to a developing personal sense of belonging.

In contrast to this, some participants felt uncomfortable in the rehabilitation environment, there was a perception of being different, excluded and abandoned by staff and close relatives. This carried with it a sense of sadness which comes through in the participants' powerful use of words.

#### **4.7 Chapter summary**

This chapter commenced with an overview of the participants through the use of vignettes in order to familiarise the reader with the individual participants. While there is an acute appreciation that each participant had a very different story to tell, the first theme of *loss after loss, after loss* highlights that nearly all participants had experienced some sort of loss prior to their move to the unit. While they may not have experienced the same loss, the personal sense of loss, and in some cases multiple losses, felt a heavy burden to carry.

This uniqueness of the individuals is evident in the dialectics which form and were described in each of the remaining three themes: *power and control, the paradox of rehabilitation and a sense of belonging*. Each overarching theme offered two or three different perspectives, or sub-themes, within that theme, suggesting that while themes have emerged, they cannot be consistently applied across the whole study population. What feels like the right amount of support, involvement or time for one participant, may feel too much or too little for the next. Similarly, what makes the unit feel like home to one person is not recognised by another. These similarities and differences in thoughts, feeling and experiences have been drawn into themes, but the uniqueness of the individual experience is still present in the recognition of the dialectical tensions in each of the themes, where a balance or tension has been used to articulate the differences of experience. The next chapter presents a thematic analysis from the interviews conducted at phases 2 and 3.



## **Chapter Five – Findings (2)**

### **Thematic analysis of phase 2 and phase 3 interviews**

#### **5.1 Introduction**

This chapter is in two sections: Section 1 presents a thematic analysis of the interviews conducted at phase 2 (at the time discharge plan were being finalised); Section 2 presents the thematic analysis of the interviews conducted at phase 3, approximately 3 to 6 months post discharge, when the participants were living in their new accommodation.

The phases have been kept separate in recognition of the very different places participants are in during the two phases, both in terms of where they were living, and from a recovery journey perspective in terms of how they were living. To blend them together would not be a true representation of how participants were feeling as discharge approached and how they felt 3 to 6 months later.

#### **5.2 Section 1 - Phase 2 interviews**

Phase 2 included 10 participants as presented in Table 5.1 below. Each of the interviews, except Mark's, took place in the rehabilitation unit. Mark's took place at his request in his new flat on a day that he was visiting. The interviews ranged from around 10 to 32 minutes.

Table 5.1 *Overview of participants in Phase 2 data collection*

	Data collection method		
	IV	AMPS	QOL
Marco	x	x	x
Frank	x	x	x
Jason	x	x	x
Nigel	x	x	x
Mabel	x	x	x
Mark	x	x	x
Rita	x	x	x
Susan	x	x	x
Steve	x	x	x
Mohammad	x	x	x

Thematic analysis elicited three themes with corresponding sub-themes, detailed below:

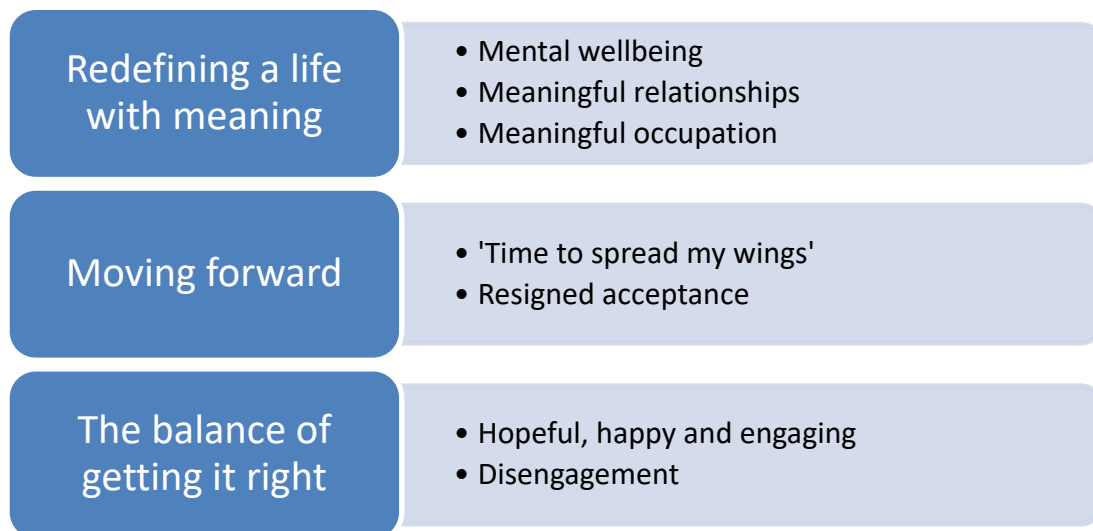


Figure 5.1 Themes and sub-themes emerging from phase 2 interviews

### 5.2.1 Redefining a life with meaning

The theme of redefining a life with meaning considers three areas of life which participants have identified as important a) mental wellbeing b) meaningful relationships and c) meaningful occupation.

The process of redefining a life is a non-linear process that may take many years to achieve. This is particularly the case for people with long-term mental health needs, whose previous lives have been defined, as we have seen in the preceding chapter, by losses, a lack of control and a sense of mistrust. The sub-themes within this theme are presented as building blocks to redefining a life with meaning.

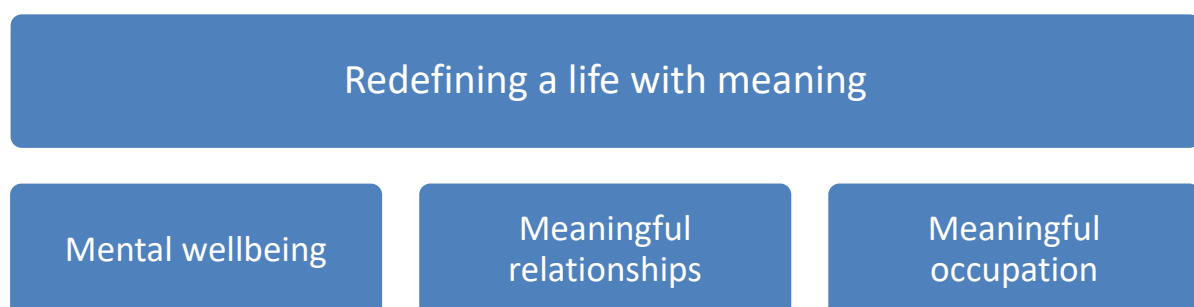


Figure 5.2 Redefining a life with meaning

a) Mental wellbeing

This first sub-theme recognises the need to establish a level of mental wellbeing. Medication is identified as a pivotal factor in achieving and maintaining wellbeing, as described by Steve, Mabel and Mohammad.

*'(I have had) lots of support and help dealing with my illness and stuff: one to ones and help with medication. They got me used to it I suppose and now I am doing it on my own.'* (Steve)

*'I did all my medical tablets with (key nurse). She photocopied them. I have them in my file upstairs, all the side effects of my medication that I'm on.'* (Mabel)

*'Mum's willing to have me back home and I'm ready to go home because I want to impress people with my medication this time. The thing is, the most important thing is the medication is just right. It's spot on. I am a lot better - not so many hallucinations and stuff.'* (Mohammad)

However, mental wellbeing is recognised as being much wider than establishing a medication routine - a number of participants identified a range of self-management approaches that would help them take care of their mental health in the future.

*'Well, you know, the wellness chart has been really helpful, how you're going to get yourself well, you know, for moving on.'* (Mabel)

*'We filter the plan, the crisis plan, so we went deep into my progress so now I am more aware than before of what is my illness and how to fight against it, not fight against.'* (Marco)

*'I like it in (my bedroom) ... I have had the chance to sleep, have a rest during the night, the whole night ... I have learnt that it's bedtime before 12 o'clock.'* (Jason)

Medication and self-management, and recognising one's own limitations became an essential part of Susan's routine:

*'I still need to keep reminding myself that when I feel better I should not take on more. It is like medication, if it works carry on taking it. And taking on more stuff when I am better is like reverting to not taking my medication. You have got to maintain what you have got so I'm very keen to maintain the key three things that I do in my week.'* (Susan)

Medication and self-management, including sleep and routine, as a way to achieve mental wellbeing are identified by the participants as a building block to redefining life - without them, other aspects, such as meaningful relationships and occupations, would be harder to achieve and maintain.

## b) Meaningful relationships

The second sub-theme of redefining meaning to life is built around developing new friends and re-engaging with old acquaintances.

Marco and Jason talk about increasing their friendship circles:

*'Hopefully yes (we will keep in contact), we have swapped numbers, telephone numbers, already so they are positive friendships according to me ... we shared our food and drink, they are quite nice people'* (Marco)

*'I thought that going to another alternative gym would be a bit more sociable, so I can be a bit more sociable if I turned up at (day centre) where I get to talk to friends.'* (Jason)

Whereas Nigel and Rita catch up with old friends:

*'Oh I pop into (area of town)...about halfway up you have got a coffee house, 1950s style. I know the owner, we have a bit of a chin wag, yes. Yes I pop in there for a cup of latte. When it is nice and sunny I sit outside, have a coffee, have a cigarette and watch the world go by.'* (Nigel)

*'Normally we see each other (best friend) when I am on home leave, she lives on her own as well, we have known each other since we were at school.'* (Rita)

Interestingly, Susan views friends as preventative medicine, *'You know they say a friend a day you know keeps the doctor away.'* (Susan)

## c) Meaningful occupations

The final sub-theme of redefining life focuses on the pleasure gained and increased competence through engaging in day to day occupations. There is also a sense of anticipation of being able to engage in leisure activities once discharged which would further enhance quality of life.

Steve, Rita and Frank discuss how regaining their confidence with domestic chores has prepared them to be more independent and how they feel more equipped to live on their own:

*'I am more independent now, I know how to cook and stuff ... keeping my room tidy and cooking and making sure I have regular showers and stuff like that. Having a routine and looking at (my) budgeting and saving money and stuff like that.'* (Steve)

*'I have been getting rehabilitated back to my own home ... walking, cooking, just everyday things - cooking my own meals, going for walks on the common, doing the*

*art group - what they are doing is gradually rehabilitating me back home. I have a date for leaving. It's the 4th July.'* (Rita)

*'I am better at cleaning things than I was before and getting food, I am a bit more better at getting food you know, looking after myself than I was before really ... I put it in the microwave, but I show more confidence about cooking you know, pans on the cooker and stuff like that, I got more confidence about that ... potatoes, beans, sometimes some sort of meat, pea you know, sprouts, carrots all kinds of things really.'* (Frank)

Similarly, as they prepare for discharge, Nigel and Mabel share their ideas as to how they could, through personal interests develop and maintain meaningful occupations. Nigel talks about restarting his interest in model planes and boats, whereas Mabel has many ideas about what she would like to do.

*'I thought I'd just check the internet, like start off with the Hampshire area. I could just go to the (local) area. It wouldn't be too far then would it?'* (Nigel)

*'Well, you know, I hope I can get to church a bit more and that and do a bit more baking and that and, you know, get myself involved with the computer.'* (Mabel)

Attending a day service as a user has developed into voluntary work where Susan can offer support to others, giving her a great sense of efficacy and meaning:

*'It is like a sort of day service, like a three hour drop-in for people with, well service users but, also their supporters can go as well, so it is a bit more open and basically I've just been going along lately and got taken on as a volunteer which is just basically like providing refreshments, chatting to clients, you know, and sharing a bit of peer support really which is good.'* (Susan)

#### 5.2.1.1 Summary of redefining a life with meaning

This theme has identified three areas participants felt were important to redefining their lives as they prepared for discharge from the unit: mental wellbeing, meaningful relationships and meaningful occupations. While the final destination for all participants was different, with some preparing to live on their own for the first time in their adult life, some returning to the community after many years of institutionalisation, and others returning to live with a partner, all described a desire to feel better and have a more balanced and meaningful life.

Confidence and an enhanced sense of self efficacy have increased for some, particularly in relation to undertaking domestic chores. While some have started some voluntary work, social connectivity for many of the participants is in its early days. Recovery and the redefining of oneself is a long-term project, but it appears to be a journey that most of the participants in this study have commenced and progressed in.

### 5.2.2 Moving forward

This second theme of phase 2, Moving Forward, identified many views of participants shortly to be discharged from the unit. While most participants felt the time was right to move on, despite some anxieties in relation to the move, this was not a feeling expressed by all. This theme has two sub-themes, a) 'time to spread my wings' and b) resigned acceptance. The opposing sub-themes are represented in Figure 5.3 below as a gear motion, representing the potential tensions between moving forward in a timely way, and that of resigned acceptance and the resistance.

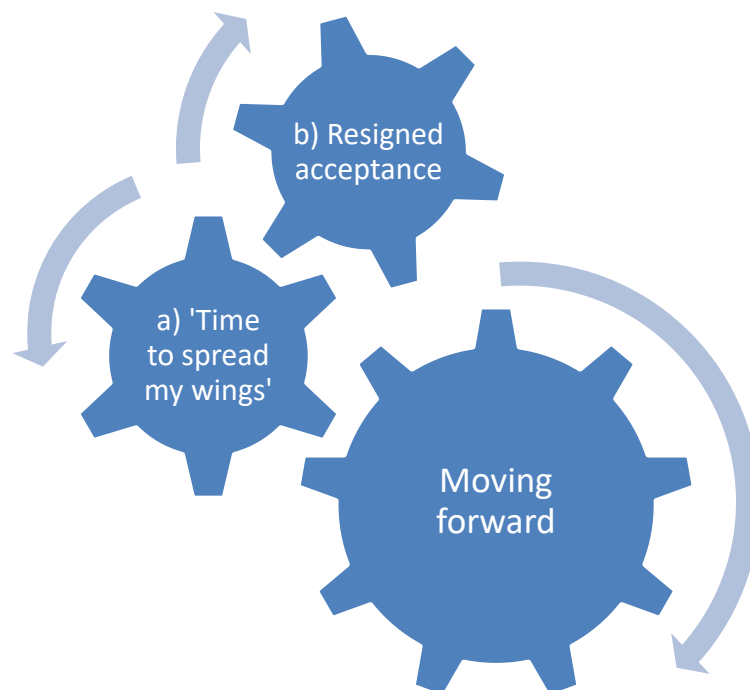


Figure 5.3: Moving forward: the tensions identified

- a) 'Time to spread my wings'

This sub-theme focuses on how the participants identified and articulated that they were ready to leave the unit. On discussing their imminent moves Susan, Marco and Steve all expressed a state of readiness and eagerness to go:

*'I am more independent and sort of going out more. Sometimes I feel kind of a bit hemmed in. So I know that it's sort of you know time to spread my wings really.'*  
(Susan)

*'I have improved month after month and I am able to be discharged now ... I will be able to, to lose myself in the community more appropriately ... trying to be a normal person with the others.'* (Marco)

*'I feel happy about it (being discharged), I have a lot of good behaviour, and of course keeping myself to myself.'* (Steve)

At the unit it is common practice for discharge to happen gradually. This involves the participant slowly increasing the number of days and nights they spend in their new accommodation. However, Mabel did not wish to do this, demonstrating impatience and a new level of confidence at facing her future:

*'I feel I won't need to come back to sleep once I go, I'll go ... I notice you know the other girls come back to sleep, and you know yes, but you know go and then come back at night and then go again the next day and that, but I feel I would be alright you know just going and you know staying there.'* (Mabel)

Nigel however demonstrated some apprehension - although he was ready to move on from the unit, he did not feel ready to move into an independent flat. Given this, he chose a gradual move towards independence:

*'I just did not want to go straight out into a one bedroomed flat, no way, I don't think ... I am not ready for it. As I have gone on I have been getting more and more responsibility given to me, which can be translated as freedom sort of thing, but like I said I am not going to run before I can bloody walk. At (24 hour supported accommodation) you are supported, you know, at the back of your mind 24/7 care - brilliant. To me just that is like security, I still need it (the security).'* (Nigel)

While some participants were very much ready to go, others wished to take it a little slower, and some did so with a sense of resigned acceptance - the choice to leave the unit was not theirs.

#### b) Resigned acceptance

Resigned acceptance comes from participants identifying that they did not feel ready for discharge, feeling anxious and apprehensive at the prospect. However, given that discharge was inevitable, Rita, Frank and Mark all adopted a position of resigned acceptance:

*'[I feel] a bit nervous ... a bit apprehensive of being on my own ... I don't think I was every ready, but I have to go on July 4<sup>th</sup> so I have set my mind on that. I just think I will need more independence and more confidence and not being sick all the time, going to sleep. Lying down and going to sleep, I want to get out of that.'* (Rita)

*'I still just want to get the house back... it (the house) still hangs about in your mind a lot ... (I would like) help to get my house back, been conned by con men you know, they conned me and took the house out of me ... feel I am still learning. My health (is) not ready to go into a flat, just have to see what happens.'* (Frank)

*'I mean, they tried, yes they tried ... I'm still no better really, am I?... I suppose there is not a lot they can do for me is there, really. I've had blood tests over there, scans and ECGs and they haven't really found out what it is ... that's my hope, but they can only do so much for whatever it is in there.'* (Mark)

The reasons for not feeling ready are clear for each individual, but each of them gave a message of hopelessness and being out of control. Frank in particular had very strong feelings about his move:

*'Well, as I say I am a bit surprised at their attitude sometimes about this flat business you know - if you don't pick the first flat then you will be shipped onto the streets. I don't know why they do that, they're not supposed to do that ... it does bug me. What I can't understand is, say I don't pick the next flat [because] it's not the flat for me, I was told they are going to chuck me out on the streets. My mate - I don't want to mention any names - he done that twice, he's said 'Look I don't like this flat', he's done it twice and they don't touch him, you know so I was wondering what as different about me, sort of thing, you know. Do you know what I mean, why should I be any different?'* (Frank)

#### 5.2.2.1 Summary of moving forward

When the time arrived to be discharged from the unit and to move forward with their lives some participants were absolutely ready to go and spread their wings, and some without the need for a staged discharge process – for example Mabel. Others did not feel ready to go and felt they had little option but to go along with the decision made, which created a sense of unfairness and hopelessness again.

#### 5.2.3 The balance of getting it right

The final theme of phase 2 is the balance of getting it right, which identifies both positive and negative responses to the experience of living in the unit - essentially a small psychiatric hospital in the community (as detailed in Chapter 4 above).

While the participants are granted more freedom and flexibility in the self-catering unit, each person having a small weekly budget to purchase their own food, it is still managed like hospital in terms of policy and procedures. This brings challenges at times and there is a balance to be had between living in a hospital and preparing to live in the community. This theme has two sub-themes, a) happy, hopeful and engaging, and b) decreased opportunities



for some which are represented as a see-saw. The theme identifies the fine balance required to meet individual needs (Figure 5.4).

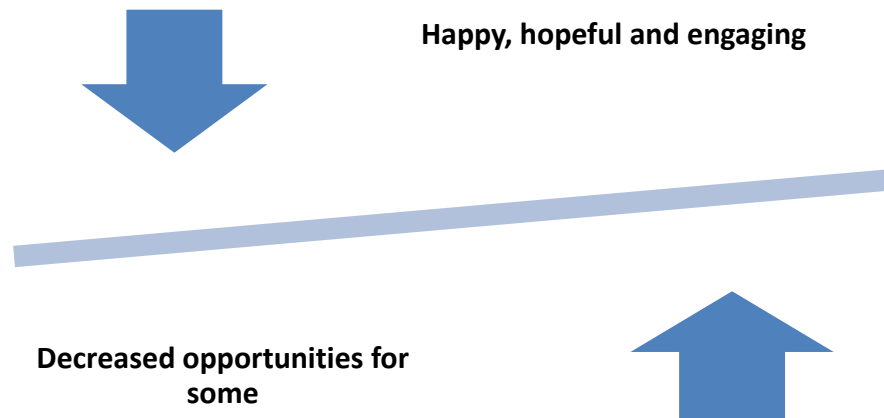


Figure 5.4: The balance of getting it right

a) Happy, hopeful and engaging

The attitude of one person towards another can have an effect on the interpersonal relationship between the two people, and can impact across the unit as Mohammad points out.

*'They are very helpful, happy and cheerful which kind of picks other people up as well when we are low and down.'* (Mohammad)

However, the 'right attitude' is subjective, and therefore difficult to completely define. Yet, when the attitude of a person towards you feels right, it just feels right, as Nigel explains:

*'I could only say it is like bits and pieces, bits here, bits there, pieces over there. But it has all gone like cogs in a machine... because these guys have got my trust and they are nice people, they have been nice to me, you know.'* (Nigel)

For Mabel and Nigel it would appear that the staff demonstrated a hopeful attitude:

*'Well you know, they're hopeful, you know, I suppose a bit better of a future and something to look forward to.'* (Mabel)

*'I think I have more hope of getting better I think here, finally I feel a bit more positive.'* (Mark)

Similarly Nigel, Rita and Susan appreciated the emotional and practical support offered by staff:

*'They have helped me. They have nurtured me in a way if you want to call it that. Like I have said I couldn't have done it without them. There is no 'I'm in team ... the staff have been there for me, and not just my own team but the other members of staff as well.'* (Nigel)

*'Quite often, she [named nurse] gets me motivated, she gets my bearings and I get up and put the washing on and have a shower, she kind of prompts me. She has been very helpful with my benefits and everything, sorting everything out for me for when I go home.'* (Rita)

*'I just get encouragement and the space to do that, you know, the time and space to relearn in a way living skills and getting into good habits.'* (Susan)

An engaging attitude was also expressed informally and it would appear that playing together might help build positive relationships. Susan recalls a particularly enjoyable time:

*'I think sort of the majority of relationships with staff are quite good. We have jokey times sometimes with staff. There is quite a bit of camaraderie. It's like also things that we have done like when we built a snowman.'* (Susan)

While there is evidence to suggest that on a number of occasions the staff have worked and engaged with the participants in a way to suit the individual, there is also a juxtaposition within the theme where some participants feel a sense of not being treated fairly, with a very real sense of hopelessness. This is explored in the next sub-theme.

b) Decreased opportunities for some

In comparison to the positive feelings and experiences above, some participants also experienced a situation where they felt there was very little to do in the way of interesting, stimulating or helpful activities, as explained by Susan and Mabel:

*'I know the activities are not happening because our OT has been off, but I would like to see more structured activities every day ... there needs to be more stimulation for people during the day ... I would say my impression is that people don't really get out that much.'* (Susan)

*'I think it would have been good to have the opportunity to update my WRAP in sort of a WRAP atmosphere, because I found that I did a course in the community and it wasn't so hot ... so I'm still searching out another WRAP group, basically but it would have been quite good to have one here I think.'* (Susan)

*'I'd like to see, you know, people with psychiatric problems, being able to go to the countryside or to the seaside or work in a garden centre or in a zoo or, you know ...*

*or where they could go and get their heads together, you know, without having to go into hospital and that, you know.'* (Mabel)

In addition to this, there is a sense that having less to do and fewer opportunities to engage is an accepted norm:

*'I just keep myself to myself you know. You do when you are ill, don't you? You close everything, you don't want to face anything.'* (Frank)

*'I pretty much kept myself to myself, that's about it. I didn't really join in any of the activities. I just used to go shopping once every couple of weeks and see my mum and dad. That's about it really.'* (Mark)

While some expressed active disengagement in the rehabilitation process (Frank), others were 'allowed' to 'opt out' of the rehabilitation process as opportunities for engagement were not actively pursued by staff:

*'It's just nice to be somewhere with a roof over your head, you know ... gives you a bed to sleep in rather than be outside on the verge, in the street you know.'* (Frank)

*'I like the idea that the cleaners come and tidy the room up and everything, clean everything up. My room is normally tidy anyway but they mop and clean the floor - you do not have to do it yourself. They do my shopping and that. We've done shopping and so on, although I only went once. I'm supposed to go weekly ... but I eat at mum's anyway, so I won't bother shopping or cooking. We are looked after here and our needs are met, whatever they may be.'* (Mohammad)

Engagement is always going to be a challenge for clients and staff in a rehabilitation unit, by the very nature of the requirement for clients to be there. However, this sub-theme indicates an element of passivity in regard to the promotion of meaningful engagement and an acceptance of disengagement when it occurs.

#### 5.2.3.1 Summary of the balance of getting it right

While a balance is always to be found between engagement in activity and rest, this section has again presented two opposing views, sometimes by the same participants, about the balance of engagement opportunities and how participants feel about the support they have received to engage. On the one hand it is felt that the staff have provided an atmosphere and experience that feels hopeful, helpful and engaging, while on the other side there is a sense that there is little to do and an acceptance of this. A question is raised however as to how much the participants might have engaged and made the best of the opportunities presented to them had staff facilitated engagement in a way that appealed to all, not just some of the participants.

#### 5.2.4 Summary of Phase 2

While the range of skills participants acquired and the activities they engaged in are not unexpected, what emerges is how important it is for people to feel accepted - be that within the rehabilitation unit feeling they are being treated with fairness, or within the community where they will be moving on to. There is recognition that mental wellness and the ability to attend to domestic chores is paramount for successful community living.

The attitude of staff was felt to be influential in the participants' experience of rehabilitation and where it had a positive effect, the participants report a happy, hopeful and engaging experience. Where the experience was less positive, participants describe disengagement - either because they perceived there was nothing interesting and stimulating to do, they had shut down mentally, or disengagement was an accepted state for some. This may or may not have contributed to some participants feeling ill equipped and resigned to discharge.

#### 5.3 Section 2 - Phase 3 interviews

Phase 3 was the smallest phase with just six participants completing an interview at follow-up. Five of the six interviews were conducted in the participant's own home. Jason chose to be interviewed at a local day centre on a day that he normally attended. The interviews occurred between three months and five months post-discharge and on average lasted 25 minutes, ranging from 9 – 41 minutes. Details of the participants involved in Phase 3 are given in Table 5.2 below.

Table 5.2 *Overview of participants in Phase 3 data collection*

	Data collection tools		
	IV	AMPS	QOL
Marco	x	x	x
Frank	x	x	x
Jason	x	x	x
Nigel	x	x	x
Mabel	x	x	x
Mark			x
Rita			x
Susan	x		x

The thematic analysis of the phase 3 interviews elicited three themes with corresponding sub-themes (Figure 5.5)



Figure 5.5: The themes and sub-themes that emerged from phase 3 interviews

### 5.3.1 Maintaining wellness

This first theme of maintaining wellness highlights some of the subtle changes the participants made in relation to keeping well. In the theme redefining a meaning of life which was identified at phase 2 (Figure 5.2), the participants identified a number of building blocks contributing to redefining a life for themselves. In this theme, those foundations have been built on and further established. This theme is presented as a triangle, with each point metaphorically linked to maintaining wellness, viewed as key components to keeping well (Figure 5.6).

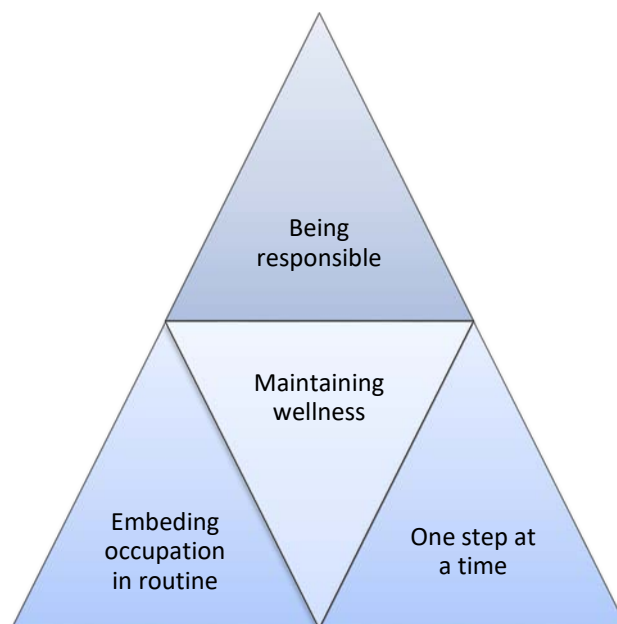


Figure 5.6: Maintaining wellness

a) Embedding occupation in routine

The first sub-theme of embedding occupation in routine was identified by five participants. It was accepted that keeping a weekly routine, with regular events and occupations scheduled, was something that helped keep them well. A routine was something identified by the participants as being absent in phase 1 and something they had worked on at phase 2. Three participants identified exercise as a key component of their routine:

*'There's gym today and fitness training at (local school) ... Tuesday it's the men's group ... Wednesday it's shopping and the gym... Thursday its photography, and Friday its gym again ... and Saturday I walk into town, maybe go to the pub or something.'* (Jason)

*'We go for a walk around the common, we pop into (the community mental health team base) for a cup of coffee. The gym is Mondays and Thursdays.'* (Nigel)

*'Activity, particularly exercise, is key for my mood.'* (Susan)

Although Marco and Mabel did not identify exercise as part of their routine, they both imply that routine and having something scheduled to do is important for their wellness. Marco is attending English lessons whereas Mabel has weekly activities which revolve around her home and family:

*'It is twice a week, two hours per time, Mondays and Wednesdays ... then I have homework, so it keeps me busy and interested in this language. English is the language I really like, still I am not able to reach the standard I would like to, that's why I joined the course ... and I like the company of my class mates.'* (Marco)

*'Well I do the place over on a Monday and then on a Thursday I do go shopping and that, and on a Friday I do my washing and that, and Saturday or Sunday I go to church, yes. Tuesday or Wednesday I go to Robert House.'* (Mabel)

While most participants were able to identify that they had a range of weekly occupations embedded within their routines, only Susan made an explicit link between routine, activities and maintaining her wellness - the others would appear to be enjoying what they are doing:

*'No walking or no swimming or nothing I become back to being a vegetable, essentially, mentally. It's like coming out of a coma, and it is key. I always feel much better after a swim.'* (Susan)

Frank on the other hand described a lack of routine, and being occupationally deprived, with nothing to do:

*'[I] just lay down basically, I don't do ... I just walk around the town, I don't do too much.'* (Frank)

## b) Being responsible

Developing and maintaining personal responsibility for their medication, sleep and exercise was identified by four of the six participants. Nigel, like the others, was serious about being responsible, but for him the focus was on his medication and not abusing or risking his newly found freedom:

*'I was on a therapeutic level of drugs ... the way I think of it, I still need the tablets so that is important, I take them religiously. It's a big responsibility because (name of medication) are on a register ... (I am) looking after (my) money, obviously not having takeaways every bloody night (and) I still haven't drunk any alcohol for a long time ... (it) gets better and better and better and better. As it gets better and better, more responsibility comes along.'* (Nigel)

Similarly, Marco and Jason demonstrated their personal responsibility to maintain their wellness:

*'After a certain period the responsibility lies with you ... so now I am getting my own daily medication, as they teach me while I was there.'* (Marco)

*'It is going to bed on time and getting up early. Doing the stuff you've got to do.'* (Jason)

On the other hand, Susan identified that her ability to be responsible and exercise control as still variable, and could depend on how her day was going:

*'I've decreased the amount of money I spend on scratch cards and I've got that under control more or less. Although the last sort of three days have been a bit of a nightmare, I spent more money than I would have liked, there have been days though in the last week when I think I bought nothing, none at all.'* (Susan)

Given this variability, Susan acknowledges that part of maintaining her wellness is to recognise it is not always easy to exercise control, but it is important to be easy on herself:

*'I've realised that through not judging other people I don't judge myself so harshly anymore, and I don't beat myself up as much.'* (Susan)

Being responsible for themselves in relation to medication, sleep and/or their finances was a theme identified by most of the participants. Susan identified in addition to this that being kind to herself and not judging herself too harshly was also a positive. This is linked to the next sub-theme of one step at a time.

## c) One step at a time

This third sub-theme is entitled 'one step at a time'. While it emphasises a level of independence, determination and self-control required to maintain successful community living, it also gives a strong message that rehabilitation continues outside of the rehabilitation

unit and that recovery takes time. Susan, Marco and Nigel present individual accounts of what one thing at a time means for them:

*'I am beginning to learn to paddle my own canoe. I am getting better at my own company. I am learning to pace myself and I am asking myself, checking in and saying "Am I doing too much, am I doing too little?" (Susan)*

*'Right now I am doing my course in English so I will look for a job later on, hopefully I will have my certificate of learning in English from the exams and hopefully I will be able to look for a job.'* (Marco)

*'I went (to the rehabilitation unit), I needed that step, it was right for me. The right time to go, the right time to leave ... a very important stepping stone. I have not run before I can walk ... I am not jumping in both feet first, you know ... I don't want to run before I can walk.'* (Nigel)

For Susan, Marco and Nigel there is a definite sense that things take time, need to be done in order, and to rush things could have negative consequences.

#### 5.3.1.1 Summary of maintaining wellness

Maintaining wellness is a strong theme. It is made up of three key strands which highlight the importance of keeping an occupation focused routine, being personally responsible for one's own actions and taking one step at a time. For participants in this phase routine was important, and for three of this six the routine included exercise. Being responsible encompassed medication, sleep and financial management, however there was an awareness amongst the participants that rehabilitation and recovery is a slow and continuing process, and not a process to be rushed if wellness is to be maintained.

#### 5.3.2 Being respectful

Self-respect and the respect afforded to others is not a given, but something that grows and develops over time. Respect is demonstrated by thoughtful and considered words and actions showing an appreciation of the person's situation. Self-respect is about being firm but gentle with oneself, not being overly critical while at the same time recognising achievements. Respect for other people is linked to honesty, trust and reliability - we only respect those who we believe have acted with sincerity and authenticity.

Self-respect can be damaged as a consequence of mental illness, so too can a person's ability to respect others. Both take time to rebuild, and this theme highlights some of the factors which participants identified to help rebuild their own self-respect and how they demonstrated respect for others. This theme has two sub-themes and is represented as an



equation, signifying the relationship between the sub-themes in understanding the impact on respect (Figure 5.7).

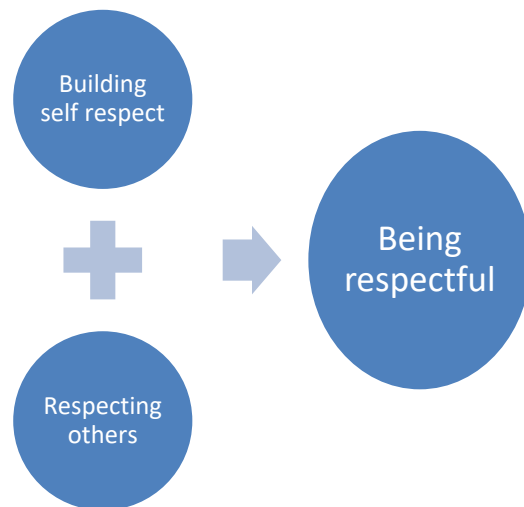


Figure 5.7 Being respectful

a) Building self-respect

Self-respect is multi-faceted and depends on many variables, it is a component of a positive self-identify. However, as Marco and Susan highlight, gaining self-respect requires a significant amount of resolve and determination to overcome self-stigmatisation of oneself and disrespect from others.

*'Mainly I would like to be a warehouse assistant, but that is not easy to find in my situation - I will accept some easy job. I study Economics and Commerce in (home country), but my English is not very good and the rules are different, so I have no chance to work as a clerk or something like that, so I will have to accept some other kind of job.'* (Marco)

*'I go to a little shop in Asda, and they only charge £20 for back, neck and shoulders. Bit noisy but she's very good. You can hear all the tills and everything but the actual massage itself is quite good. I am looking for somewhere else, but at the moment obviously that is quite good for half an hour and it relaxes me totally.'* (Susan)

Despite the challenges to regaining self-respect, five participants at this phase identified a positive shift. Mabel was proud of how she handled living on her own for the first time in her life:

*'Well I'm really settled in, yes indeed, you know it took a couple of days and that, but I went straight from (the rehabilitation unit), I didn't have any sleep-overs like some of the other girls had. I went straight from (the rehabilitation unit) to here and I settled in straight away.'* (Mabel)

For Frank, who had previously lost his home, the re-emergence of self-respect came the fact he now had a flat to call his own:

*'It is nice to go to bed at night and know you have your own independence – when you go to bed it's a good feeling you know.'* (Frank)

Nigel and Susan's self-respect is evident in their sense of achievement and the value that they placed on their physical health and mental wellbeing:

*'I have lost some weight. When I go out, I always try to do a brisk walk.'* (Nigel)

*'I have started to treat myself better, like pamper myself more. I have been for a massage twice - back, neck and shoulders - which is really relaxing. I've made it a kind of little promise that on a Tuesday when I do aqua fit I will have a massage afterwards.'* (Susan)

In addition to an internal sense of achievement described by participants above, Marco's had gained self-respect and identity from praise and recognition from an external source:

*'My life now is very good, I am very happy with my independence in the flat and with my English course. The teacher there tell me that my writing is not to bad, so I am very happy, they praise me, they say I am not so bad ...'* (Marco)

Building renewed self-respect is a strong theme at phase 3. Five out of the six participants interviewed identified aspects of their lives they felt proud and pleased about. However, there was an acknowledgement that this takes time and one has to commit to investing in oneself and learning to respect others.

#### b) Respecting others

The sub-theme of 'respecting others' focuses on where participants have felt strong enough in themselves to take a step back and evaluate their relationships with others. Marco articulates this well, in respect of being a good neighbour and fitting into this new block of flats:

*'I regain my quietness, my self-esteem and am more respectful of the others.'*  
(Marco)

Susan demonstrated her ability to respect others by giving to others, and feeling comfortable in the giving role:

*'I feel that I've been generally more supportive in my volunteering role. I've been able to stand back from people a bit and I've also been able to communicate effectively with people so that we've got like a mentor.'* (Susan)

Similarly, Mabel appreciates time alone and with others:

*'Well you know I value friendships more and that, and being happy to be by oneself and that and then happy to be with other people.'* (Mabel)

While respecting others was identified by three out of six participants, there was a commonality about putting the needs of others above their own and valuing their company. Respecting others could only come after a person respects him or herself, so the fact that fewer participants identified with this highlights the individuality of their journeys.

#### 5.3.2.1 Summary of being respectful

This theme identified that five out of six participants were starting to develop a renewed sense of self-respect, albeit facing challenges. This was evidenced by each of them identifying a small, often insignificant, event such as having their own bed to sleep in or losing some weight - but pride was evident in their words. There was also a very definite sense of participants reflecting on their relationships with others, appreciating the needs of others, and expressing how they are starting to value and respect other people, and play a role in other people's lives.

#### 5.3.3 Some things are not quite right

This final theme in phase 3 draws together areas where five of the six participants described things as not being quite right - not being quite as they had hoped, anticipated or expected. For some, this was a retrospective view on what it was like to spend time in the rehabilitation unit, for others it was a disappointed realisation that expectations of living in the community had not materialised. This theme is represented as a downwards arrow to acknowledge aspects of the participants' lives that were not quite right, and the potential negative effect it might have on rehabilitation (Figure 5.8).

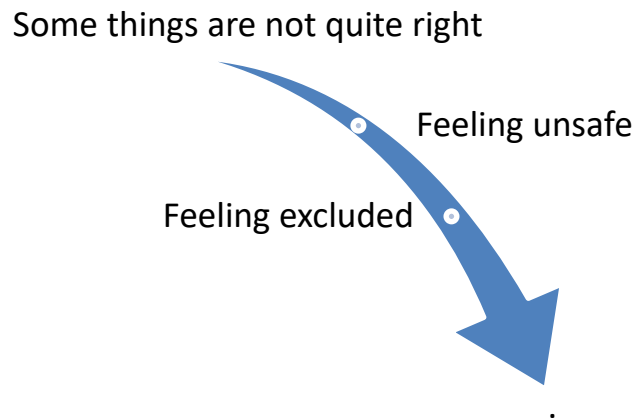


Figure 5.8: Some things are not quite right

a) Feeling unsafe

This sub-theme is essentially a reflection back on the participant's time in rehabilitation. During their time at the unit, two participants experienced feelings of disrespect and vulnerability. Susan talks about the general attitude of support, with reference to the team as a whole as well as individual staff, whereas Jason referred to the temptation of illegal drugs:

*'She would do things, like she'd come out of the office and she'd say, "Where's your melon catcher?" i.e. bra, right? ... when I tried to talk the psychiatrist about my abuse, she just accused me of being negative. And people would just walk into my room, they wouldn't knock, they'd walk in. I felt walked all over there. And I felt unsupported generally.'* (Susan)

*'It was just something that you could fall for. You could ... every chance you take is always ... just every chance you take the closer in reach you become to touching or smoking drugs. It's like vulnerable, it's like a bit vulnerable again, you know.'* (Jason)

While this was a reflection on being in the unit, three to six months earlier, the memories of unhappy times are strong and visual. It is a reminder of how both the staff and the environment can impact on the recovery and rehabilitation of individuals.

b) Feeling excluded

This second sub-theme identifies that the majority of participants experienced themselves as being different - to some extent separated, excluded from others, despite living in the community and out of a hospital setting. This has some similarities with the earlier theme in phase 1 (a sense of belonging 4.6.4). Jason and Marco express the stigma attached to their illness:

*'Where I am now (I) should I think myself lucky ... not vulnerable but ... like if I was invited round to someone's house, you know, I am just to say no, you know, because of circumstances. Because I am a mental health patient.'* (Jason)

*'I was interested in a partner, but still it is not very easy to find one. I am not working, I am 51, and it is not easy to find a person for a psychiatric patient. (I am) ten years single, so I am able to live alone. It is not nice, but still I am able to run my life.'* (Marco)

Frank lives alone in a council flat and describes with a sense of sadness how he is excluded from any enjoyment in life:

*'(I) just laid down basically, I don't do ... I just walk around the town, I don't do too much ... well there is so much to do, sort of thing really - cleaning, keeping the payments up, and if you are not working it's really hard.'* (Frank)

While Mabel does have family locally with whom she has regular contact, she was not invited to attend a major family holiday:

*'I'd love to go to Lourdes to the Holy Shrine if at all possible, to go with the Diocese of X; my brother, his wife and their family and her two brothers and their families went on my brother's father-in-law's 80<sup>th</sup> birthday in the summer, they went to Lourdes.'* (Mabel)

Despite some very obvious positive aspects of living in the community, exclusion through choice was evident for four of the six participants. Self-exclusion because of stigma was present for two participants, self-exclusion because of finances and family exclusion accounted for the others.

#### 5.3.3.1 Summary of some things are not quite right

The final theme of phase 3 concludes with again two opposing experiences. On one hand the experience of rehabilitation at times left the participant feeling unsafe. These negative feelings continued into the community where the stigma of mental illness led to participants feeling excluded with a sense that life was passing them by. On the other hand, strength and determination come through, with participants striving to make the best of the situation they found themselves in.

### 5.4 Summary of phase 3

Three themes emerged from the analysis of phase 3 interviews: 'maintaining wellness', 'being respectful' and 'some things are not quite right'. The themes of maintaining wellness and being respectful build on and further develop the building blocks identified by

participants in phase 2. However, in phase 3 this moved beyond just doing what works and developing a life, to doing what is meaningful and has value. The participants in this phase talk about maintaining their own wellness through taking personal responsibility, and developing self-respect through personal achievement, developing respecting of others through being with others in need and giving their time.

Although there is evidence of a shift in self-belief for the participants, there was also a definite feeling for the majority of participants that somethings were not quite as right as they could be. Susan and Jason felt, looking back on their experience in rehabilitation, that they actually felt quite unsafe in the rehabilitation unit. Marco, Frank and Mabel felt and continued to feel excluded and different from others around them. Nevertheless there was resilience as participants strove to make the best of the situation they found themselves in.

### **5.5 Chapter summary**

Chapter Five has presented the results of phase 2 and phase 3 thematic analysis. While the themes reflect the participants' journey through rehabilitation, they also add awareness of how rehabilitation is perceived by those who use the service, illuminating both positive and not so positive aspects of being in this particular unit and beyond. In terms of positive aspects, it was been possible to identify what has contributed to the participants becoming more independent in developing a new life for themselves, and becoming established in their community with newly identified habits and routines. As the participants readjust to live their lives in the community, there was an identification of the need to remain well and to maintain the respect of themselves and others.

The less positive aspects included not feeling ready to be discharged, disengagement with activities and staff, which contributed to an air of hopelessness and a sense of things not being quite right. The themes across phase 2 and 3 built on some of the themes identified in phase 1 to support the ubiquitously used concept in mental health of being 'a journey' with hope and hopelessness being central to this. The next chapter reviews the results of the Quality of Life and Assessment of Motor and Process Skill results.

### **5.6 Overall summary of thematic analysis**

The main themes to emerge from thematic analysis over three phases of this study have been presented throughout pictorially (Figures 4.1, 5.2 and 5.5). This final section presents an overall summary of the experiences to encapsulate the experience of rehabilitation over

time and describe the areas of personal change explored and acknowledged by the participants.

While the themes at each phase are different, there are some commonalities that thread across all three phases, not least in some of the dichotomies that have been presented. This final representation of themes across the three phases (Figure 5.9) summarises the participant's view of rehabilitation, with a backdrop of fluctuating hope and hopelessness:

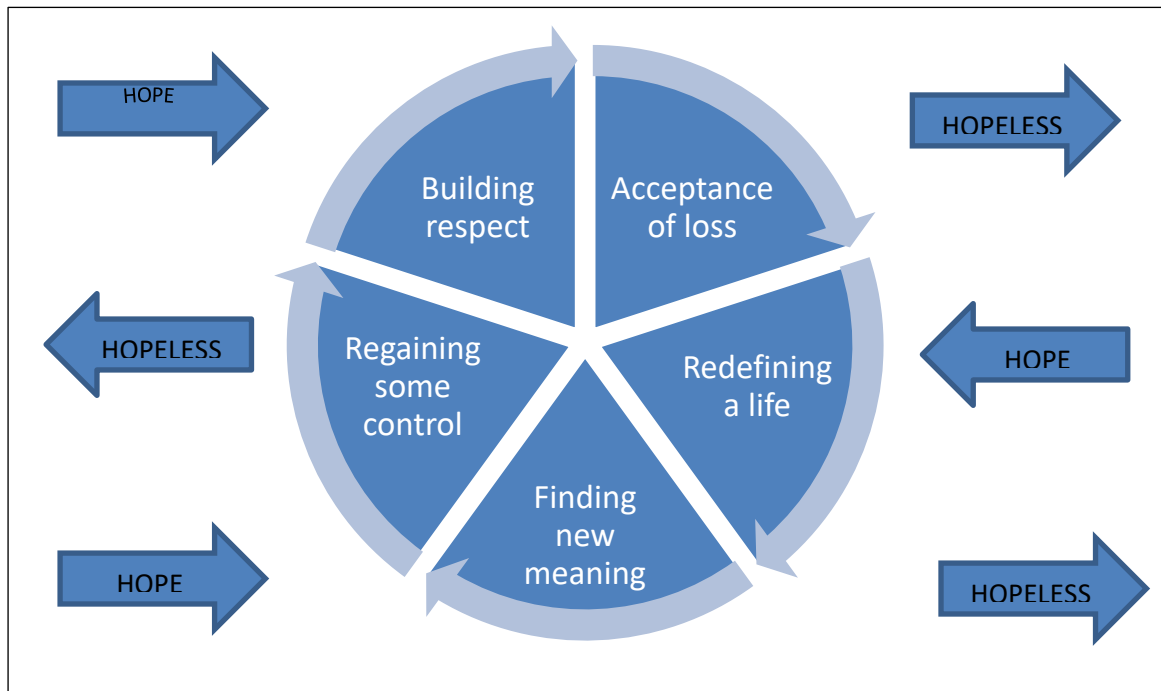


Figure 5.9: Participant's view of a rehabilitation journey

While the focus of this study has been very much the individual's journey, the commonalities of accepting ongoing losses, striving to redefine a new life - finding meaning and ultimately building respect are highlighted as being particularly relevant to a recovery focused rehabilitation. The ebb and flow of hope symbolises the inconsistency of it, as experienced by different individuals over time, and highlights the ongoing importance of finding meaning through an individual's rehabilitation process.

The next chapter presents the individual findings of the Assessment and Motor Process Skills.

## **Chapter Six – Findings (3)**

### **Descriptive results, results of the Lancashire Quality of Life Profile and Assessment of Motor and Process**

#### **6.1 Introduction**

This chapter commences with an overview of descriptive demographic data and a brief summary of the group changes in relation to Quality of Life (QoL) (Oliver, Huxley et al. 1997) Assessment of Motor and Process Skills (AMPS) (Fisher and Bray Jones, 2012). As the main focus in this study is on individual change, the chapter then presents individual changes for participants who have a complete set of comparable data across three phases (Marco, Frank, Jason, Nigel and Mabel). Data is then presented for Mark, Rita, Susan, Steve and Mohammad who have two sets of comparable data.

Results are presented individually for each of the 10 participants in a subsection under their name heading. Change between time one – admission, and time two - discharge ( $t^1/t^2$ ) and change between admission and time three - follow-up ( $t^1/t^3$ ) are reported where available. The number of participants who completed the QoL and AMPS tools varied across the phases (Table 6.1 and 6.2).

The chapter concludes with a presentation of five case studies for the participants who completed all phases of data collection (Marco, Frank, Jason, Nigel and Mabel). The case studies highlight for each individual the experience of rehabilitation, bringing together their personal narratives with changes in occupational functioning and quality of life.

#### **6.2 Demographic findings**

From descriptive analysis of demographic information all participants in the study except one were found to have primary diagnosis of a psychotic type illness, including schizophrenia and bipolar disorder. On average, the participants had a 12 year history of using mental health services, ranging from 6 months to 25 years. The women in the study had on average used services for 16 ½ years prior to their move to rehabilitation, while the figure for men was just over 10 years.

Of the 10 participants who completed phases 1 and 2 and had plans for discharge, the mean time residing in the unit was 41 weeks with a range from 7 to 65 weeks. In terms of discharge plans, six participants (60%) had plans to move, or had already moved, into a



housing association or privately rented home with various levels of daytime support. One participant moved back to live with his mother and three participants moved or were planning to move into sheltered accommodation, two of which had 24 hour support, while the other had staff present during the day and an on call facility at night.

The mean age of all participants in the study at the time of admission was 40 years, ranging from 22 to 56 years. The average age of the women at admission was 42 years, while the average age of the men was 39 years. The mean age at admission, the age of leaving full time education, and age at the onset of illness increased in each of the two subsequent phases. For example, the mean age of participants leaving school at phase 1 was 16 ½ years, rising to a mean age of 18 at phase 3. Similarly, the mean age of when participants first became unwell increased across all three phases from 28 years at phase 1 to 31 and 38 years for those who completed phases 2 and 3 respectively (Table 6.1)

Table 6.1: *The mean age of participants*

	t <sup>1</sup> (n=19)		t <sup>2</sup> (n=10)		t <sup>3</sup> (n=5)	
	Mean	Range	Mean	Range	Mean	Range
Age of leaving school	16.5	12- 25	17.5	14-25	18	15-24
Age of first episode of mental illness	28	17-53	31	18-53	38	19-53
Age admitted to rehab	40	22-56	40	23 -56	48	33-56

At admission, 12 participants (63%) reported some sort of physical health problem, this is compared to two participants (40%) at phase 3. At phase 1 nine out of the 19 participants (47%) were on a section of the Mental Health Act, two were moved to the rehabilitation unit under Section 37/41 of the Mental Health Act<sup>10</sup>, seven were on Section 3 of the Mental Health Act<sup>11</sup>, the remaining 10 participants were informal<sup>12</sup>. At phase 3, of the two participants who been admitted to the unit while on section, one remained on section, but this was transferred to a community treatment order<sup>13</sup>. It is interesting to note the low prevalence of participants in a permanent relationship (two at admission, one at follow-up) and how few had children (five at phase 1, one at follow-up) (Table 6.2). The reason for participant drop out can be read in Appendix 4.1.

<sup>10</sup> Section 37/41 is part of the Mental Health Act applied to patients that the criminal courts consider should be in hospital rather than prison, and where there is a restriction order where the court deems the public to be at risk

<sup>11</sup> Section 3 is a treatment order, where the patient may be detained in hospital for treatment for up to six months

<sup>12</sup> Not detained under a Section of the Mental Health Act

<sup>13</sup> Can be recalled to hospital under the Mental Health Act at any time by law

Table 6.2: *Percentage of participants with key social and personal factors*

	<u>t<sup>1</sup> (n=19)</u>	<u>t<sup>2</sup> (n=10)</u>	<u>t<sup>3</sup> (n=5)</u>
	% yes	% yes	% yes
In a permanent relationship	10	10	20
Children	26	30	20
Physical illness	63	60	40
Section of the Mental Health Act	47 <sup>14</sup>	40 <sup>15</sup>	40 <sup>16</sup>

### 6.3 Overview of Quality of Life and the Assessment of Motor and Process Skills

The number of participants who completed the QoL and AMPS varied across the three phases. The following two tables summarise which tools each participant completed at which phase for both the QoL (Table 6.3) and the AMPS (Table 6.4). The range of AMPS tasks completed may be viewed in Appendix 6.1.

Table 6.3 *Participants who completed the Lancashire Quality of Life profile at each of the three phases*

	<u>Phase 1 (n=19)</u>		<u>Phase 2 (n=10)</u>	<u>Phase 3 (n=8)</u>
Lancashire Quality of Life Profile	Marco	Jan	Marco	Marco
	Frank	William	Frank	Frank
	Jason	Warren	Jason	Jason
	Nigel	Mick	Nigel	Nigel
	Mabel	Richard	Mabel	Mabel
	Mark	Pete	Mark	Mark
	Rita	Maria	Rita	Rita
	Steve	Michelle	Susan	Susan
	Susan	Dave	Steve	
	Mohammad		Mohammad	

Table 6.4 *Participants who completed the AMPS at each of the three phases*

	<u>Phase 1 (n=18)</u>		<u>Phase 2 (n=10)</u>	<u>Phase 3 (n=5)</u>
Assessment of Motor and Process Skills	Marco	Jan	Marco	Marco
	Frank	William	Frank	Frank
	Jason	Warren	Jason	Jason
	Nigel	Mick	Nigel	Nigel
	Mabel	Richard	Mabel	Mabel
	Mark	Pete	Mark	
	Rita	Maria	Rita	
	Steve	Michelle	Susan	
	Susan		Steve	
	Mohammad		Mohammad	

<sup>14</sup> 7 x Section 3, 2 x Section 37/41

<sup>15</sup> 1 x Section 3, 1 x Section 17 leave

<sup>16</sup> 1 x Section 3, 1x Section 37/41

## 6.4 Overview of group changes across both QoL and AMPS

While the focus of results is on individual change, it is useful to consider the results of the group to gain an overall understanding of the impact of rehabilitation on quality of life and functional performance. It is also useful to understand whether there is a collective change, and if this change is sustained in the community. Tables 6.5 and 6.6 present the summary of the QoL and AMPS results respectively.

### 6.4.1 Group quality of life changes

At  $t^1/t^2$  positive changes above the MDC threshold were noted for perceived quality of life:  $n=3$  (30%), psychological wellbeing  $n=8$  (80%), and self-esteem  $n=2$  (25%). Negative changes above the MDC threshold were noted for perceived QoL  $n=1$  (10%) and psychological wellbeing  $n=1$  (10%).

At  $t^1/t^3$  positive changes above the MDC threshold were noted for perceived quality of life  $n=2$  (25%), psychological wellbeing  $n=4$  (50%), and self-esteem  $n=2$  (25%). Negative changes above the MDC threshold were noted for perceived QoL  $n=1$  (12.5%), psychological wellbeing  $n=1$  (25%), and self-esteem  $n=1$  (25%).

*Table 6.5:* Summary of MDC across perceived QoL, psychological wellbeing and self-esteem

	Perceived QoL		Psychological wellbeing		Self-esteem	
	n=10	n=8	n=10	n=8	n=10	n=8
	$t^1/t^2$	$t^1/t^3$	$t^1/t^2$	$t^1/t^3$	$t^1/t^2$	$t^1/t^3$
Marco	Yes (+)	Yes (+)	Yes (+)	No	No	No
Frank	No	No	Yes (+)	Yes (-)	No	Yes (+)
Jason	No	Yes (-)	Yes (-)	Yes (-)	No	Yes (+)
Nigel	No	No	No	Yes (+)	No	No
Mable	No	Yes (+)	Yes (+)	Yes (+)	No	No
Mark	Yes (+)	No	Yes (+)	Yes (+)	No	Yes (-)
Rita	Yes (+)	No	Yes (+)	No	No	No
Susan	No	No	Yes (+)	Yes (+)	Yes (+)	No
Steve	No	n/a	Yes (+)	n/a	No	n/a
Mohammad	Yes (-)	n/a	Yes (+)	n/a	Yes (+)	n/a
	30% (+) 10% (-)	25% (+) 12.5% (-)	80% (+) 10% (-)	50% (+) 25% (-)	20% (+)	25% (+) 12.5% (-)

### 6.4.2 Group AMPS changes

At t<sup>1</sup>/t<sup>2</sup> 20% (n=2) of the sample population demonstrated a statistically significant change in a positive direction with regards to ADL motor skill: 10% (n=1) made a statistically significant change in a negative direction with regards to ADL motor skill, 30% (n=3) made a statistically significant change in a positive direction with regards to ADL process skills.

At t<sup>1</sup>/t<sup>3</sup>, 40% (n=2) of the sample population made a significantly statistical change in a positive direction with regards to ADL motor skill, 20% (n=1) made a statistically significant change in the negative direction. One participant (20%) made a positive change at t<sup>1</sup>/t<sup>2</sup> and maintained this change at t<sup>3</sup>. 40% (n=2) demonstrated a statistically significant change in a positive direction with regards to ADL process skill. One participant (20%) made a positive change at t<sup>1</sup>/t<sup>2</sup> and maintained this change at t<sup>3</sup>.

Table 6.6: Summary of statistically significant change across ADL motor and process skills

	ADL motor		ADL process	
	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> / t <sup>3</sup>
Marco	No	Yes	No	No
Frank	No	No	No	Yes
Jason	No	No	No	No
Nigel	No	Yes (-)	No	No
Mable	Yes	Yes	Yes	Yes
Mark	Yes		Yes	
Rita	No		No	
Susan	No		No	
Steve	Yes (-)		No	
Mohammad	no		Yes	
	20% (+)	40% (+)	30% (+)	40% (+)
	10% (-)	20%(-)		

Group comparison is of some interest as discussed above. Given the small population sample and the focus on individual change, the rest of this chapter presents detailed QoL and AMPS findings for each of the 10 participants with comparative data to highlight individual meaningful change.

### 6.5 Individual QoL and AMPS results

The QoL results are given below, where mean scores with the exception of the subscale 'work' (section 3.6.3) are presented for each test phase (t<sup>1</sup>, t<sup>2</sup> and t<sup>3</sup>)<sup>17</sup>. The MDC threshold, calculated in accordance with the manual (Donoghue and Stokes, 2009, section 3.6.3.1), allows

<sup>17</sup> Work was not included on the advice of the authors due to insufficient information available at phase 1(Oliver, Huxley et al. 1997)

changes from t<sup>1</sup> / t<sup>2</sup> and t<sup>1</sup>/ t<sup>3</sup> to be readily observed. The Life Satisfaction Score (LSS) subscales are then combined to give an overall perceived quality of life, a psychological wellbeing, and a self-esteem score (Thornicroft and et al, 2006).

The AMPS scores are initially presented as a table for each of the test phases (t<sup>1</sup>, t<sup>2</sup> and t<sup>3</sup>), presenting the logit scores for each of the motor and process scales and show whether the participant is above or below the competency cut-off (criterion-referenced). Any changes between each test phase are highlighted and identified as either observable (a change of at least 0.3 logits) or statistically significant (a change of at least 0.5 logits on motor and 0.4 logits on process). The table also presents norm-referenced data, and shows whether the participant is functioning within the expected range of an aged matched well person (Z score).

Two graphic reports are also presented for each participant, providing a visual representation of the participants' motor and process ability measures and where they are relative to an age-matched normative sample.

## **6.6 Marco**

Table 6.7 below summarises Marco's QoL scores across all three test phases and demonstrates Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

*Table 6.7: Summary of Marco's QoL across the test phases*

LSS Subscales	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>	Change from t <sup>1</sup> /t <sup>3</sup>
Leisure	5.00	6.00	6.33	1.55	1	1.33
Religion	7.00	6.00	6.00	1.86	-1	-1
Finances	3.00	6.00	6.00	2.02	3**	3**
Living Situation	4.43	4.71	5.71	1.41	0.28	1.28
Safety	4.00	4.50	6.50	2.05	0.5	2.5**
Family relations	2.50	3.50	4.50	2.02	1	2
Social relations	2.00	3.00	4.00	1.86	1	2**
Health	5.33	5.67	6.00	1.55	0.34	0.67
Perceived QoL	3	5	4.5	0.80	2.00**	1.5**
Psychological wellbeing	-0.20	0.40	0.20	0.44	0.6**	0.4
Self-esteem	0.60	0.80	1.00	0.47	0.20	0.40

\*\* denotes a change above the minimum detectable change threshold

### 6.6.1 Change from t<sup>1</sup>/t<sup>2</sup>

Marco reported change, above the MDC threshold on the LSS subscale of finances, and this was reflected in his overall perceived quality of life with a positive change in perceived QoL. There was a change above the MDC threshold in a positive direction for psychological wellbeing.

### 6.6.2 Change from t<sup>1</sup>/t<sup>3</sup>

Between t<sup>1</sup>/t<sup>3</sup> Marco's self-reported QoL satisfaction scores demonstrated detectable change (above MDC threshold) on the finance, safety and social relations LLS subscales, with a corresponding positive change in perceived QoL.

Table 6.8 summarises Marco's AMPS results across all three test phases and highlights any observable or statistically significant changes in his ADL motor and process ability measures. It also shows where his ADL motor and process ability is comparable to an age-matched normative (Z score) sample. Graphic reports Figure 6.1a and 6.1.b below provide a visual representation of Marcos ADL motor and process ability measures compared to an age-matched normative sample.

Table 6.8: *Change in Marco's ADL motor and process logits across the test phases*

ADL ability measure	ADL motor						ADL process					
	Competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>	Competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>
		1.5	1.9	2.4	0.4	0.9		1.4	1.7	1.7	0.3	0.3
		<u>Observable change</u>					<u>Observable change</u>					
		no      yes					No      no					
		<u>Statistically significant change</u>					<u>Statistically significant change</u>					
		no      yes					No      no					
Norm reference (Z score)	Range † 3.58 – 1.74 Mean 2.66 <sup>18</sup>	-2.0	-1.3	0.3			Range† 2.68 -1.08 Mean 1.88	-0.3	0.3	0.3		

† Range of scores for a well person of the same age

<sup>18</sup> Fisher and Jones 2010 page 15-43 Mean ADL Motor and Process Ability Measures (logits) for the Well Person in an AMPS Standardisation Sample (n =12,773)

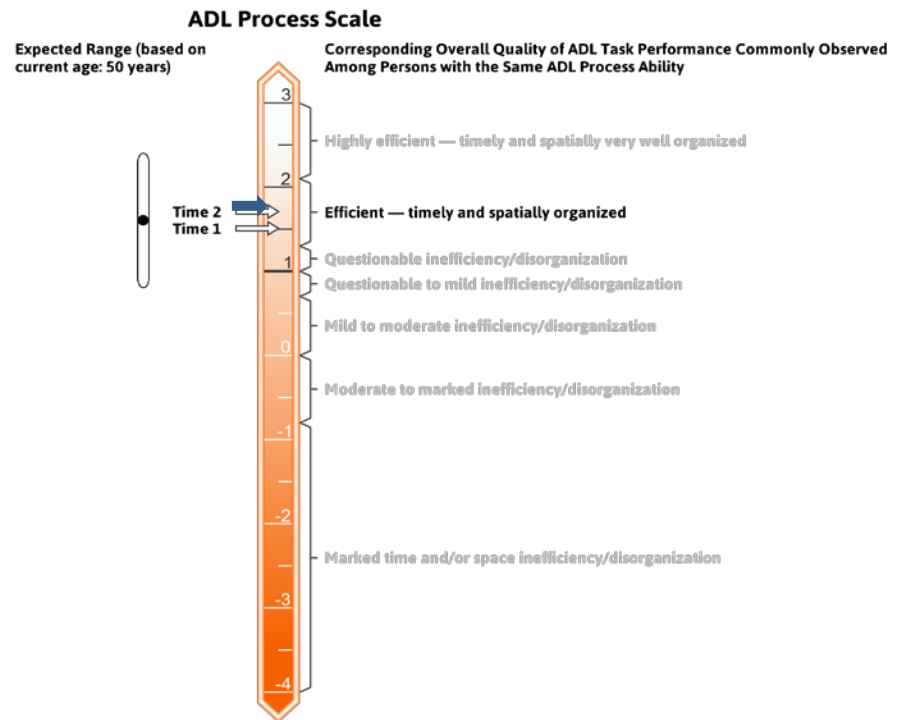
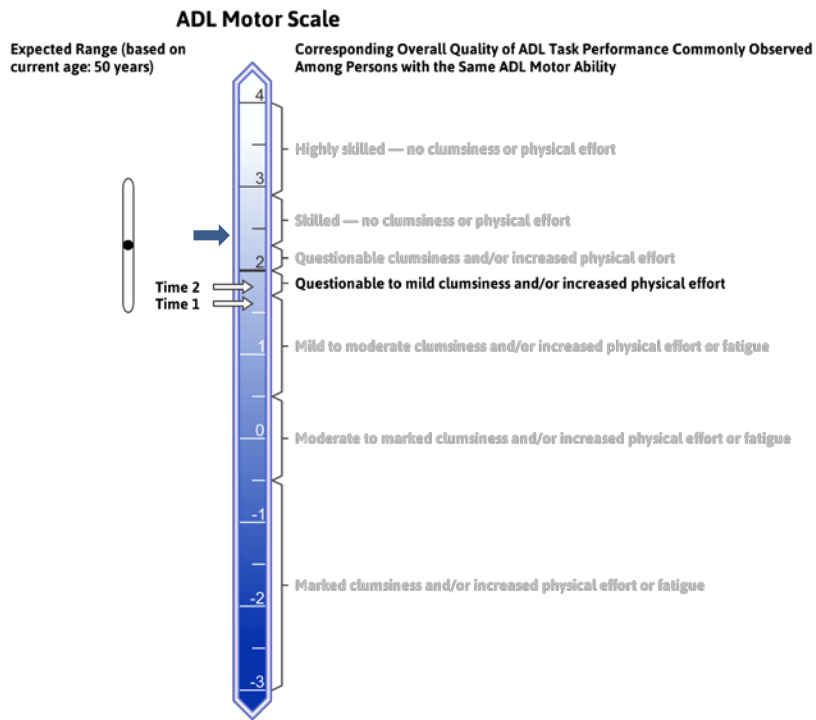
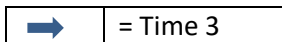


Figure 6.1.a: Marco's ADL motor scale across the three test phases

Figure 6.1.b: Marco's ADL process scale across the three test phases

Key:



### 6.6.3 ADL motor

Marco's motor ability measure was below the competence cut-off of 2.00 logits at admission and discharge, indicating that he was experiencing some clumsiness and physical effort. His motor ability measure increased to above the competence cut-off at follow-up. The first change (increase of 0.4 logits) was neither observable nor statistically significant. The second increase of 0.9 logits between test phase 1 and test phase 3 was observable and significant.

When compared to an age-matched normative sample, Marco's overall change of 0.9 logits moved him from -2.0 SD below the mean to +0.3 SD above the mean. The observation scores on the motor scale predicted that Marco would demonstrate some clumsiness and a mild increase in physical effort but would be unlikely to need assistance when performing familiar activities of daily living.

### 6.6.4 ADL process

Marco's process ability score increased from 1.4 logits at test phase 1 to 1.7 logits at test phase 2, and remained at 1.7 logits at test phase 3, indicating that he was competent in process ability as he was above the competency cut-off of 1.00 logits. However, this change was neither observable nor statistically significant.

When compared to the age-matched normative sample Marco's ADL process ability measure was well within the range, moving to above the mean at follow-up. Observation scores on the process scale predicted that Marco would demonstrate efficient processing skills that would allow him to complete activities of daily living in a timely and organised way.



## 6.7 Frank

Table 6.9 below summarises Frank's QoL across all three test phases and highlights Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

Table 6.9: *Summary of Frank's QoL across the test phases*

LSS Subscales	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>	Change from t <sup>1</sup> /t <sup>3</sup>
Leisure	4.00	4.67	4.67	1.55	0.67	0.67
Religion	6.00	4.50	5.00	1.86	-1.50	-1.00
Finances	3.00	3.50	2.00	2.02	0.50	-1.00
Living Situation	4.43	4.71	4.29	1.41	0.28	-0.14
Safety	7.00	4.00	5.00	2.05	-3.00**	-2.00
Family relations	4.50	5.00	4.00	2.02	0.50	-0.50
Social relations	4.50	4.50	5.00	1.86	0	0.50
Health	5.00	5.00	5.00	1.55	0	0
Perceived QoL	4.80	4.49	4.37	0.80	-0.31	-0.43
Psychological wellbeing	2.00	3.50	1.50	0.44	1.50**	-0.50**
Self-esteem	-0.4	-0.8	0.2	0.47	0.40	0.60**

### 6.7.1 Change from t<sup>1</sup>/t<sup>2</sup>

Frank reported change above the MDC threshold on the safety LSS subscale. This change was in a negative direction, but was not reflected in his overall perceived quality of life. There was a detectable change above the MDC threshold for psychological wellbeing, this change was in a positive direction.

### 6.7.2 Change from t<sup>1</sup>/t<sup>3</sup>

Between t1 and t3 Frank reported change above the MDC threshold: on psychological wellbeing in a negative direction, and on self-esteem in a positive direction.

Table 6.10 below summarises Frank’s AMPS results across all three test phases and highlights any observable or statistically significant changes in his ADL motor and ADL process ability measures. It also shows his level of ADL motor and ADL process ability as compared to an age-matched normative (Z score) sample. The graphic reports (Figures 6.2a & 6.2.b) provide a visual representation of Frank’s ADL motor and process ability measures compared to an age-matched normative sample.

Table 6.10: *Change in Frank’s ADL motor and process logits across the test phases*

ADL ability measure	ADL motor					ADL process						
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>
		1.0	1.4	1.1	0.4	0.1		0.5	0.6	1.0	0.1	0.5
		<u>Observable change</u>					<u>Observable change</u>					
		yes no					no yes					
		<u>Statistically significant change</u>					<u>Statistically significant change</u>					
		no no					no yes					
Norm reference (Z Score)	Range † 3.58 – 1.74 Mean 2.66	<-3.0	-2.3	-3.0			Range† 2.68 -1.08 Mean 1.88	-2.8	-2.5	-1.5		

† Range of scores for a well person of the same age

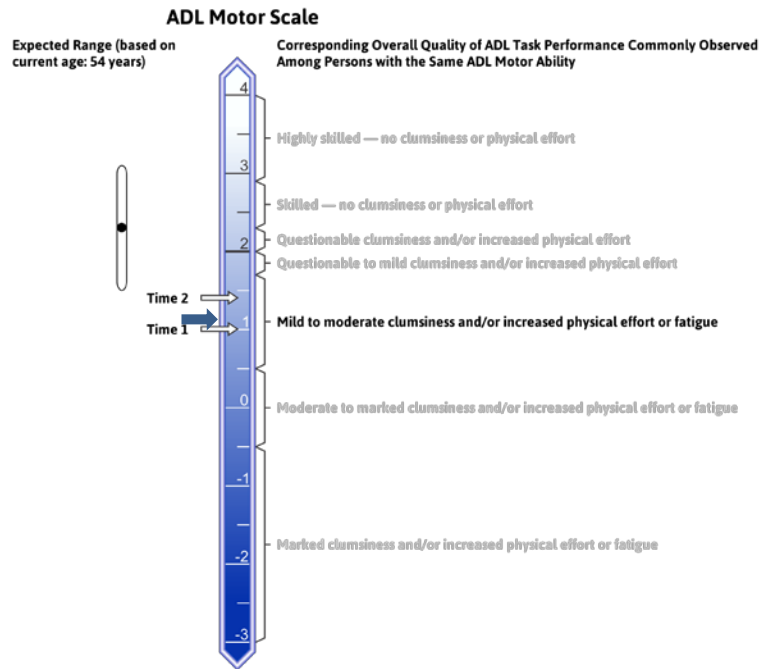


Figure 6.2a: Frank's ADL motor scale across the three test phases

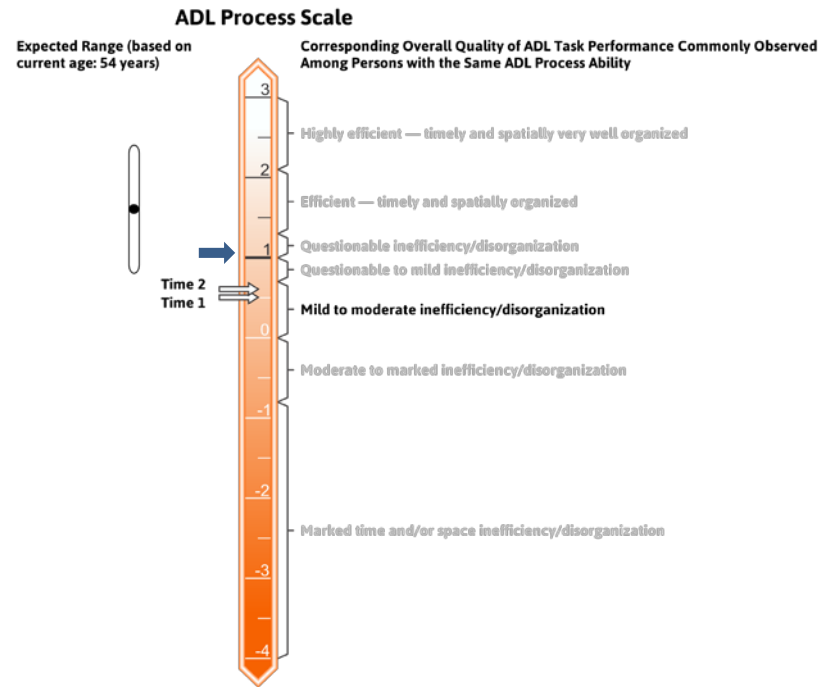
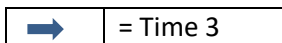


Figure 6.2.b: Frank's ADL process scale across three test phases

Key:



### 6.7.3 ADL motor

Frank's motor ability score was below the competence cut-off of 2.00 logits across all three test phases, however there was an observable change between admission ( $t^1$ ) and discharge ( $t^2$ ) of 0.4 logits, but this change was not maintained at test phase 3. There were no significant changes in Frank's ADL motor ability across the test phases.

When compared to an age-matched normative sample, Frank's motor ability of -3.0 SD at follow-up was far below what would be expected for his age and placed him in a range below 97% of the sample population. The observation scores on the motor scale predicted that Frank would demonstrate mild to moderate clumsiness with some increased physical effort or fatigue, making it difficult for him to effectively and safely carry out familiar activities of daily living.

### 6.7.4 ADL process

Frank's process ability score was below the competency cut-off at admission and discharge, increasing to the cut-off of 1.00 logit at follow-up. This increase of 0.5 logits moved Frank to the competency cut-off, and this change was both observable and statistically significant.

When Frank's process ability score was compared to the age-matched normative sample, his process ability competency, moved from -2.8 SD below the mean to -1.5 SD below the mean. This increase in ADL process ability score moved Frank from outside the range to within the range, but he remained below the mean for an aged matched normative sample.

The observation scores on the ADL process scale indicated that Frank had moved from experiencing mild to moderate inefficiency and disorganisation to questionable inefficiency and disorganisation.

## 6.8 Jason

Table 6.11 summarises Jason's QoL scores across all three test phases and highlights Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

*Table 6.11: Summary of Jason's QoL across the test phases*

Jason	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>	Change from t <sup>1</sup> /t <sup>t</sup>
Leisure	7.00	7.00	5.67	1.55	0	-1.33
Religion	6.50	6.00	4.00	1.86	-0.50	-2.50**
Finances	7.00	7.00	6.00	2.02	0	-1.00
Living situation	7.00	6.29	5.29	1.41	-0.71	-1.71**
Safety	6.00	7.00	5.50	2.05	1.00	-0.50
Family relations	7.00	7.00	4.50	2.02	0	-2.50**
Social relations	6.00	6.50	6.50	1.86	0.50	0.50
Health	7.00	6.67	5.67	1.55	-0.33	-1.33
Perceived QoL	6.69	6.68	5.39	0.80	-0.01	-1.30**
Psychological wellbeing	6.00	3.00	4.20	0.44	-3.00**	-1.80**
Self-esteem	-0.80	-1.0	0.80	0.47	-0.20	1.60**

### 6.8.1 Change from t<sup>1</sup>/t<sup>2</sup>

As illustrated in Table 6.11, Jason reported change above the MDC threshold on psychological wellbeing - this change was in a negative direction.

### 6.8.2 Change from t<sup>1</sup>/t<sup>3</sup>

Between t<sup>1</sup> and t<sup>3</sup> Jason's reported change above MDC threshold on the religion, living situation, family relations LSS subscales. All these changes were in a negative direction, and were reflected in a detectable change in his perceived QoL. There was change above the MDC threshold in his psychological wellbeing in a negative direction, and a change above the MDC threshold for self-esteem in a positive direction.

Table 6.12 summarises Jason’s AMPS results across all three test phases and highlights any observable or statistically significant changes in his ADL motor and process ability measures. It also shows where his level of ADL motor and process ability is compared to an age-matched normative (Z score) sample. The graphic reports (Figures 6.3a & 6.3.b) provide a visual representation of Jason’s ADL motor and process ability measures compared to an age-matched normative sample.

Table 6.12: *Change in Jason’s ADL motor and process logits across the test phases*

ADL ability measure	<u>ADL motor</u>					<u>ADL process</u>						
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>
		1.8	1.7	1.4	-0.1	-0.4		1.3	1.1	1.1	-0.2	-0.2
		<u>Observable change</u>					<u>Observable change</u>					
		no yes(-)					no no					
		<u>Statistically significant change</u>					<u>Statistically significant change</u>					
		no no					no no					
Norm reference (Z Score)	Range † 3.93 – 2.05 Mean 2.99	-1.5	-1.8	-2.5			Range† 3.14-1.14 Mean 2.14	-0.8	-1.3	-1.3		

† Range of scores for a well person of the same age

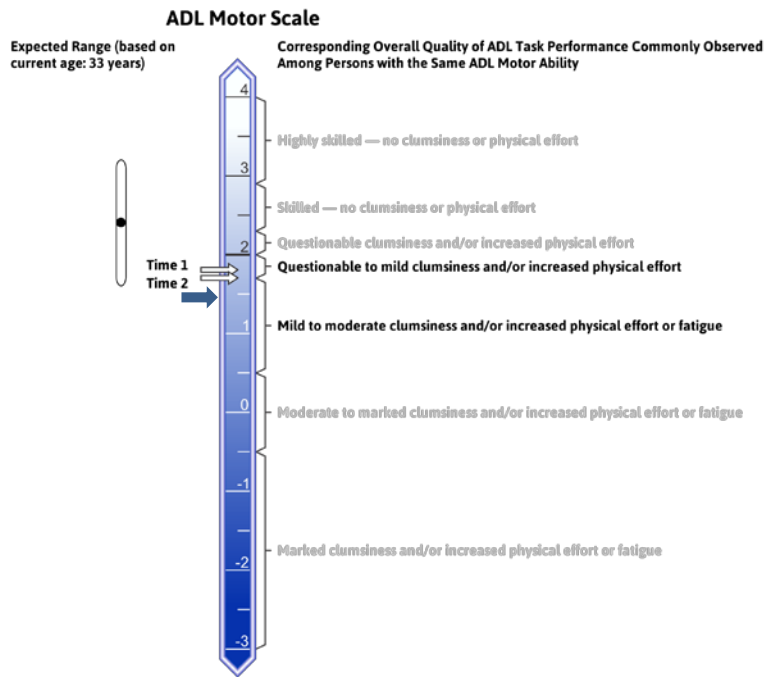


Figure 6.3a: Jason's ADL motor scale across the three test phases

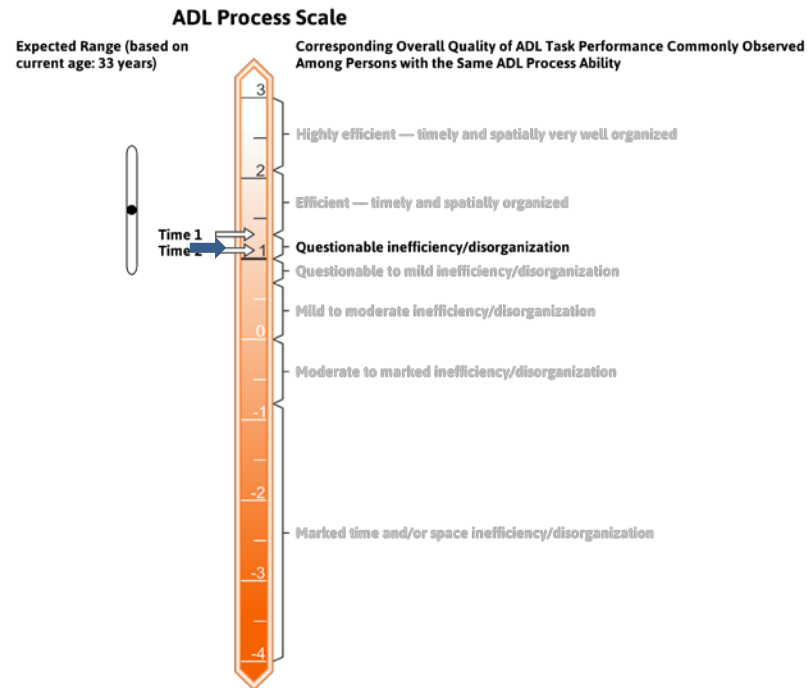
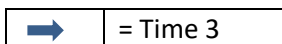


Figure 6.3b: Jason's ADL process scale across the three test phases

Key:



### 6.8.1 ADL motor

Jason's motor ability score was below the cut-off of 2.00 logits at admission and decreased at each test phase, resulting in an overall decrease of 0.4 logits. While this overall decrease was observable, it was not statically significant, but it did move Jason's ADL motor ability competence from questionable inefficiency and disorganisation to mild to moderate inefficiency and disorganisation.

When compared to an age-matched normative sample, Jason's ADL motor ability moved from -1.5 SD below the mean at admission to -2.5 SD at follow-up, meaning that his motor ability competency was far lower than would be expected of someone his age.

The observation scores on the motor scale at follow-up predicted that Jason would demonstrate mild to moderate motor ability, meaning that he would experience some difficulty when carrying out familiar activities of daily living and that he would experience a degree of increased physical effort or fatigue.

### 6.8.2 ADL process

Jason's process ability score decreased from 1.3 at admission to 1.1 logits at discharge and it remained at 1.1 logits at follow-up, meaning that he was above the competency cut-off of 1.00 logits at all test phases - he has competent ADL process skills. The decrease in score between admission and follow-up was neither observable nor statistically significant.

When compared to the age-matched normative sample, Jason's process ability moved from -0.8 SD below the mean to -1.3 SD below the mean, meaning that while he was still within the range, he was functioning less than would be expected for his age.

The observation scores on the process scale predicted that Jason would demonstrate questionable inefficiency and disorganisation in performing familiar activities of daily living.



## 6.9 Nigel

Table 6.13 summarises Nigel's QoL scores across all three test phases and highlights Minimal Detectable Change <sub>95</sub> (95% of non-genuine changes are below the MDC)

*Table 6.13: Summary of Nigel's QoL across the test phases*

LSS subscales	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>	Change from t <sup>1</sup> /t <sup>2</sup>
Leisure	4.67	6.33	6.33	1.55	1.66**	1.66**
Religion		7.00	6.00	1.86	N/A	N/A
Finances	5.00	6.00	5.50	2.02	1.00	0.50
Living Situation	4.57	4.43	5.29	1.41	-0.14	0.72
Safety	6.50	6.00	6.00	2.05	-0.50	-0.50
Family relations	6.00	7.00	6.50	2.02	1.00	0.50
Social relations	5.00	6.00	6.00	1.86	1.00	1.00
Health	6.00	6.00	6.00	1.55	0	0
Perceived QoL	5.40	6.10	5.95	0.80	0.70	0.55
Psychological wellbeing	4.50	4.50	5.00	0.44	0	0.50**
Self-esteem	-1.00	-1.00	-1.00	0.47	0	0

### 6.9.1 Change from t<sup>1</sup>/t<sup>2</sup>

Nigel reported change above the MDC threshold on the leisure subscale, but this change was not reflected in his overall perceived QoL.

### 6.9.2 Change from t<sup>1</sup>/t<sup>3</sup>

Between t<sup>1</sup> and t<sup>3</sup> Nigel reported change above the MDC threshold for leisure, but again this was not reflected in his overall perceived QoL. There was a change above the MDC threshold for psychological wellbeing.

Table 6.14 below summarises Nigel's AMPS results across all three test phases and demonstrates the observable and statistically significant changes in his ADL motor process ability measures. It also shows his level of ADL motor and process ability compared to an age-matched normative (Z score) sample. The graphic reports (Figures 6.4a & 6.4b) provide a visual representation of Nigel's ADL motor and process ability measures compared to an age-matched normative sample.

Table 6.14: *Change in Nigel's ADL motor and process logits across the test phases*

ADL ability measure	<u>ADL motor</u>						<u>ADL process</u>					
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>
		2.2	2.0	1.5	-0.2	-0.7		1.5	1.5	1.5	0.0	0.0
		<u>Observable change</u>				<u>Observable change</u>						
		no    yes(-)				no    no						
		<u>Statistically significant change</u>				<u>Statistically significant change</u>						
		no    yes(-)				no    no						
Norm reference (Z Score)	Range † 3.86 -1.90 Mean 2.88	-0.5	-1.0	-2.3			Range† 2.99 – 1.07 Mean 2.03	-0.3	-0.3	-0.3		

† Range of scores for a well person of the same age

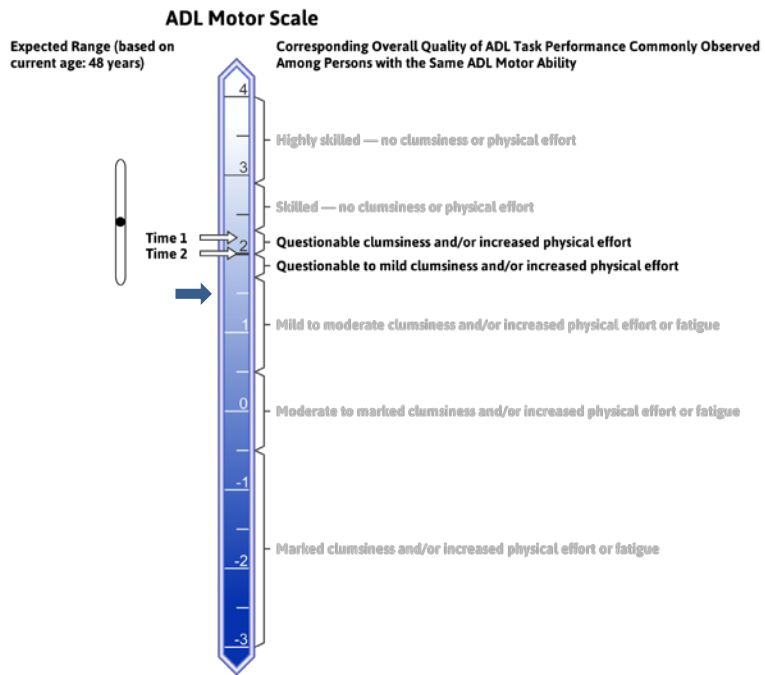


Figure 6.4a: Nigel's ADL motor scale across the three test phases

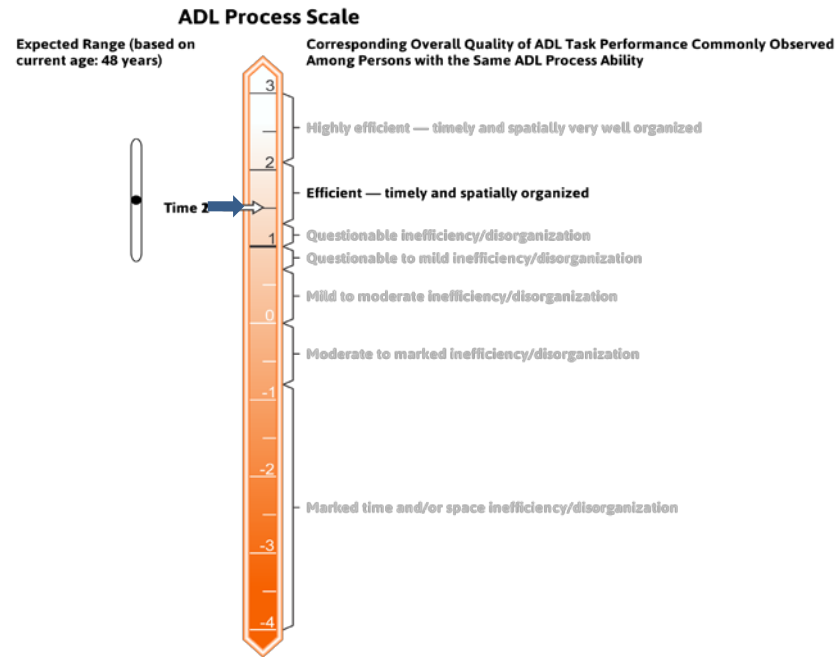
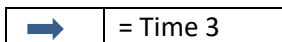


Figure 6.4b: Nigel's ADL process scale across the three test phases

Key:



### 6.9.3 ADL motor

Nigel's motor ability score was above the competency cut-off of 2.00 logit at admission, but decreased to the cut-off (2.00 logits) at discharge, to below the cut-off (1.5 logits) at follow-up. The total decrease between admission and follow-up of -0.7 logits was both an observable change and significant.

When compared to an age-matched normative sample, Nigel's overall change of -0.7 logits moved him from -0.5 SD below the mean of the age-matched normative sample at admission, to 2.3 SD below the mean at follow-up. This means throughout all test phases his ADL motor ability was less than would be expected for his age.

The observation scores on the ADL motor scale predict that Nigel would demonstrate mild clumsiness and or increased physical effort in carrying out familiar activities of daily living.

### 6.9.4 ADL process

Nigel's ADL process ability score remained the same across all three test phases. The score of 1.5 logits was above the competency cut-off of 1.00 logits, meaning that Nigel had process skills above the level of competence.

When Nigel's ADL process ability score is compared to the age-matched normative sample his process ability competency was well within the range, and therefore he was performing at a level expected for his age.

The observation scores on the process scale predict that Nigel would demonstrate, in the main, efficient and timely processing skills that would enable him to organise himself, his environment and the equipment needed to complete a task effectively.

## 6.10: Mabel

Table 6.15 below summarises Mabel's QoL scores across all three test phases and highlights Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

*Table 6:15: Summary of Mabel's QoL across the test phases*

LSS Subscales	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>	Change from t <sup>1</sup> /t <sup>3</sup>
Leisure	5.00	6.00	7.00	1.55	1.00	2.00**
Religion	5.50	4.00	7.00	1.86	-1.50	1.50
Finances	2.50	3.50	2.50	2.02	1.00	0
Living Situation	3.86	4.86	5.29	1.41	1.00	1.43**
Safety	6.50	5.50	7.00	2.05	-1.00	0.50
Family relations	6.50	6.50	6.00	2.02	0	-0.50
Social relations	5.50	5.00	6.00	1.86	-0.50	0.50
Health	3.33	5.00	4.67	1.55	1.67**	1.34
Perceived QoL	4.84	5.04	5.68	0.80	0.20	0.84**
Psychological wellbeing	1.70	4.50	5.50	0.44	2.80**	3.80**
Self-esteem	-0.60	-1.00	-0.6	0.47	-0.40	0

### 6.10.1 Change from t<sup>1</sup>/t<sup>2</sup>

Mabel reported change above MDC threshold on the health LSS score but this was not reflected in her overall perceived quality of life. There was a change above the MDC threshold in a positive direction for psychological wellbeing.

### 6.10.2 Change from t<sup>1</sup>/t<sup>3</sup>

Between t<sup>1</sup> and t<sup>3</sup> Mabel reported change above the MDC threshold on the leisure and living situation LSS subscales. This was reflected in a detectable change above the MDC threshold on perceived QoL. There was also a detectable change above the MDC threshold in a positive direction for psychological wellbeing.

Table 6.16 summarises Mabel's AMPS results across all three test phases and highlights any observable or statistically significant changes in her ADL motor and process ability measures. It also shows where her level of ADL motor and process ability is compared to an age-matched normative (Z score) sample. The graphic reports (Figures 6.5a & 6.5b) provide a visual representation of Mabel's ADL motor and process ability measures compared to an age-matched normative sample.

*Table 6.16: Change in Mabel's ADL motor and process logits across the test phases*

ADL ability measure	<u>ADL motor</u>					<u>ADL process</u>						
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	t <sup>1</sup> /t <sup>2</sup>	t <sup>1</sup> /t <sup>3</sup>
		0.4	1.2	1.1	0.8	0.7		0.8	1.3	1.4	0.5	0.6
		<u>Observable change</u>					<u>Observable change</u>					
		yes    yes					yes    yes					
		<u>Statistically significant change</u>					<u>Statistically significant change</u>					
		yes    yes					yes    yes					
Norm reference (Z Score)	Range † 3.58 – 1.74 Mean 2.66	<-3.0	-2.8	-3.0			Range† 2.68 – 1.08 Mean 1.88	-2.0	-0.8	-0.5		

† Range of scores for a well person of the same age

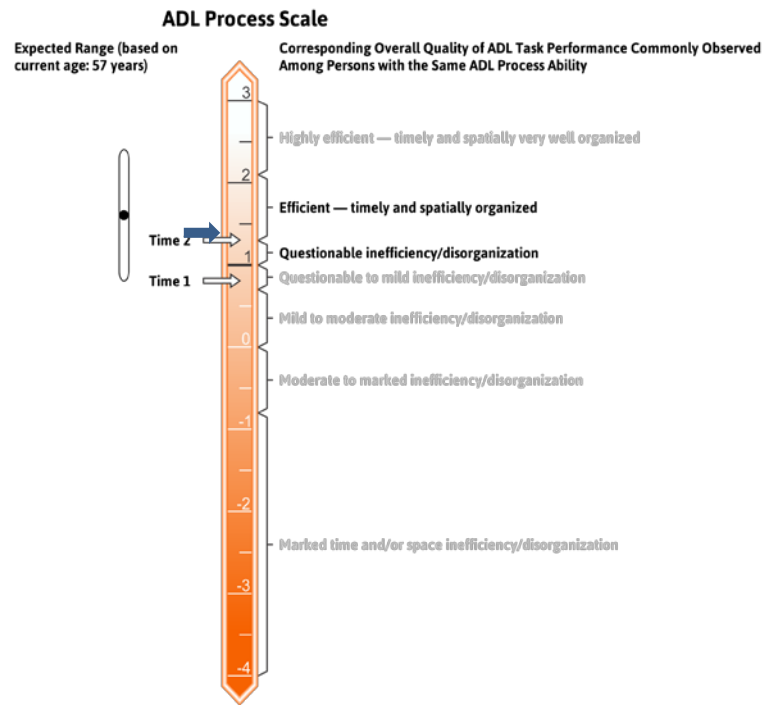
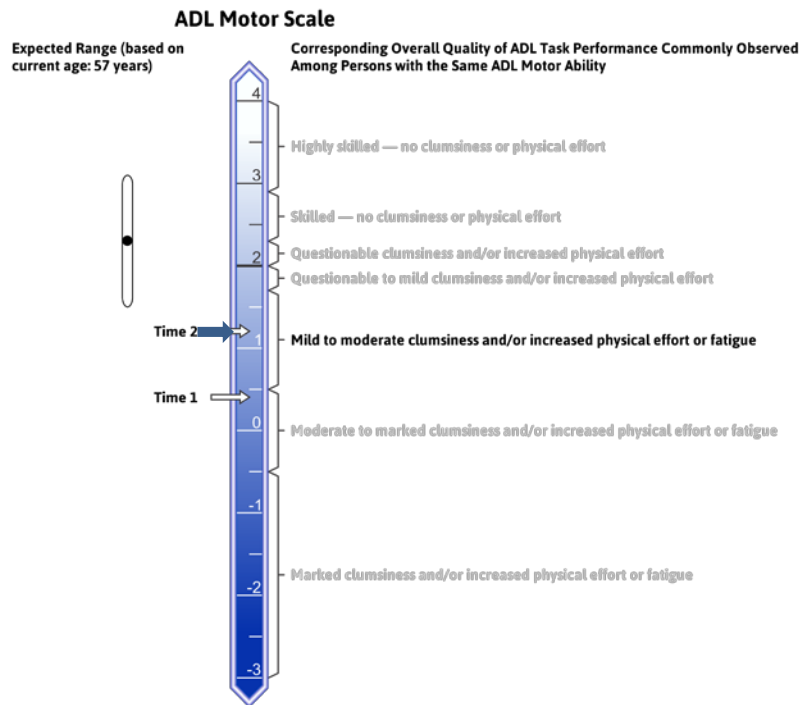
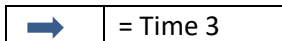


Figure 6.5a: Mabel's ADL motor scale across the three test phases    Graph 6.5b: Mabel's ADL process scale across the three test phases

Key:



### 6.10.3 ADL motor

Mabel's ADL motor ability score remained below the competency cut-off score of 2.00 logits for each test phase. However, an overall increase of 0.8 logits at discharge and 0.7 logits at follow-up are both observable and statistically significant.

When compared to an age-matched normative sample, Mabel's ADL motor ability moved from <-3.0 SD below the mean to -3.0 SD below the mean, meaning that she remained outside of the range and was performing at a level far below what would be expected for her age. This places her in a range below 97% of the sample population.

The observation scores on the ADL motor scale predict that Mabel would demonstrate a moderate degree of inefficiency and or disorganisation when carrying out familiar activities of daily living, and she was also likely to experience a degree of increased physical effort or fatigue.

### 6.10.4 ADL process

Mabel's ADL process ability score increased from 0.8 logits (below the competence cut-off of 1.00 logits) at admission ( $t^1$ ), to 1.3 logits at discharge ( $t^2$ ), to 1.4 logits at follow-up ( $t^3$ ). Both changes were observable and statistically significant.

When Mabel's process ability score is compared to the age-matched normative sample, her ADL process ability competency was 2.0 SD below the norm at admission, moving to -0.5 SD at follow-up.

The observation scores on the ADL process scale predict that Mabel would demonstrate, in the main, efficient processing skills that are timely and organised.



## 6.11. Mark

Table 6.17 summarises Mark's QoL scores across all three test phases and highlights Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

Table 6.17: Summary of Mark's QoL across the test phases

LSS Subscales	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>	Change from t <sup>1</sup> /t <sup>3</sup>
Leisure	1.33	4.33	3.33	1.55	3.00**	2.00**
Religion	4.50	4.00	5.00	1.86	-0.50	0.50
Finances	5.00	5.50	5.50	2.02	0.50	0.50
Living situation	4.71	4.29	5.29	1.41	-0.42	0.58
Safety	5.50	7.00	7.00	2.05	1.50	1.50
Family relations	5.00	5.50	6.00	2.02	0.50	1.00
Social relations	3.00	5.00	3.00	1.86	2.00**	0
Health	2.00	2.33	2.00	1.55	0.33	0
Perceived QoL	3.88	4.74	4.64	0.80	0.86**	0.76
Psychological wellbeing	1.00	1.80	1.50	0.44	0.80**	0.50**
Self-esteem	1.20	1.20	0.60	0.47	0	-0.60**

### 6.11.1 Change from t<sup>1</sup>/t<sup>2</sup>

Mark reported a change above the MDC threshold on the leisure and social relations LSS subscales, and this is reflected in a detectable change in a positive direction in his perceived QoL. There is also detectable change in a positive direction in his psychological wellbeing.

### 6.11.2 Change from t<sup>1</sup>/t<sup>3</sup>

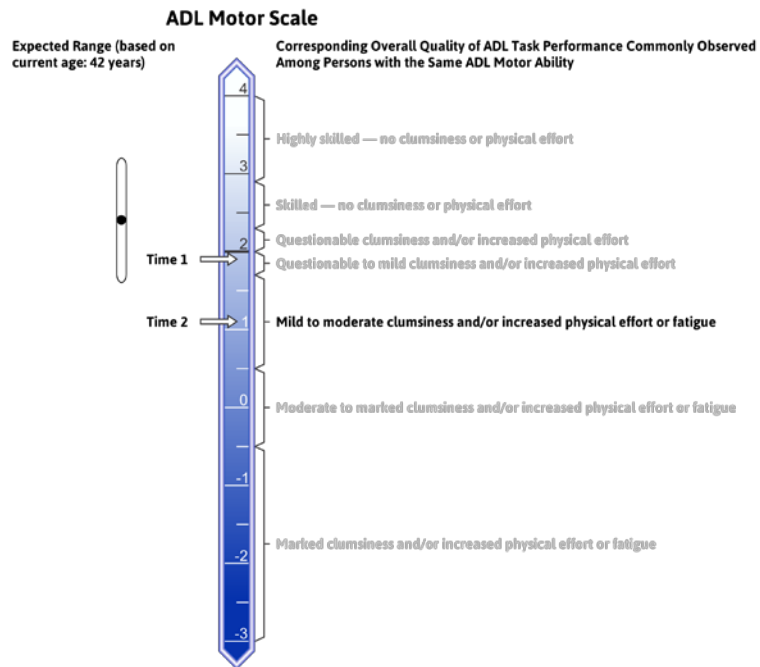
Between t<sup>1</sup> and t<sup>3</sup> Mark reported change above MDC threshold on the leisure LSS subscales, but this was not reflected in his overall perceived QoL. There was a change, above the MDC threshold for psychological wellbeing in a positive direction with detectable change in a negative direction for self-esteem.

Table 6.18 summarises Mark's AMPS results across two test phases and highlights any observable or statistically significant changes in his ADL motor and process ability measures. It also shows his level of ADL motor and process ability compared to an age-matched normative (Z score) sample. The graphic reports (Figures 6.6a & 6.6b) provide a visual representation of Mark's ADL motor and process ability measures compared to an age-matched normative sample.

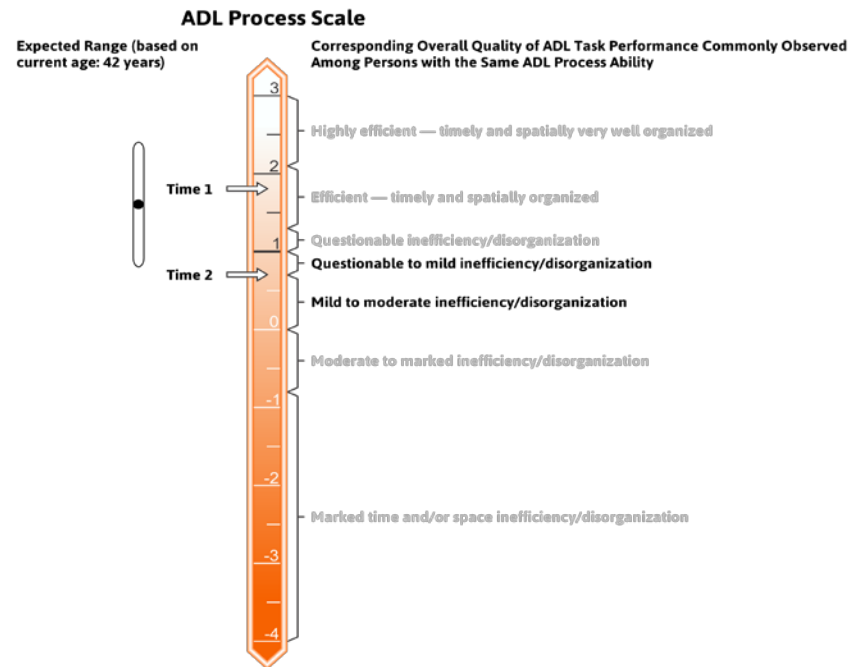
*Table 6.18: Change in Mark's ADL motor and process logits across the test phases*

ADL ability measure	<u>ADL motor</u>			<u>ADL process</u>				
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>
		1.9	1.1	-0.8		1.8	0.7	-1.1
		<u>Observable change</u>			<u>Observable change</u>			
		yes(-)			yes(-)			
		<u>Statistically significant change</u>			<u>Statistically significant change</u>			
		yes (-)			yes(-)			
Norm reference (Z Score)	Range † 3.68 – 1.90 Mean 2.88	-0.3	<-3.0		Range† 2.99 – 1.07 Mean 2.03	0.5	-2.3	

† Range of scores for a well person of the same age



Graph 6.6a: Mark's ADL motor scale across phase 1 and 2



Graph 6.6b: Mark's ADL process scale across phase 1 and 2

### 6.11.3 ADL motor

Mark's ADL motor ability was below the competency cut-off of 2.00 logits, decreasing from 1.9 logits at admission to 1.1 logits at discharge. This change is both observable and statistically significant.

When compared to an age-matched normative sample, Mark's ADL motor ability moved from -0.3 SD below the mean to <-3.0 SD below the mean, meaning that at discharge his ADL motor competency was outside of the range and he was performing at a much lower level than would be expected for his age.

The observation scores on the motor scale predict that Mark would experience mild to moderate clumsiness and a degree of difficulty with carry out familiar activities of daily living. He might also experience a degree of increased physical effort or fatigue.

### 6.11.4 ADL process

Mark's ADL process ability measure moved from 1.8 logits at admission (above the competency cut-off of 1.00 logits) to 0.7 logits at discharge (below the cut-off). This decrease in competence is both observable and significant.

When compared to an age-matched normative sample, this decrease moved Mark from within the range (0.5 SD) to outside of the range (-2.3 SD).

The observation scores on the process scale predict that Mark would experience a mild to moderate degree of inefficiency and or disorganisation when carrying out familiar activities of daily living.

## 6.12 Rita

Table 6.19 summarises Rita's QoL scores across all three test phases and highlights Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

*Table 6.19: Summary of Rita's QoL across the test phases*

LSS Subscales	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>	Change from t <sup>1</sup> /t <sup>3</sup>
Leisure	4.00	5.33	2.33	1.55	1.33	-1.67**
Religion	4.50	5.00	5.50	1.86	0.5	1.00
Finances		n/a	n/a	2.02	n/a	n/a
Living situation	4.29	4.43	2.71	1.41	0.14	-1.58**
Safety	4.00	6.00	3.50	2.05	2.00	-0.50
Family relations	4.50	6.00	6.00	2.02	1.50	1.50
Social relations	5.00	6.00	5.50	1.86	1.00	0.50
Health	3.33	4.33	2.00	1.55	1.00	-1.33
Perceived QoL	4.23	5.39	4.07	0.80	1.16**	-0.16
Psychological wellbeing	2.70	3.40	2.30	0.44	0.70**	0.40
Self-esteem	-0.20	0	0.20	0.47	0.20	0.40

### 6.12.1 Change from t<sup>1</sup>/t<sup>2</sup>

Rita reported change above MDC threshold on perceived quality of life and psychological wellbeing - both these changes were in a positive direction.

### 6.12.2 Change from t<sup>1</sup>/t<sup>3</sup>

Between t<sup>1</sup> and t<sup>3</sup> Rita reported change above MDC threshold on the leisure and living situation LSS subscales. These changes were in a negative direction but were not reflected in her overall perceived quality of life.

Table 6.20 summarises Rita’s AMPS results across two test phases and highlights any observable or statistically significant changes in her ADL motor and process ability measures. It also shows where her level of ADL motor and process ability is compared to an age-matched normative (Z score) sample. The graphic reports (Figures 6.7a & 6.7b) provide a visual representation of Rita’s ADL motor and process ability measures compared to an age-matched normative sample.

*Table 6.20: Change in Rita’s ADL motor and process logits across the test phases*

ADL ability measure	ADL motor			ADL process				
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>
		1.5	1.3	-0.2		1.2	1.1	-0.1
		<u>Observable change</u>			<u>Observable change</u>			
		no			no			
		<u>Statistically significant change</u>			<u>Statistically significant change</u>			
		no			no			
Norm reference (Z Score)	Range † 3.58- 1.74 Mean 2.66	-2.0	-2.5		Range† 2.68 – 1.08 Mean 1.88	-1.0	-1.3	

† Range of scores for a well person of the same age

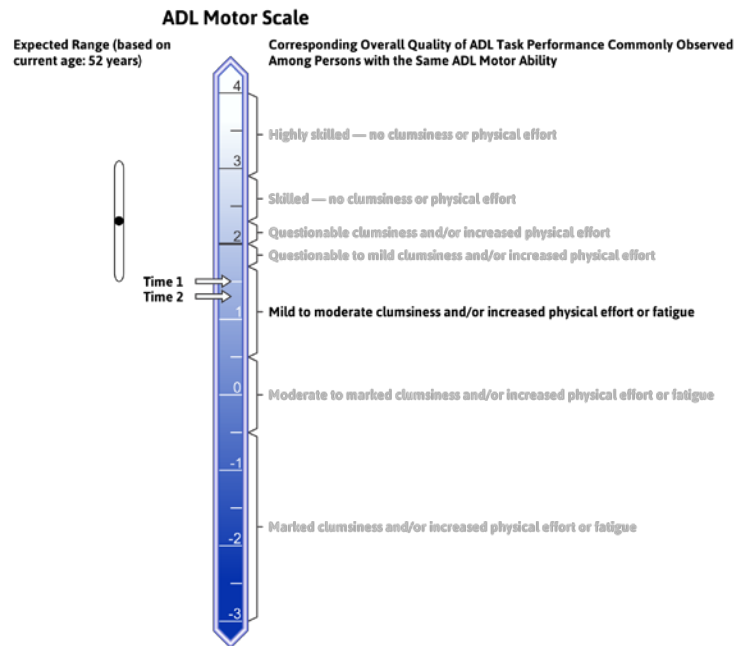


Figure 6.7a: ADL Rita's Motor scale across phase 1 and 2

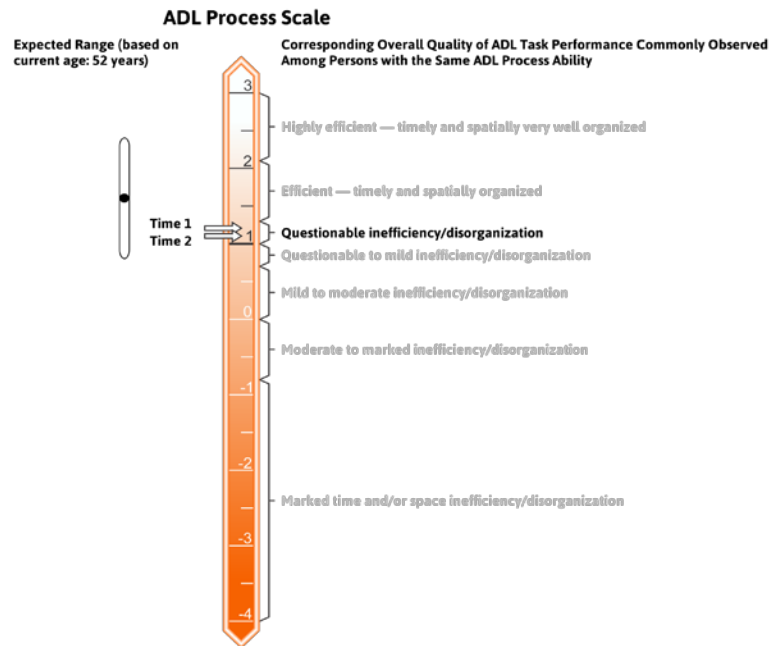


Figure 6.7b: ADL Rita's Process scale across phase 1 and 2

### 6.12.1 ADL motor

Rita's ADL motor ability remained below the competence cut-off of 2.00 logits, reducing from 1.5 logits at admission to 1.3 logits at discharge. This decrease is neither observable nor statistically significant.

When compared to an age-matched normative sample, Rita's ADL motor ability score of -2SD below the mean at admission ( $t^1$ ) dropped to -2.5 SD at discharge ( $t^2$ ), meaning that her motor competence was well below what is expected of an aged-matched norm.

The observation scores on the motor scale predict that Rita would demonstrate mild to moderate clumsiness while carrying out familiar activities of daily living and she was likely to experience increased physical effort or fatigue as a result.

### 6.12.2 ADL process

Rita's ADL process ability measures were above the competency cut-off 1.00 logits. Although there was a slight decrease from admission (1.2 logits) to discharge (1.1 logits), this change was neither observable nor statistically significant.

When compared to an aged-matched norm Rita's ADL processing skills were -1.0 SD below the mean at admission and -1.3 SD below the mean at discharge, meaning that she was still within the range, with processing skills at a level that could be expected for her age.

The observation scores on the process scale predict that Rita would demonstrate questionable inefficiency and disorganisation when performing everyday familiar tasks.



### 6.13 Susan

Table 6.21 summarises Susan's QoL scores across all three test phases and highlights Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

*Table 6.21: Summary of Susan's QoL across the test phases*

LSS Subscales	t <sup>1</sup>	t <sup>2</sup>	t <sup>3</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>	Change from t <sup>1</sup> /t <sup>3</sup>
Leisure	3.33	5.33	5.33	1.55	2.00**	2.00**
Religion	5.00	5.50	5.00	1.86	0.50	0
Finances	1.00	3.50	2.50	2.02	2.50**	1.50
Living situation	3.71	3.57	4.00	1.41	-0.14	0.29
Safety	5.50	4.00	4.50	2.05	-1.50	-1.00
Family relations	5.50	5.00	5.00	2.02	-0.50	-0.50
Social relations	6.00	5.50	6.00	1.86	-0.50	0
Health	2.33	4.33	4.67	1.55	2.00**	2.34**
Perceived QoL	4.05	4.59	4.62	0.80	0.54	0.57
Psychological wellbeing	2.20	3.50	3.70	0.44	1.30**	1.50**
Self-esteem	-0.20	0.40	-0.20	0.47	0.60**	0

#### 6.13.1 Change from t<sup>1</sup>/t<sup>2</sup>

Susan reported change above MDC threshold on the leisure, finances and health LSS subscales, without a detectable change in perceived quality of life. There was also a change above the MDC threshold in a positive direction for psychological wellbeing and self-esteem.

#### 6.13.2 Change from t<sup>1</sup>/t<sup>3</sup>

Between t<sup>1</sup> and t<sup>3</sup> Susan reported a change above MDC threshold on the leisure and health LSS subscales, with no detectable change in perceived quality of life. There was a positive change above the MDC threshold for psychological wellbeing.

Table 6.22 summarises Susan’s AMPS results across two test phases and highlights any observable or statistically significant changes in her ADL motor and process ability measures. The table also shows where her level of ADL motor and process ability is comparable to an age-matched normative (Z score) sample. The graphic reports (Figures 6.8a & 6.8b) provide a visual representation of Rita’s ADL motor and process ability measures compared to an age-matched normative sample.

Table 6.22: Change in Susan’s ADL motor and process logits across the test phases

ADL ability measure	ADL motor			ADL process				
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>
		1.2	0.9	-0.3		1.1	0.8	-0.3
		<u>Observable change</u>				<u>Observable change</u>		
		Yes (-)				Yes(-)		
		<u>Statistically significant change</u>				<u>Statistically significant change</u>		
		no				no		
Norm reference (Z Score)	Range † 3.86 – 1.90 Mean 2.88	-3.0	<-3.0		Range† 2.99-1.07 Mean 2.03	-1.3	-2.0	

† Range of scores for a well person of the same age

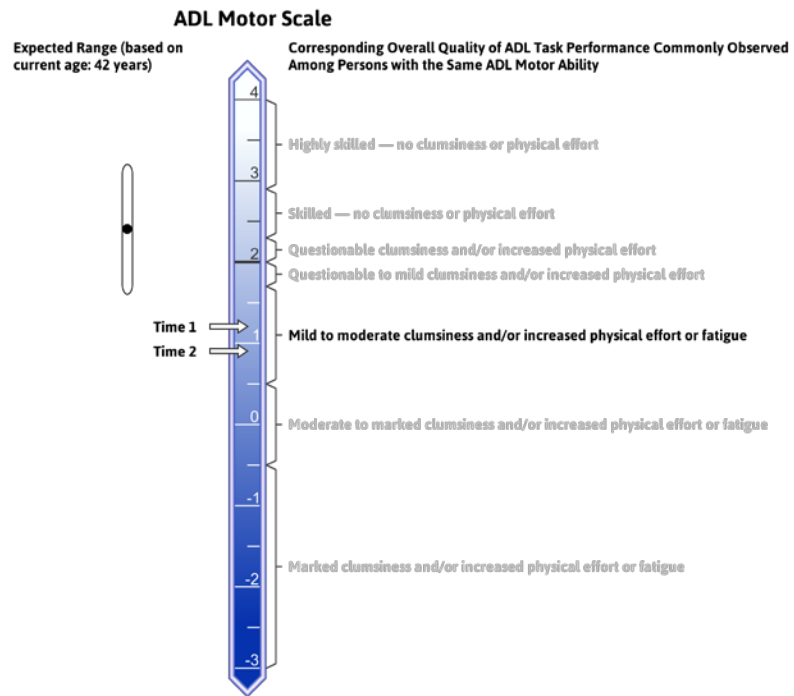
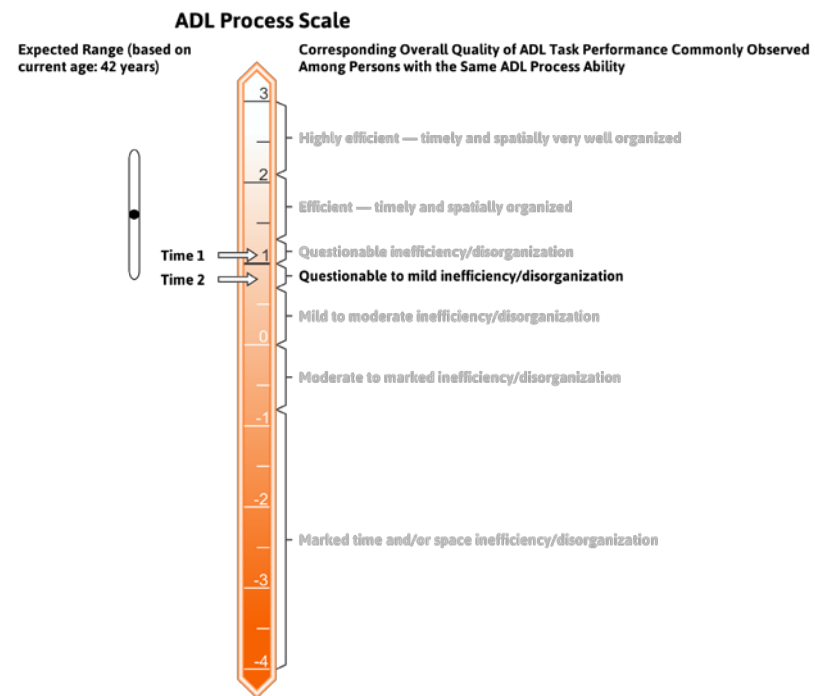


Figure 6.8a: Susan's ADL motor scale across phase 1 and 2



Graph 6.8b: Susan's ADL process scale across phase 1 and 2

### 6.13.3 ADL motor

Susan's ADL motor ability scores were below the cut-off of 2.00 logits and decreased from 1.2 logits at admission to 0.9 logits at discharge. This decrease is observable but not statistically significant.

When compared to an age-matched normative sample, Susan moved from -3.0 SD below the mean to <-3.0 SD below the mean, meaning that her ADL motor ability was outside of the range, indicating that she was functioning at a level very much lower than would be expected for her age.

The observation scores on the motor scale predict that Susan would demonstrate a mild to moderate degree of clumsiness when carrying out familiar activities of daily living and was likely to experience increased physical effort or fatigue as a result.

### 6.13.4 ADL process

Susan's ADL process ability score was above the competence cut-off score of 1.00 logits at admission (1.1 logits) but this decreased at discharge to 0.8 logits. This decrease was observable but not statistically significant.

When compared to an age-matched normative sample, Susan's ADL process ability skill at discharge was -2.0 SD below the mean, meaning that she was on the threshold between falling within the expected range for her age and falling outside of it.

The observation scores on the process scale predict that Susan would demonstrate questionable to mild inefficiencies and disorganisation when carrying out familiar everyday tasks.

## 6.12: Steve

Table 6.23 summarises Steve's QoL scores across all three test phases and highlights Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

Table 6.23: Summary of Steve's QoL across the test phases

LSS Subscales	t <sup>1</sup>	t <sup>2</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>
Leisure	5.33	6.00	1.55	0.67
Religion	4.00	5.50	1.86	1.50
Finances	6.00	6.50	2.02	0.50
Living situation	5.71	4.43	1.41	-1.28
Safety	5.00	5.50	2.05	0.50
Family relations	5.50	5.50	2.02	0
Social relations	3.50	5.50	1.86	2.00**
Health	4.67	6.00	1.55	1.33
Perceived QoL	4.96	5.62	0.80	0.66
Psychological wellbeing	5.00	5.50	0.44	0.50**
Self-esteem	-0.20	-0.20	0.47	0

### 6.14.1 Change from t<sup>1</sup>/t<sup>2</sup>

Steve reported change above MDC threshold on the social relations LSS sub scale. This change is in a positive direction, but it was not reflected in his overall perceived QoL. There was a change above the MDC threshold in a positive direction for psychological wellbeing.

Table 6.24 summarises Steve’s AMPS results across two test phases and highlights any observable or statistically significant changes in his ADL motor and process ability measures. It also shows where his level of ADL motor and process ability is comparable to an age-matched normative (Z score) sample. The graphic reports (Figures 6.9a & 6.9b) provide a visual representation of Steve’s ADL motor and process ability measures compared to an age-matched normative sample.

*Table 6.24: Change in Steve’s ADL motor and process logits across the test phases*

ADL ability measure	<u>ADL motor</u>			<u>ADL process</u>				
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>
		0.9	0.4	-0.5		0.7	0.9	0.2
		<u>Observable change</u>				<u>Observable change</u>		
		Yes (-)				no		
		<u>Statistically significant change</u>				<u>Statistically significant change</u>		
		Yes (-)				no		
Norm reference (Z Score)	Range † 3.99- 1.91 Mean 2.95	<-3.0	<-3.0		Range† 2.94-1.22 Mean 2.08	-2.0	-1.5	

† Range of scores for a well person of the same age

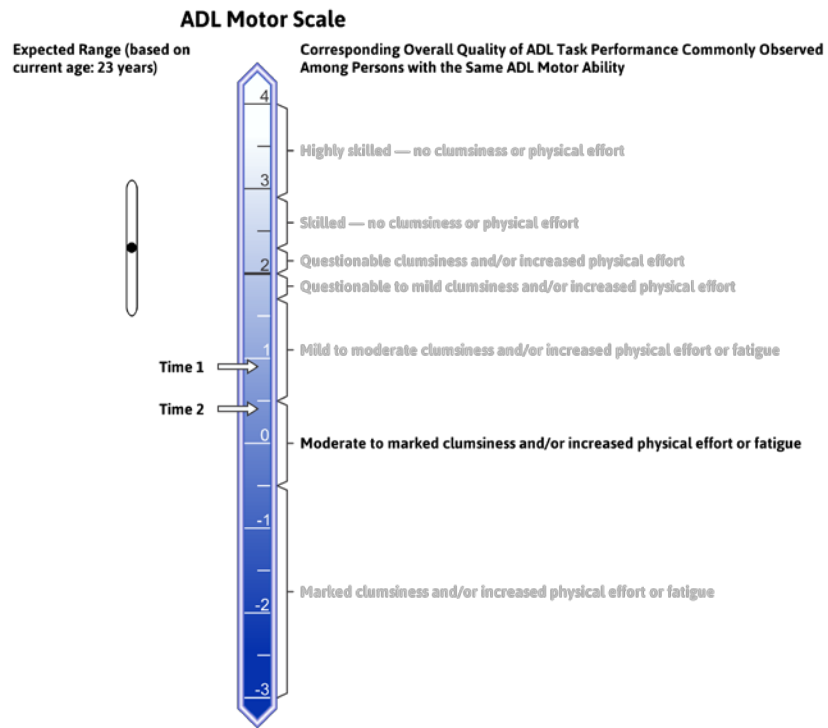


Figure 6.9a: Steve's ADL motor scale across phase 1 and 2

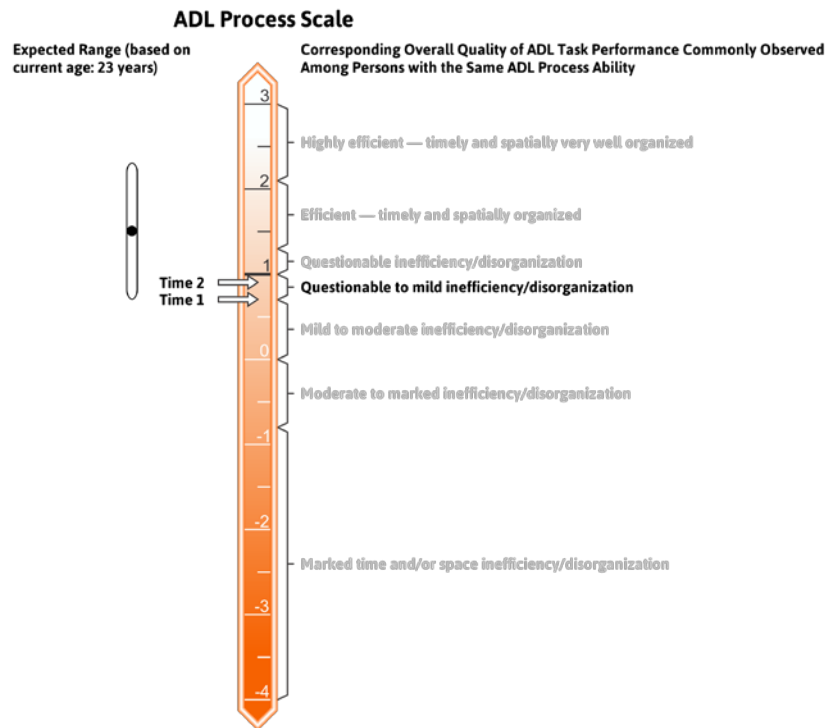


Figure 6.9b: Steve's ADL process scale across phase 1 and 2

### 6.14.2 ADL motor

Steve's ADL motor ability scores were below the competence cut-off of 2.00 logits at admission (0.9 logits) and decreased at discharge to 0.4 logits. This decrease is observable and statistically significant.

When compared to an age-matched normative sample, Steve's ADL motor competence at discharge was  $<-3.0$  SD below the mean, meaning that he was functioning well below the expected level for his age.

The observation scores on the motor scale predict that Steve would demonstrate moderate to marked clumsiness and inefficiency when carrying out familiar activities of daily living. He was also likely to experience increased physical effort or fatigue.

### 6.14.3 ADL process

Steve's ADL process ability score was below the competency cut-off of 1.00 logits. While there was a slight increase of 0.2 logits between admission and discharge, this increase was neither observable nor statistically significant.

When compared to the normative age-matched samples, Steve's ADL process ability moved from  $-2.0$  SD below the mean to  $-1.5$  SD below the mean, meaning that Steve's functioning had increased and he was now functioning within the mid-range expected for someone of his age.

The observation scores on the process scale predict that Steve would demonstrate questionable to mild processing skills deficit when organising himself, his environment and the equipment needed to efficiently and safely carry out the activities he chooses to do.



## 6.15. Mohammad

Table 6.25 summarises Mohammad's QoL scores across all three test phases and highlights Minimal Detectable Change<sub>95</sub> (95% of non-genuine changes are below the MDC)

*Table 6.25: Summary of Mohammad's QoL across the test phases*

LSS Subscales	t <sup>1</sup>	t <sup>2</sup>	MDC value for subscale	Change from t <sup>1</sup> /t <sup>2</sup>
Leisure	5.67	4.00	1.55	-1.67**
Religion	5.50	4.50	1.86	-1.00
Finances	5.50	5.50	2.02	0
Living situation	4.29	4.29	1.41	0
Safety	6.50	3.50	2.05	-3.00**
Family relations	5.00	3.50	2.02	-1.50
Social relations	6.50	3.50	1.86	-3.00**
Health	5.67	5.33	1.55	-0.34
Perceived QoL	5.58	4.26	0.80	-1.32**
Psychological wellbeing	3.00	4.70	0.44	1.70**
Self-esteem	-0.60	0	0.47	0.60**

### 6.15.1 Change from t<sup>1</sup>/t<sup>2</sup>

Mohammad reported change above MDC threshold on the leisure, safety and social relations LSS subscales, with a corresponding detectable change in the negative direction of perceived quality of life. There was a detectable change above the MDC threshold in a positive direction for psychological wellbeing and self-esteem.

Table 6.26 summarises Mohammad’s AMPS results across two test phases and highlights any observable or statistically significant changes in his ADL motor and process ability measures. It also shows where his level of ADL motor and process ability is comparable to an age-matched normative (Z score) sample. The graphic reports (Figures 6.10a & 6.10b) provide a visual representation of Mohammad’s ADL motor and process ability measures compared to an age-matched normative sample.

*Table 6.24: Change in Mohammad’s ADL motor and process logits across the test phases*

ADL ability measure	<u>ADL motor</u>				<u>ADL process</u>			
	competence cut-off 2.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>	competence cut-off 1.00	t <sup>1</sup>	t <sup>2</sup>	t <sup>1</sup> /t <sup>2</sup>
		1.2	1.2	0.0		0.7	1.3	0.6
		<u>Observable change</u>				<u>Observable change</u>		
		No				yes		
		<u>Statistically significant change</u>				<u>Statistically significant change</u>		
		no				yes		
Norm reference (Z Score)	Range † 3.58 -1.74 Mean 2.66	-2.8	-2.8		Range† 2.68 -1.08 Mean 1.88	-2.3	-0.8	

† Range of scores for a well person of the same age

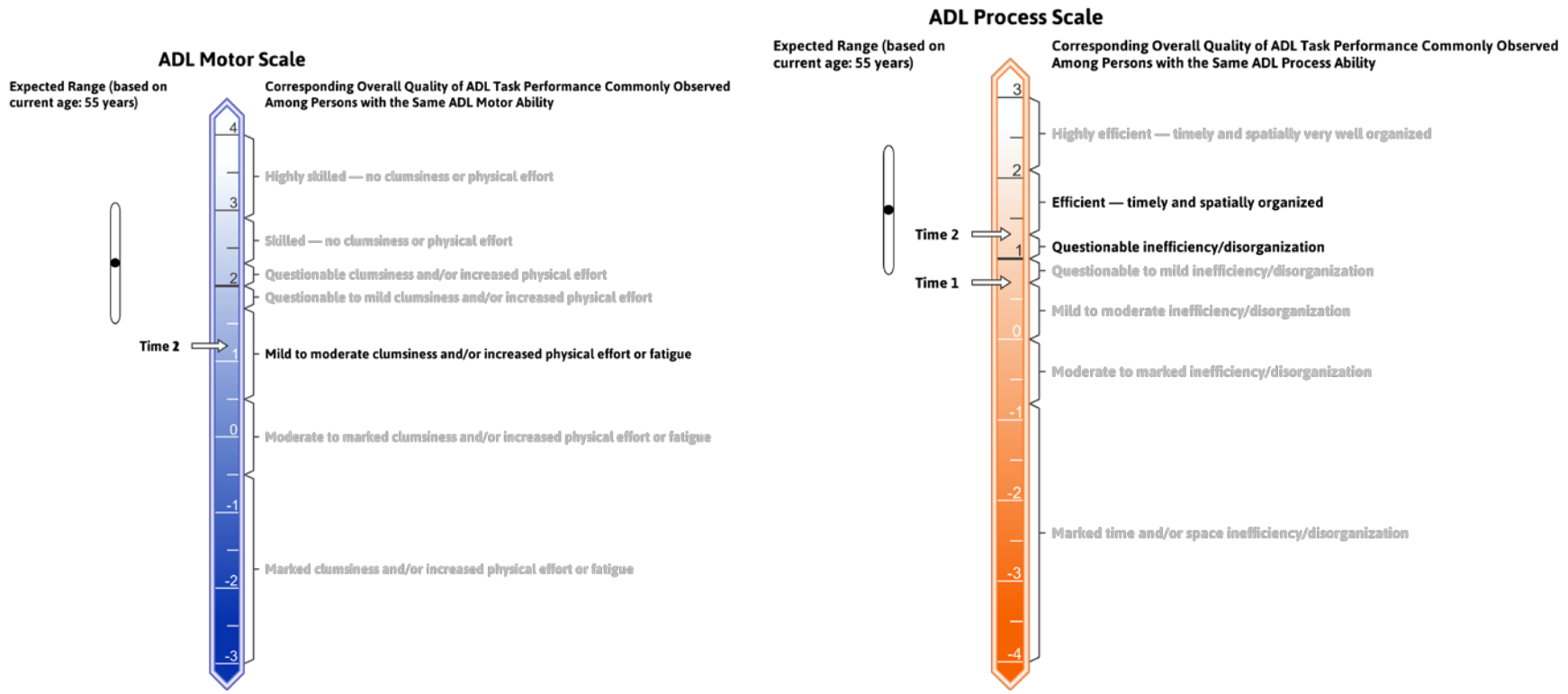


Figure 6.10a: Mohammad’s ADL motor scale across phase 1 and 2    Graph 6.10b: Mohammad’s ADL process scale across phase 1 and 2

### 6.15.2 ADL motor

Mohammad's ADL motor ability scores were unchanged at 1.2 logits and remained below the competency cut-off of 2.00 logits.

When compared to an age-matched normative sample he was -2.8 SD below the mean, meaning that he was functioning out of the range and at a level much lower than would be expected for his age.

The observation scores on the motor scale predict that Mohammad would demonstrate mild to moderate clumsiness and/or increased physical effort or fatigue when undertaking familiar ADL activities.

### 6.15.3 ADL process

Mohammad's ADL process ability score increased from 0.7 logits at admission ( $t^1$ ) to 1.3 logits at discharge ( $t^2$ ), placing him above the competency cut-off of 1.00 logits. This change is both observable and statistically significant.

When compared to an age-matched normative sample, at admission Mohammad's ADL process ability was -2.3 SD below the mean, moving to -0.8 SD below the mean. This meant that he had moved from outside the range for a person of his age to well within the range of functioning.

The observation scores on the process scale predict that Mohammad would demonstrate a level of efficiency in his processing skills, being organised both timely and spatially.

## **6.16 Case study presentations**

Case studies by their nature are representations of one or more cases, characteristic and typical of a particular group of people. They highlight the idiosyncrasies of an individual's experience and contribute to empirical data by documenting, in depth, the detail of that experience (Kumar, 2005; Legault and Rebeiro, 2001). While case studies are predominately used within qualitative studies, they are not exclusively so. This research study has been designed for concurrent triangulation of data, collecting separate qualitative and quantitative data which now need to be merged into one. This demonstrates a holistic approach to research, akin to the holistic, person-centred approach of occupational therapy.

A case study approach with integration of the results, using one set of data to understand the other (Creswell, 2014), helps to provide a more detailed appreciation of the rehabilitation journey - it offers explanations and interpretations for any similarities and differences in those journeys. In addition to this, an appreciation of the individual's current situation through an occupational therapy lens helps to increase awareness of situations that participants find themselves in. The occupational therapy lens offers a unique way of understanding the contribution of rehabilitation in a person's journey.

This section presents the case studies of Marco, Frank, Jason, Nigel and Mabel. These five participants are brought to the fore as those people who completed all aspects of data collection and moved through rehabilitation to live in the community. They are presented in order of completion.

### **6.16.1 Marco**

Marco is 49 years old, divorced with two grown-up daughters. He has a diagnosis of schizophrenia, has a 10 year history of mental health needs, and has been in rehabilitation previously.

Prior to this admission Marco was sleeping in his car in London, looking for work and gradually becoming more unwell. During his first month in the rehabilitation unit, Marco identified occupational imbalance and injustices such as occupational alienation - he was without work, isolated from his daughters and had little social interaction with other people. *'My problems are*

*not related to my illness, mainly with a lack of company, with friends, a partner, my daughters mainly.'*

While in rehabilitation Marco identified an increase in his general confidence, a greater awareness of his illness, and had made positive steps towards making new friends. In terms of quality of life, Marco demonstrated a positive change above the MDC threshold for general wellbeing and perceived QoL, and this was maintained at follow-up. This change may be attributed to his practical achievements of decorating his flat, managing his money or his ability to live in the moment while having hopes for the future. *'I am very excited about my new flat ... I [have] just finished decorating it and assembling the furniture.'* Marco had started to establish meaningful occupations.

This level of occupational engagement is reflected in his functional performance levels where improvements were noted on both motor and process ADL scales from admission, with a significant improvement on his ADL motor scale. This level of competence places him above the competency cut-offs for both scales indicating skilled motor and efficient processing skills. According to the AMPS results, Marco demonstrated the highest level of ADL competence of all five participants.

As Marco moved into his own flat, he needed minimal support from the community mental health team and his life started to feel very different. He regained some occupational balance, was enjoying the company of his classmates, and was starting to feel ready to address some occupational injustices, such as considering suitable employment: *'Right now I am doing my course in English so I will look for a job later on, hopefully I will have my certificate of learning English from the exams and hopefully I will be able to look for a job.'*

However despite a significant improvement in global wellbeing at discharge, this was not sustained at follow-up and may be reflective of living alone in a flat, being divorced and estranged from his two daughters and with a desire for a new relationship. *'I was interested in a partner but still it is not very easy to find one - I am not working, I am 51, and it is not easy to find a person for a psychiatric patient. (I am) ten years single, so I am able to live alone. It is not nice, but still I am able to run my life.'* Marco, at follow-up was still expressing occupational deprivation and occupational alienation, and was feeling stigmatised.

### 6.16.2 Frank

Frank is 53 years old and has never been married. He first became unwell approximately 2 years before his admission to hospital, and he attributes his illness to his house being repossessed. He has a diagnosis of psychotic depression and was admitted to rehabilitation following an admission to the local acute mental health unit.

Prior to becoming unwell, Frank had lived with his parents and it was only after their deaths that he started to struggle with life. He spoke at length about the past, particularly the fun he had in the 1970's and how things were different now: *'Things have changed a lot as my best friend is now dead, my parents are dead ... I am the only one left.'* He also expressed a great deal of disbelief and regret over agreeing to an equity release scheme on the family home, which eventually led it to being repossessed: *'I just want to get the house back.'* Frank was experiencing occupational alienation, as he felt his life had lost purpose and he was no longer in control of the choices available to him.

In addition to these feelings, Frank really did not like being in the rehabilitation unit, using words such as 'strict' and 'inhumane' to describe the staff and their actions. He expressed occupational alienation and exclusion while at the unit: *'I definitely don't feel like I am one of them you know [the staff] ... it seems like they want it all their own way, their own sort of system you know.'* There is also a very strong sense of occupational injustice, in that he does not see himself as having the same opportunities as people walking by him: *'Well I just go down the town, sit down in here I don't do a lot I must be honest, I am not working see, I can't afford to do a lot really.'*

However when the time came to be discharged from the unit Frank did not feel ready to go: *'I feel I am still learning. My health is not ready to go into a flat, just have to see what happens'* - although as recorded on the QoL tool he felt unsafe in the unit. While on the unit he continued to experience a strong perception of occupational injustice, feeling that he was being treated differently from others on the unit: *'It's not the flat for me, I was told they are going to chuck me out on the streets. My mate ... he's said look I don't like this flat, he's done it twice and they don't touch him, you know so I was wondering what as different about me sort of thing, you know. Do you know what I mean, why should I be any different?'*

At follow-up, Frank continued to articulate occupational imbalance: '*[I] just laid down basically, I don't do ... I just walk around the town, I don't do too much ... well there is so much to do, sort of thing really: cleaning, keeping the payments up, and if you are not working it's really hard.*' However, this was not picked up across the phases in perceived QoL, general wellbeing, or global wellbeing.

Frank's inability to engage in meaningful activity might be attributed to his below age functional performance level, as recorded on the AMPS. Frank was identified as the lowest functioning participant at the end of test phase 3 and over the course of rehabilitation. His ADL motor skills did not change, remaining well below the competency cut-off, but without any obvious physical disability. While there was a statistically significant increase in his ADL process skill from admission to follow-up, Frank was still below the mean for an age-matched normative sample. This is reflected in his occupational capacity on follow-up and is evidenced by the lack of a second set of bed sheets and a tin opener (see excerpt from reflective log, Appendix 6.1). It would appear that Frank's occupational competence, the development of skill through practice, did not increase beyond discharge.

### **6.16.3 Jason**

Jason is 33 years old and lives with his civil partner. He has a diagnosis of schizophrenia and HIV and has had mental health needs for 14 years.

Jason was the youngest of all five participants to be presented as a case study. He was also the only participant to be in a long term and stable relationship, and the only participant to have been admitted from his home into the unit. The main reason for admission was to enable him to develop skills in completing household domestic tasks, to increase his independence and become self-reliant in preparation for his partners failing health. Jason very much viewed the admission as something to achieve, almost as a test: '*Well, you know, maybe a letter to say that I was here and whatever. Certification that I cook my own meals ... I actually go to bed on time, I go out and about ... have I completed my tasks, kept my goals.*' It would appear that initially Jason demonstrated a high level of occupational participation with his admission to the unit.

As Jason moved towards being discharged back to his flat there was a sense that he had started to become more self-aware and was starting to make some positive changes to his lifestyle: '*I am in control of my own destiny*' and '*I have learnt that it's bed time before 12*



*o'clock', suggesting he was developing a strong sense of occupational justice and balance. Once back at home, Jason describes a life that is occupationally balanced, suggesting that his time in rehabilitation had achieved the goals it had set out to do. 'There's gym today and fitness training at (local school) ... Tuesday it's the men's group ... Wednesday it's shopping and the gym ... Thursday its Photography, and Friday its gym again ... and Saturday I walk into town, maybe go to the pub or something.'*

However, both Jason's QoL and functional performance levels declined over his time in the unit. In terms of his QoL, it decreased across perceived QoL, general wellbeing and global wellbeing, although the only change above the MDC was for global wellbeing. When looking at the specific data in more detail, there was a change in a negative direction above the MDC threshold for the LSS sub domains of religion, living situation and family relationships.

In regards of Jason's functional performance, although not a statistically significant change, both his ADL motor skill and ADL process skill declined from admission to discharge, with a further decline of his ADL motor skill at follow-up. While Jason's narrative of his occupational habits is clear, the results of the QoL and AMPS measures tell a different story.

#### **6.16.4 Nigel**

Nigel is 47 years old and has never been married. He has an 18 year history of using mental health services, including 6 years spent in a forensic hospital. While at the hospital he progressed to the rehabilitation flat.

Prior to his move to the rehabilitation unit Nigel had spent four years in a secure forensic hospital. While he was pleased to be at the rehabilitation unit, he was keen to take things slowly, particularly in building up trust with the medical staff: *'I am going to ask Dr X if I can have a bit more time out ... I know I have to build that up over a period of time, but you know it's like her having to get to know me and me getting to know her sort of thing.'*

While in the unit Nigel established a routine and had started to address some of the occupational imbalance and deprivation he had experienced at the forensic hospital: *'I pop into (area of town)... about half way up you have got a coffee house, 1950s style. I know the owner, we have a bit of a chinwag, yes. Yes I pop in there for a cup of latte. When it is nice and sunny I sit outside, have a coffee, have a cigarette and watch the world go by.'*

On discharge, Nigel moved into a flat with 24 hour support. He was very clear that while the rehabilitation unit was *'a very important stepping stone'* he did not wish to *'jump in with both feet first'* into independent living, saying that he did not want to *'run before I can walk'*. He said *'I just did not want to go straight out into a one bedroomed flat, no way, I just don't think ... I am not ready for it.'* Nigel wanted to take the time to increase his occupational competence (skill base) before extending his occupational capacity to new activities and occupations.

After discharge, Nigel continued to build up his network of friends and increase his activity level, addressing any occupational deprivation that arose while being in a forensic setting for a number of years. He attended the gym on a Monday and Friday, made an effort to walk briskly, and had recently lost some weight. *'[We] go for a walk around the common, we pop into (the community mental health team base) for a cup of coffee.'* In addition to taking control of his ongoing recovery post rehabilitation, Nigel articulated a clear sense of responsibility, *'There is a lot more freedom, don't get me wrong there is a responsibility side to it as well, you can't mess around with that, it's not good if you do try to mess around with it.'*

Nigel's change in routine is reflected in a positive change above the MDC threshold in his general wellbeing and in the LSS subscales of leisure and positive affect from admission to follow-up. However, between admission and follow-up Nigel's functional performance as measured by the AMPS declined significantly for his ADL motor skill. His ADL process skill remained the same. This decline in his ADL motor skill is surprising, and could be attributed to the support with domestic chores available in his accommodation, suggesting that Nigel is not continuing to practise and use such skills. There is a risk that Nigel's occupational competence may decline and he will need ongoing support with occupational engagement to further his competencies.

#### **6.16.5 Mabel**

Mabel is 57 years old and has never been married. She lived with her mother until her death, and spent approximately two years living in a residential home for older adults. She has used mental health services for 4 years and has a diagnosis of bipolar disorder.

Mabel moved to the rehabilitation unit from a residential care home where she had lived with her elderly mother. After her mother's death Mabel continued to live at the home for another year, where she maintained some occupational balance by helping in the kitchen. Her move to the unit was abrupt, without notice or planning: *'On the Wednesday he said "Up and out of it Mabel," so he said, "I'll be back to take you out," he said, "at 14:00 and that," and after 14:00 he come on the Wednesday and the lady had to get like the carers to come in to help me pack up and that, and I left on the Wednesday and I've been here ever since.'*

As Mabel had never lived independently, being occupationally deprived and marginalised for all of her adult life. On moving to the rehabilitation unit she hoped to cook, become involved in craft activities and keep in contact with her friends from the home, thereby increasing her occupational engagement. She very much wanted to address the occupational deprivation and marginalisation, which had formed a significant part of her adult life, and start to live a life which until rehabilitation she had not had the opportunity to do. She also wanted some stability in her life: *'[to] start to put down roots. I feel as if I have been a nomad all these years. Well, I think I was too young to be living in a nursing home.'*

Despite her sudden upheaval at the start of rehabilitation, Mabel reflected on her time in rehabilitation positively: *'It's sort of been a resting process, you know, able to get one's head together and able enough to see a future and be able to move on I mean.'*

On living on her own, in a housing association, warden-controlled-flat, Mabel talks about having a real sense of occupational balance: *'I do the place over [clean] on a Monday and then on a Thursday I do go shopping and that, and on a Friday I do my washing and that and Saturday or Sunday I go to church, yes. Tuesday or Wednesday I go to Robert House.'* She describes a sense of pride and occupational justice in what she had achieved: *'Well I'm really settled in, yes indeed, you know it took a couple of days and that, but I went straight from (the rehabilitation unit), I didn't have any sleep-overs like some of the other girls had. I went straight from (the rehabilitation unit) to here and I settled in straight away.'*

Of the five participants Mabel was the only one to made statistically significant changes on both the ADL motor and ADL process scales. Despite such an improvement in her functional performance, she remained well below the competency cut-off for ADL motor, reflective of her marked spinal scoliosis. Mabel also made changes above the MDC threshold for perceived QoL and psychological wellbeing, with the LSS subscales of leisure and living situation both showing

a positive change above the MDC threshold. The increase in her QoL and occupational performance are reflective of each other and in keeping with her personal narrative.

### 6.17 Understanding the reason for dropout

The dropout rate for participants engaged in mental health rehabilitation has been noted to be as high as 50% (Arfken et al 2002) and may be attributed to generalised reasons such as inconvenient appointment times, patient burden, unclear expectations and limited clinical/rehabilitation progress (Costello, 2016). Given the burden of data collection in this study, these generalised reasons for dropout may be applicable within the study. While 3 participants dropped out at phase 1, this was not before they had completed one or two of the measures, before declining to continue, which shows initial interest that was not sustained for some reason.

However as the participants moved from phase 1 to phase 2 the dropout reasons included readmission to hospital, (n=1) transfer to prison (n=1), self-discharge from the unit (n=1) and still in receipt of active rehabilitation treatment (n=3) - all of which are outside of the remit of the study design. Of those participants moving from phase 2 to phase 3, three were readmitted to hospital and two were lost to follow-up (Table 6.27). These participants are discussed in more detail in Chapter 7

*Table 6.27: Reasons for participant dropout*

<b>Name</b>	<b>Phase of dropout</b>	<b>Reason for dropout</b>
Mark	2	Readmitted to hospital
Rita	2	Lost to follow-up
Susan	2	Readmitted to hospital
Steve	2	Lost to follow-up
Mohammad	2	Readmitted to hospital
Jan	1	Readmitted to hospital
Warren	1	Self-discharged
Mick	1	Moved to prison
Richard	1	Not finished rehab
Pete	1	Not finished rehab
Maria	1	Not finished rehab
William	1	Declined to continue
Michelle	1	Declined to continue
Dave	1	Declined to continue

## 6.18 Chapter summary

This chapter commenced by presenting an overview of demographic results and a summary of participants' group QoL and AMPS results. Individual changes were then presented across time for the 10 participants with comparable data. Five case studies were then presented through an occupational lens to bring together personal narratives with changes in quality of life and occupational performance levels. This novel approach to understanding rehabilitation illuminates its complexity, and highlights the need to understand the effect of rehabilitation from a number of different perspectives. This will be addressed in more detail in the chapter 7.

Overall rehabilitation would appear to have a positive effect for some participants. There was a statistically significant positive change in functional performance for between 20-30% of the sample between admission and discharge, and a change for 40% of the sample between admission and follow-up. Between 10-20% decreased their ADL motor skills over time, but with no decline in the ADL process skills.

In terms of QoL 80% of the sample reported an increase between admission and discharge in their psychological wellbeing, with a 50% increase between admission and follow-up. There were also positive changes in perceived QoL and self-esteem at discharge (30% and 20% respectively) and follow-up (25% and 25% respectively) when compared to admission. A small number of participants experienced a decrease in the perceived QoL and psychological wellbeing between admission and discharge (10%) but this was not noted for self-esteem. There was also a decrease across all areas between admission and follow-up with the biggest decrease noted for psychological wellbeing (25%).

On an individual basis Mabel probably gained the most from her time in rehabilitation, as both her motor and process skills improved significantly and she identified some positive changes in some aspects of her quality of life. Marco also noted some positive changes in the quality of life and there was a significant increase in his motor skills from admission to discharge. Nigel had a statistically significant decrease in his motor skills from admission to discharge, but he noted a change in some aspects of his quality of life. Given this quantitative evidence, it would be reasonable to suggest that Marco, Nigel and Mabel benefited from being in rehabilitation in a way that prepared them for community living.

Given his quantitative results, it would also be reasonable to surmise that Frank, who had a statistical change in his processing skills between admission and discharge but reported a

decrease in aspects of his quality of life, gained little from rehabilitation. Similarly, it could be considered that Jason gained no benefit from rehabilitation - there were no significant changes in his ADL skills and he noted a decrease in three subscales of his quality of life between admission and discharge.

The case studies discussed above illustrate how varied the experiences were, that participants' quality of life and functional performance may increase as well as decrease. The consideration of quantitative data alongside individual narratives through an occupational lens has added to the depth of understanding around the effect of rehabilitation for each of the five participants. This will be considered in more depth in chapter 7.

### **6.19 Summary of key findings**

The key findings of this research can be summarised as:

1. A range of losses had been experienced by the study's population which might go unnoticed. Unless a detailed personal narrative is taken, the impact of these losses on their recovery may not be fully appreciated.
2. While rehabilitation can create hope and be a step towards achievable goals for recovery, not all interactions with staff in the rehabilitation unit can be viewed as recovery oriented or facilitative of hope.
3. Hope is at its lowest when participants are not included in key decisions impacting on their life, for example at admission and discharge to and from rehabilitation.
4. For some of the participants in the study, occupational performance and quality of life increased as well as decreased over time.
5. For some of the participants in this study quality of life would appear to be tentatively linked to occupational performance.

## **Chapter Seven**

### **Discussion**

#### **7.1 Introduction**

This research is timely given the renewed interest in mental health rehabilitation (Killaspy *et al.*, 2017; NHS England, 2016) and the emerging influence of the recovery agenda across all mental health care pathways (Perkins and Slade, 2012). It is of particular relevance as the literature review indicated four areas of shortfall in contemporary rehabilitation research, namely: research exploring personal experiences of rehabilitation; limited opportunities within cohort studies to explore personal change; evaluation of skill development as opposed to a reduction in undesirable behaviours; little evaluation of the impact of rehabilitation on quality of life. This study therefore addresses the identified gaps through its use of a prospective cohort residing in a recovery-oriented rehabilitation unit. It also offers a longitudinal view of rehabilitation from admission through to discharge and follow-up, with a client group known to have recruitment and retention challenges (Arfken, Wilson and Hegedus, 2002).

Key findings from this study (Section 6.19) demonstrate the importance of going beyond simply an evaluation of the impact of rehabilitation through high level cognitive and social functioning, without an applied relevance to day-to-day functional activities. The findings also indicate that the use of discharge destination and readmission rates as a measure of the effectiveness of rehabilitation is flawed where there is no appreciation of the individual's context and functional performance levels within their own environments. Attention is also drawn to the importance of engagement in meaningful occupations and the need to embed those occupations into routines to help overcome occupational injustices so often associated with long-term mental health needs (Baker, Procter 2014).

This study, viewed through an occupational lens, has uniquely brought together the quantifiable measurements of individual occupational performance and quality of life, triangulated with the qualitative lived experience of rehabilitation. In doing so, the principles of recovery and person centeredness are embraced, offering a contemporary evaluation of rehabilitation, and adding to a modest current evidence base of mental health rehabilitation focus research (Richards *et al.*, 2016; Ryan *et al.*, 2016).

After presenting a summary of the participants, this chapter goes on to discuss the impact of their losses experienced prior to rehabilitation. It then moves on to consider the interplay for participants of relationships with others, meaningful occupations and sense of control in relation to hope, and goes on to explore the tentative links between occupational performance and quality of life. The chapter concludes with a critique of the research study before offering some recommendations for practice, education and further research.

## **7.2 Study participants**

Studies involving the mental health rehabilitation population are well known for having high participant dropout rates (Arfken, Wilson and Hegedus, 2002). However the dropout rate in this study is favourable when compared to other studies in a similar setting (Killaspy and Zis, 2013). Communication templates, contact details and follow-up protocols in longitudinal studies are recognised as important retention strategies within a research protocol to reduce dropout rates (Abshire, Dinglas et al. 2017). While every effort was made to set out clear expectations and conveniently timed appointments (in particular with Rita), this was often not enough to retain participants when life in the community was resumed. However, dropout need not always be viewed negatively as some mental health rehabilitation participants may fit the notion of 'positive dropout' (Cordella, Greco et al. 2017) a term developed for people dropping out of community methadone programmes as they found alternative, less dependent ways of managing their drug dependency. Viewing rehabilitation dropouts in this way fits well with the concept of recovery, and in particular the concept of positive risk-taking in the community (Stickley, Felton 2006). This could certainly be applied to Steve who was lost to follow-up due to work and education commitments. Arguably, he felt going to work and college was a better use of his time than engaging in the third phase of data collection, despite being very willing to engage in the two previous phases. A follow-up protocol may be a useful addition in the future studies, particularly where there are ethical challenges with people with a mental health need.

Despite the issues of follow-up, the demographic findings of this study indicate that the population of this study is representative of the current national profile of rehabilitation users in terms of diagnosis, average age of admission to rehabilitation and ethnic origin, with between 65% (Killaspy *et al.*, 2016) to 70% (Ryan *et al.*, 2016) of the rehabilitation population being male, and with 90% of the population being White British (Killaspy *et al.*, 2016). This predominance of white British males is concerning, given the high prevalence of schizophrenia in second generation black Caribbean communities in the UK (Pinto, Ashworth and Jones, 2008) and



suggestive of admissions to rehabilitation units being based on variables other than clinical need. This is an area worthy of further investigation, as the ethnic mix of the present study's population was limited.

The average length of contact with mental health services for the participants in this study, prior to rehabilitation was on average 12 years, the same as the national average (Killaspy *et al.*, 2016). However, the mean length of stay for this study's participants was 41 weeks, 10 weeks longer than the national average (Killaspy *et al.*, 2016). This may be linked to an increased pressure on community accommodation from recent closures of nearby rehabilitation units and/or the loss of a dedicated community rehabilitation team. The extended stay in rehabilitation noted in this study may also be linked to the slightly more favourable percentage of participants living independently after rehabilitation (60%) (Section 4.4) as compared to the national average (56%) (Killaspy *et al.*, 2016). The data from this study also suggests that commitment to rehabilitation might be associated with a later age of illness onset, a higher school-leaver age, and a greater range of previous life experience (Tables 4.4 and 4.5). These are only speculative associations, but worthy of further investigation.

### **7.3 The impact of loss**

The findings of this research are first and foremost a reminder that schizophrenia (and other psychotic disorders) is a '*disorder[s] of loss*' (Hochman, Fritz and Lewine, 2005, pg. 280). Generally, loss associated with mental illness has been categorised into four areas; self-care and identity, work and employment opportunities, relationships, and future-oriented losses (Baker, Procter et al. 2009). More specifically, for people with psychosis and schizophrenia, the most common losses (as measured by the Grief in Schizophrenia Questionnaire) are work or school attendance (50%), relationships (42%) and sense of self (25%), with 46% reporting reduced self-esteem and 50% reporting a return to work or higher level of functioning (33%) would signify an improvement (Wittmann, Smith et al. 2010). These findings are reflected in the present study, where the participants spoke about a multitude of losses. At various points throughout the participant's individual rehabilitation journeys, they spoke about the loss of a home and the loss of future potential, including work opportunities (Baker, Procter 2014). The findings also reveal a general and pervasive sense of loneliness (Walid and Zaytseva, 2011) - participants spoke about the sustained effects of a loss of potential (Mauritz and van Meijel, 2009), a loss of hope for the future, the loss of self-identity with the inability to conceptualise a different future for themselves (Baker, Procter et al. 2009). While some participants spoke literally about

their losses, others used metaphors to portray a deep sense of loss (Section 4.6.1c) (Davidson and Stayner, 1997). On each occasion there was a sense that the loss was still being mourned and that acceptance of the loss was for some difficult to achieve, increasing a feeling of hopelessness. Frequently participants spoke about one loss often leading to the next and with the pain of those losses continuing for many years after the event (Panksepp, 2003).

While loss is recognised as cohabiting alongside a wide range of mental illness (Baker, Procter et al. 2009), losses associated with mental illness are thought to be '*a more nebulous and stigmatised form of loss*' (Baxter, Diehl 1998, p350). For example, the concept of loss has frequently been used in derogatory ways, often being connected with losing one's mind, having 'a screw loose' or being a lost soul (Baker, Procter et al. 2009).

As such, recovery from the losses associated with mental health may not necessarily follow the stages of recovery associated with the five stages of grief following the death of a loved one (Kübler-Ross, Kessler 2005). Instead it is thought to require a greater emphasis on education, support and the identification of goals and dreams to discover a 'restructured personhood' (Baxter, Diehl 1998, p352)

Despite rehabilitation being recognised as being well placed to address the rebuilding of social connections and social inclusion (Leff and Warner, 2006), grief work is not a usual feature of rehabilitation practice (Hochman, Fritz et al. 2005). Therefore it could be suggested that for the participants here, the psychological effects of loss were superficially addressed, and there is possibly more that could be done.

However, during their time in rehabilitation and once in the community the participants started to identify and describe new and existing occupations, which gave their days and weeks a sense of routine, for example going to the gym. They were establishing or had a desire to establish new social contacts and were starting to build up their self-respect and self-efficacy with everyday occupations in an attempt to redefine their lives. Yet it felt as if they were all at the start of this journey, still feeling very much on the outside of life waiting to be fully included in family life, receive invitations to friends' houses and to find love again (section 5.3.1) (Davidson and Stayner, 1997). This will be explored in more detail in the next section.

On a practical level, the loss of a home was most frequently mentioned by the participants in this study - they spoke of having to live in cars, in tents, and on a friend's sofa before being admitted to hospital, usually under the Mental Health Act. We know that the prevalence of

mental illness amongst the homelessness population in the UK is high - somewhere between 45% and 80% (Mental Health Foundation, 2016) - and therefore it is understandable that previous research has viewed accommodation post-rehabilitation with high importance (Killaspy and Zis, 2013; Svensson, Hansson and Nyman, 2000). It is readily accepted that good quality housing is essential for good mental health (MIND, 2017; Mental Health Network, 2011), but unless personal losses are addressed, a new sense of personhood discovered (Baxter, Diehl 1998 p.352) and the individual has the skills to function in their environment, accommodation alone will not be sufficient.

One of the unique characteristics of this study has been in the hearing of personal stories, particularly those of loss, as participants entered a new phase of their lives: rehabilitation. The losses are varied in the nature, their timespan and their impact on recovery. However, by listening to the personal narratives alongside the quantifiable measures of functioning, this study has gained an insight into why some people, despite long admissions to a rehabilitation unit, require ongoing support and extra time to redefine a meaning to life for themselves.

The next section considers the interplay of the participants relationship's with others throughout the rehabilitation process and the impact this has on their readiness for discharge.

#### **7.4 The interplay of relationships with others and its impact on hope**

People who use mental health rehabilitation services have traditionally been unwell for many years (Killaspy *et al.*, 2016), they are often stigmatised (Brohan *et al.*, 2010; Jenkins and Carpenter-Song, 2009; Corrigan and Wassel, 2008), socially excluded (Leff and Warner, 2006) and occupationally alienated, with low employment rates (Davidson *et al.*, 2015; Bryant, Craik and McKay, 2004). In addition to this, they often have poor mental resilience (Davydov *et al.*, 2010) and low self-esteem (Benavides, Brucato and Kimhy, 2018). This is a tall order for any service to address, although it remains an expectation of mental health rehabilitation services, where individuals are expected to develop and maintain skills to live in the community, to attain personal goals and have the highest level of autonomy possible (Clarke *et al.*, 2009; Elliot and Harackiewicz, 1994; Eisen and Grob, 1982).

Hearing the voice of the participants as they progressed through rehabilitation to life in the community was insightful. As anticipated, the personal narratives and the mix of feelings expressed by the individuals in this study were a reminder of the uniqueness of each person's recovery journey from mental illness (Anthony, 1993). The individual experiences highlight how

rehabilitation, when felt to be personalised and validating, facilitate a sense of achievement (Thomas and Rickwood, 2016; Richter, Schmid-Ott and Muthny, 2011), but can also contribute to feeling hopeless and despairing (Deegan, 1992) when individuals do not feel respected or treated fairly. These personal stories produced data that was rich in content – their in-depth analysis has generated some contrasting themes.

One of the themes from the analysis was around relationships with others, particularly the staff at the unit. On one hand the findings demonstrate a number of favourable observations and characteristics of the staff and unit, on the other hand some findings are a cause for concern in contemporary, recovery-focused mental health practice. Relationships with family members and friends were present, but not as fulfilling as might have been hoped.

The unit, a stand-alone unit in the community, was frequently recognised by the participants for its calm, quiet and relaxing ambience (section 4.4.6a & 5.4.5), with a nice garden (Monroe, 2015) and flowers in the kitchen (Adachi, Rohde and Kendle, 2000). The staff provided participants with emotional and practical support to understand their medication and with encouragement to get out of bed and to engage in activities of daily living (section 5.2.1). Hope for the future was at its highest at the start of the rehabilitation journey, with many dreams and expectations. There was a sense of anticipation for the future, to belong and contribute, to have somewhere to live, something to do and someone to love (Dimakos *et al.*, 2016).

Staff at the unit played a role in the ambience of the unit and there were plenty of examples where staff got it right (section 5.2.3a), where they went the extra mile (section 6.1.4a) and participants felt as equals, enjoying each other's company (section 5.2.3a & 5.3.2a), all contributing to an environment that felt happy and hopeful (Luk, 2011). When the time came to be discharged, some participants were ready for discharge (section 5.2.2a) and keen to start their new life in the community.

However in contrast to this, despite the attractiveness of the unit, the unit was felt by some to be institutionalised (section 4.6.4a) or inflexible (Bunyan *et al.*, 2017). Towards the end of their time in rehabilitation, while some were ready and looking forward to being discharged, as would be hoped, others expressed feelings of being disrespected and treated inhumanly by staff (section 6.3.4), feeling socially excluded (section 5.3.3b) and vulnerable to illegal drugs being brought into the unit (section 5.3.3a). Participants described an emotional shutting down (section

5.2.3b), choosing to keep themselves to themselves, turning in on themselves, creating a feeling of being abandoned by staff (Deegan, 1988).

Words such as 'institutionalised', 'disrespected' 'exclusion' 'vulnerable' and 'inhumane' are powerful and more akin to a highly dysfunctional custodial facility such as a prison (Edgar *et al.*, 2003) than a rehabilitation unit, staffed 24 hours a day by professional health care staff. While it is not the purpose of this study to explore the staffs attitudes (staff were not interviewed), the feelings elicited through the analysis signify for some a real shift from the hopefulness expressed at admission. While there may be multiple reasons for these feelings, it was clear that these feelings have manifested into a sense of helplessness, and loss of client hope has been attributed to staff experiencing professional burn-out (Maslach, Jackson 1981, Wilkinson, Whittington *et al.* 2017)

Staff burnout is a recognised phenomenon within mental health staff groups (Wilkinson *et al.*, 2017; Campagne, 2012; Maslach and Jackson, 1981). The well-established staff group at this unit had experienced local service closures and felt their service was under threat. They were also carrying long periods of staff sickness, creating a gap in service. Recruitment to the team was anecdotally from redeployment from elsewhere within the locality. Burnout, characterised by a perceived lack of control, loss of interest and a cynical view of the job has been linked to infrequent attendance at reflective practice (Johansson, Nyström and Dahlheim–Englund, 2017) and restrictions on time for appropriate training (Cook *et al.*, 2016; Rudnick and Eastwood, 2013), combining to increase the sense of hopelessness amongst staff (Siu *et al.*, 2012; Salgado *et al.*, 2010; Snyder *et al.*, 2006). Such a cycle of hopelessness can lead to a lack of 'therapeutic optimism' (Killaspy, 2014), one of the biggest barriers to promoting recovery (Boardman *et al.*, 2010; Carroll, Pantelis and Harvey, 2004). While no attempt will be made here to condone or justify such staff interactions, only to contextualise them within the service challenges outlined in Chapter 1 of this thesis, and to remind the reader of long term staff sickness (section 5.2.3b) over the data collection period, which may have contributed to how staff were feeling.

From the individual narratives, the staff appeared to be the most prominent people in the participants lives, generating most of the positive and negative feelings. However, friends and family members were also important and featured highly both in terms of what had been lost and in future hopes. As would be expected of those participants who reached the discharge phase, they all had somewhere to live and most were exploring various meaningful occupations. However, rebuilding significant personal and family relationships and finding a loving

relationship remained out of reach for all five of the participants brought to the forefront. Arguably it could be said that rehabilitation helped address the participants' basic physiological needs of food, rest and mental wellbeing (section 5.2.1a), yet the needs which are traditionally considered as higher level needs, such as self-actualisation, proved more difficult as participants continued to feel excluded from meaningful relationships and important family events (sections 5.3.3b) (Maslow, 1943). While there is some criticism of Maslow's work, namely being hierarchical, too culturally narrow, and with the unachievability of self-actualisation except for very few (Fallatah and Syed, 2018; Neher, 1991), the findings of this study highlight how important feeling safe and secure was to the participants and how this to some extent was linked to the people most present in their lives - the rehabilitation staff, family and friends.

## **7.5 Meaningful occupation and hope**

As seen from all phases of this longitudinal study, the need to recover from a variety of losses and their impact is a sizable part of the rehabilitation journey. From the analysis of the data it has been identified that recovery from such losses takes more than just the passage of time, requiring both positive relationships and engagement in meaningful activity to help restructure a life with meaning and purpose. The value of participating in meaningful occupations has long been appreciated (Wright, 2017; Foruzandeh and Parvin, 2013; Krupa *et al.*, 2009; Law, 2002). The role of engaging in occupations to develop and maintain skills to facilitate independence, a key purpose of rehabilitation (NHS England 2016a), is widely accepted (Crouch and Alers, 2014; Waghorn, Lloyd and Clune, 2009; Van Wel, Felling and Persoon, 2003).

The data shows that the occupations in which the participants were engaged shifted over time. Initially participants spoke out structuring their days with day to day activities such as showering and establishing a medication routine; with a desire to be 'ordinary' (section 4.6.2). As they moved towards discharge and into the community, participants spoke about a sense of mastery and a higher level of competence with their personal and domestic activities of daily living (section 5.2.1), with such occupations becoming embedded within their routines. There was also an interest in leisure and work-based activities which had not been a feature at admission, suggesting a more hopeful view of their future.

Again there were contrasting themes in relation to the types and frequency of meaningful activities on offer at the unit, with some participants feeling there were sufficient activities on and

around the unit, while others felt more could be offered (Wright, 2017; Richards *et al.*, 2016). Having insufficient activities leads not only to boredom, but also to a loss of direction and a perceived lack of progress, possibly exacerbating issues of hopelessness for participants and contributing to staff burnout (Snyder 1996).

Activity within a rehabilitation setting has been traditionally perceived by the service users as predominately part of occupational therapy (Meddings and Perkins, 1999). It would appear that this remains the case at this particular unit - a number of participants mentioned waiting for the occupational therapist to return from sick leave before deciding which activities or occupations to engage in (section 5.2.3a). Waiting for the occupational therapist also suggests that some staff at the unit perceive engagement in meaningful occupations to be the sole domain of the occupational therapist.

While occupational therapists are the specialists in occupational and task analysis, prescribing meaningful occupation as an intervention, they remain under-represented in mental health rehabilitation settings (Berry, 2007). This is despite new commissioning guidelines recommending a balanced skill mix of professions (NHS England, 2016; JCPMH, 2016). When trials have been undertaken to address this imbalance by training other team members to engage service users in activity, their primary nursing-based job roles continue to take precedence, meaning that engagement in activity remains a low priority for non-occupationally trained staff (Cook *et al.*, 2016).

## **7.6 A sense of control and hope**

Similar to hope, which ebbs and flows across the rehabilitation journey, control and feeling in control of life throughout the rehabilitation journey fluctuates. Just as hope grows out of positive staff relationships fostering trust (Salzmann-Erikson, 2013), a sense of control can be developed from a shared and mutual sense respect and dignity (Kogstad, Ekeland and Hummelvoll, 2011) and a genuine interest in the individual (Critten, Bezyak and Fried, 2013).

Hope, while not without some doubt, was most evident at admission (section 4.6.3a) and discharge (section 5.2.1 and 5.2.2a). At admission rehabilitation was described as a 'fresh start' with a desire to be ordinary again (section 4.6.2d). There were aspirations for the future, with the identification of rehabilitation goals (Richter, Schmid-Ott and Muthny, 2011; Yanos, Roe and Lysaker, 2010). At discharge, participants were ready to 'spread their wings' and ready to start

new lives for themselves. However, hope was compromised for some, both at admission and discharge by the lack of control in relation to the decision to move to.

At admission, a number of participants reported feeling forced to move to the rehabilitation unit, frequently being threatened by the Mental Health Act if they did not comply. Often, participants had little or no notice as to when they were to move, with one participant describing moving so quickly she had to remove her washing from the machine. This coercive and authoritative approach to working with people with a mental illness is suggestive of a wider, cultural acceptance of unnecessary and indirect bullying and victimization of participants, which is totally at odds with recovery-oriented and client-centred approaches. While it is unknown who made the threats under the Mental Health Act, it is the doctors who have this power. Interestingly, a recent systematic review of bullying amongst junior doctors found those that had been bullied themselves were more likely to bully others (Samsudin, Isahak and Rampal, 2018).

One might expect a more coercive and authoritarian approach to be associated with a secure or forensic setting (Greenacre and Palmer, 2018) rather than with an acute hospital or community setting as in this study. Surprisingly, those who moved from a secure or forensic setting felt empowered around the decision to move to rehabilitation, they were looking forward to the move (section 4.6.2c). The level of preparedness of these participants suggests a greater level of involvement in the decision-making process (Hamann *et al.*, 2016), creating an internal locus of control (Levenson, 1973).

Similar to the contrasting themes identified in relation to personal control over admission planning, there were opposing experiences regarding involvement and decision making with discharge planning. Some participants described a high level personal control and involvement in the discharge process, and were discharged at a time when they felt ready; others felt they had no control on over their discharge destination or the timing of their discharge. The latter was the most common phenomena and was very much experienced by one participant in this study (Frank), who was not happy with his accommodation and did not feel ready for discharge (MIND, 2017; Galvin, Wills and Coffey, 2017; Grundy *et al.*, 2016; Petersen *et al.*, 2012).

Readiness for discharge is a complex concept and poor discharge planning can have detrimental effects for all patients and service users (NICE, 2016). In addition to physical and psychological stability, discharge from a rehabilitation setting requires a certain level of functional ability, including the ability to attend to activities of daily living (Notley *et al.*, 2012;



Meddings and Perkins, 2002) and the correct level of community support (Galvin, Wills and Coffey, 2017).

Upon moving to live in the community, participants' hopes for the future became integrated into a new and emerging self-identity (Thomas and Rickwood, 2016), with a reduced patient identity (Yanos, Roe and Lysaker, 2010). They were becoming members of the community (Taylor and Perkins, 1991) and developing a renewed sense of belongingness and mattering (Conrad-Garrisi, 2012). Participants were engaging in everyday activities, such as finding the time for a back massage, walking briskly to maintain weight loss and ensuring a good night's sleep (Section 5.3.1).

However, as has been common throughout this study, analysis of the data identified that this new-found hope was not evident for all of the five participants. While each participant had a story to tell, exploration of the five stories suggested that there may be very tentative links between functional performance level, including a sense of readiness to move on, and quality of life.

The next section discusses the extent to which the participants felt ready for discharge in terms of their occupational performance levels and how this might be reflected in the participant's quality of life rating.

## **7.7 The link between occupational performance levels, quality of life and discharge readiness**

Occupational performance, the process of engaging in meaningful, goal-directed and culturally defined actions to achieve a task, is dependent on an individual's functional ability and his or her motivation (Kielhofner 2008). A comprehensive understanding of occupational performance and the associated component skills of the performance is a core and unique skill of occupational therapists. Occupational therapists use this knowledge to help explain and understand barriers to effective day to day functional ability and develop occupational therapy intervention plans (Fisher, Bray Jones 2014, Fisher, Bray Jones 2012, Yerxa 1990).

While functioning and functional ability have frequently been used measures of the effectiveness of rehabilitation (section 2.5), the measures identified in the literature review were either computer based assessments of high level cognitive functioning or clinician rated

observations of a more general nature of social and global functioning (Table 2.5). While these measures have their place, they do not consider the individual performance skill components required to undertake the activity, and therefore have failed to evaluate the inherent ability of the individual to carry out the day to day activities needed to live successfully in the community.

Changes in performance skill level can be measured by the Assessment of Motor and Process Skill (Fisher, Bray Jones 2014, Fisher, Bray Jones 2012), and is a valid and reliable approach to measure this construct across all aspects of health care, including people with schizophrenia (Ayres, Panickacheril John 2015, Fischl, Fisher 2007, Fisher, Liu et al. 1992). However, the changes in occupational performance and the engagement in activities essential for successful community living have rarely been evaluated through an occupational lens (Ayres and Panickacheril John, 2015). Therefore the true essences of rehabilitation - to develop skills, manage a long term condition and maintain independence (NHS England, 2016) - have arguably been missed to date in the rehabilitation literature.

When the impact of rehabilitation is considered through an occupational lens, drawing on principles of Occupational Science (Yerxa, 1990), the occupational imbalances, injustices, deprivation and alienation are brought to the fore. This is essential if rehabilitation is committed to working in a recovery-oriented way (Shepherd, Boardman and Slade, 2008), to promote social and well as medical recovery (Leff and Warner, 2006; Deegan, 2003; Anthony, 1993) and to addresses the stigma which can impede such individual and societal progress (Jenkins and Carpenter-Song, 2009; Davidson, 2008; Link *et al.*, 2001).

Quality of life is a multi-dimensional and dynamic construct (Priebe *et al.*, 1999) and a long-established indicator of change across a variety of health conditions - it was a notable aspect in the evaluation of deinstitutionalisation (Leff and Trieman, 2000; Leff, Trieman and Gooch, 1996). In the present day the desire for an improvement in quality of life is implicit in the underpinning philosophies of both rehabilitation and recovery (section 1.5.4) with the aim of developing new meaning to life (Deegan, 2003; Anthony, 1993) – it is explicit in the principles of occupational science (Yerxa, 1990). However, the literature review identified just two studies where QoL was explored (Arfken, Wilson and Hegedus, 2002; Bruseker and O'Halloran, 1999), suggesting that this fundamental purpose of recovery-oriented rehabilitation has been over looked in recent years. This study through its inclusion of a quality of life measure makes a small, contemporary and affirmatory contribution to the literature base by addressing this omission. However, the findings

of this study are similar, with participants reporting both increases and decreases in their quality of life across their time in rehabilitation (Table 6.5). Further investigation is needed to understand why quality of life decreases during, and as a result of an intervention which is designed to increase quality of life. Consideration of the findings in context of the AMPS provides some insights into this.

Past Assessment of Motor and Process Skills (AMPS) research has identified that people on or above the competency cut-off on both the ADL motor and ADL process scales will be more safe, efficient and effective in performing the activities of daily living than people below the cut offs (Fisher and Bray Jones, 2014; Fisher and Bray Jones, 2012), ADL process skill being a more robust indicator of safety in the community than the ADL motor skill (Fisher and Bray Jones, 2014; Merritt, 2011; Merritt, 2010). The findings of this study provide further evidence to support these assertions, with all five participants having an ADL process skill level on or above the competency cut-off, and just one participant on or above the ADL motor skill competency cut-off.

While all five participants were discharged to community living, the range of accommodation varied from living independently in a flat, in a flat with a partner, in a flat with 24-hour support, to living in a warden-controlled flat. Given this information it would be reasonable to make two basic assumptions: firstly that rehabilitation was a good thing for these five participants, and secondly that those who lived most independently were likely to have higher occupational functioning and therefore more likely to report an enhanced quality of life. However, through the triangulation of individual qualitative and quantitative results with the personal narrative it has been possible challenge these assumptions and look to the detail to contextualise the uniqueness of each person's journey through rehabilitation, with a view to improving the experience for others in the future.

For example, despite moving back to live with his partner, Jason demonstrated a decrease in both his ADL motor and process skills and reported a decrease in his quality of life, clearly highlighting that rehabilitation was not a positive experience for him at this time. Only by understanding his narrative can we contextualise these results and tentatively suggest that for Jason his occupational performance and quality of life were associated. He did not want to be in rehabilitation and saw it as something to endure – consequently, being taken out of his home environment had a negative impact on Jason's ability to engage in activities of daily living and on his satisfaction with life, which possibly created a sense of occupational alienation for him. In

the past Jason may have received community-based rehabilitation (Department of Health, 1999), however, he was admitted into inpatient rehabilitation as that was the only option available to him at the time. Yet we know that in real-life challenges, such as those experienced by Jason, individual home-based occupational therapy is often effective, where skills can be practised within a natural environment (Lindström, Sjöström and Lindberg, 2013; Lindström, Hariz and Bernspång, 2012). However, while there are recognised risks with home based mental health rehabilitation, the outcomes for ADL skills is superior (Marks *et al.*, 1994).

Marco demonstrated the highest level of functional ability of all the five participants and reported a positive change in his perceived quality of life. From the results and his narrative, it would be reasonable to say that Marco benefitted greatly from rehabilitation and that again there are tentative links between a significant increase in his ADL motor skill and his quality of life. From his narrative, we know that Marco, educated to degree level, aware of his responsibilities as a father and with a strong work ethic, was excited about moving into his new flat and making it his own. However, he continued to express occupational injustices, as he remained out of work and excluded from the lives of his children. While these needs may be beyond the scope of a hospital based rehabilitation programme, it does highlight the need for higher level, community based rehabilitation to ensure individual progress is maintained and extended. It is essential that boundaries for recovery are pushed and that injustices on all levels are addressed (Townsend and A. Wilcock, 2004).

Of the five participants, Mabel and Frank continued to demonstrate the lowest functional ability when compared to an age-matched normative sample, despite Mabel making significant improvement with her ADL Motor and Process skills and Frank significant improvement with his ADL Process skills. Both reported improvements in their QoL, with Mabel noting positive changes with her perceived QoL and psychological wellbeing, Frank noting a positive change in his self-esteem but a negative change in his psychological wellbeing. For Mabel there would appear to be a somewhat clearer association between her functional ability and her quality of life. This is further supported by her narrative, given that she was now living independently for the first time in her adult life and had established some occupational balance throughout her week (Notley *et al.*, 2012).

Mabel like Marco was excited, ready and prepared for her discharge, Frank was not. Frank did not experience the same level of control and agency with his discharge planning as Mabel (Lysaker and Leonhardt, 2012; Boardman *et al.*, 2010). He also had unresolved issues relating to the

loss of his family home (Mauritz and van Meijel, 2009), and experienced substantial occupational imbalance and marginalization as he had been unable to develop a meaningful daily routine for himself while living back in the community.

While both Frank and Mabel were discharged to live on their own, Nigel, whose functional performance levels were higher and more aligned to an age-matched norm, requested to be moved into a flat with 24 hour care. Without the contextualization of his narrative, such a move would possibly raise questions from commissioners or budget holders who failed to understand Nigel's life prior to rehabilitation. It can take a long time to regain the confidence and skills to re-enter mainstream society (Tregoweth, Walton and Reed, 2012) following a number of years in a forensic setting, which are known to be highly restrictive environments (Greenacre and Palmer, 2018). Nigel's choice to take his discharge into the community more slowly than might otherwise be expected, could be attributed a newfound sense of agency and personal responsibility (Boardman *et al.*, 2010) with personal insight and self-awareness given his history (Farnworth and Muñoz, 2009; Fresán *et al.*, 2007).

This appears to be the first time rehabilitation has been evaluated using AMPS (Fisher and Bray Jones, 2014; Fisher and Bray Jones, 2012) alongside the Lancashire Quality of Life (Oliver *et al.*, 1997) and qualitative interviews. Through this method of evaluation it has been possible to understand individual rehabilitation journeys in more detail, in particular for those people entering rehabilitation from home or are taking a slower road to independence than might be ordinarily expected.

## **7.8 Summary of discussion**

This study is timely, given the current interest in rehabilitation and recovery. It and offers a unique approach in exploring mental health rehabilitation through an occupational lens. Individual occupational performance levels and quality of life have been triangulated with personal narratives over a longitudinal timeframe. While the population in this study is representative of the national profile, the findings give rise to further questions relating to the ethnic mix of a rehabilitation cohort and whether length of stay and previous life experience have an impact on the level of commitment to rehabilitation and its outcomes.

The impact of a variety of losses was a key finding of the study. While loss has been recognised previously within mental health, particularly associated with grief and depression, the study of loss within the context of mental health recovery has highlighted the need for a greater

understanding of recovery from multiple of losses for those also having a long-term mental health need. In particular it has highlighted the need to think beyond traditional 'grief work' to consider how people in a rehabilitation setting can be helped to overcome a multitude of losses, with ongoing stigma and injustices, to start to develop a restructured life.

The concept of hope featured highly throughout discussions and was considered in relation to the participants' relationships with others, their involvement in meaningful occupations and a perceived sense of control. Hope was not constant throughout an individual's rehabilitation journey, and through the analysis of the data was linked to the participants' quality of relationships with other people, what meaningful activities they were engaged in, and the amount of control they felt they had over significant decisions, such as admission and discharge to rehabilitation. While the findings affirm and support previous research in relation to the principles of recovery, it is a poignant reminder of the responsibility staff have to remain hopeful and engender hopeful relationships - which may at times be very problematic, particularly for those staff who have experienced burnout.

Over the course of rehabilitation, the activities participants became involved with changed, as did personal expectations and hope for the future. At admission, participants described wanting to develop a routine of personal and domestic activities of daily living. As they moved towards discharge, participants identified a level of mastery and effectiveness which, in the main, made them feel ready for and in control of their discharge, providing the confidence to see out work and leisure based activities.

The unique approach of looking at rehabilitation through an occupational lens has enabled tentative links to be made between occupational performance levels and quality of life, when triangulated with personal narratives. Where individuals felt some of their occupational injustices were being addressed, their quality of life appeared to increase, and vice versa. Interesting insights were gained into the experience of rehabilitation and the personal narrative provided a rich understanding of why some people appear to gain more from rehabilitation than others, and some choose a slower route to independence. While recognising the similarities between the study participants and the national profile of rehabilitation service users, recommendations arising from the present study need to be considered in the context of a single study conducted in a single rehabilitation unit. This is just one critique of the study; the following sections consider its wider strengths and limitations.

## 7.9 Critique of the study

The study design and methodology was purposively selected to address the gaps identified in the literature review. A mixed method, longitudinal design was chosen to explore quality of life and functional performance across three timeframes. The quantitative data generated from the Lancashire Quality of Life Profile and the Assessment of Motor and Process skills was triangulated with personal narratives, gathered at each of the three timeframes via one-to-one semi-structured interviews. While this purposive sample from a single unit was representative of those accessing mental health rehabilitation units, the unit itself, the attitude of its staff, and the environment were specific to that particular unit. Therefore while the findings may have wider significance, they must be interpreted with caution given the sample size.

There are recognised challenges in recruiting and retaining participants with mental health needs to research studies - this study also had its challenges, with the original sample size of 19 reducing to 5 over time. However, to put this in context, over 50% of the participants (10/19) remained in the study long enough to produce two sets of comparable data, and of that 10, three were readmitted to hospital, leaving just two who failed to engage with the final phase. One of these was identified as a 'positive dropout', the other could possibly have been more assertively followed up, but this would not have been ethical and was outside the remit of the researcher. Practical and ethical issues are explored in more detail in Chapter 8.

The remaining five participants produced a total of 45 individual sets of data - a sizeable amount of data, analysed using three different approaches before being triangulated into individual case studies. This provided a detailed view of five individual journeys through rehabilitation through an occupational lens - which is a unique feature of this study.

### a) Semi-structured interviews

Interviewing is embedded within a constructionist approach to research and by their very nature interviews provide a subjective view of events, which is important when personal experiences are being investigated. In this research study, personal experiences added a substantial and meaningful context both to understanding the individual, and in explaining the differences in the quantitative data findings. The interviews brought the quantitative data to life and meant that the

individuals were kept at the forefront of the study. However, despite assurances of confidentiality, the closeness of the participants to the unit during phase 1 and 2 might have influenced participant openness. Similarly, the distance from rehabilitation in phase 3 may have meant that experiences were reported following the period personal reflection and interpretation.

Analysis of the 31 interviews following transcription was completed by means of a table-top paper exercise, where the data was coded and themed for each of the three phases using the stages of thematic analysis as described by Braun and Clarke (Braun and Clarke, 2013). While this was a fluid and iterative process requiring multiple versions, it allowed themes to emerge from the data which had not been possible using Nvivo (see Chapter 8), which was found restrictive as a data management tool, inhibiting creativity of thought and flexibility, and was therefore aborted. One critique of semi-structured interviewing for data collection in this study was that no interview transcripts were returned by participants to suggest amendments or confirm that the transcript was a fair and accurate reflection of their interview. However, the semi-structured interview schedules were subject to external review and the themes elicited from the interviews were subject to rigorous critical debate and discussion as part of supervision, both processes increasing the rigour. Rigour could have been further enhanced through the use of staff focus groups to explore their perceptions of the unit at the time.

#### b) Lancashire Quality of Life

The Lancashire Quality of Life questionnaire was chosen as a data collection tool following a brief pilot study (section 3.3.4.2) and was typically completed on the same day as the semi-structured interview. Participant burden, although not experienced by the majority of participants, may have been part of the reason why three participants declined to continue at the start of the study (Appendix 4.1). While the questionnaire was not difficult to administer, the 100 plus questions once entered into PASW were initially challenging to work with. However with experience this process became easier. Over time analysis shifted from exploring clinically meaningful change to minimal detectable change, which given the volume of data and the mixed methods approach, was more manageable and more meaningful (Chapters 3 and 8).

Part of the questionnaire produced the Life Satisfaction Score (LSS) - 'work' was one of the nine LSS subscales (Chapter 6). However, as no participant was in work, either paid or voluntary at phase 1 of the study, no baseline data was available - it was therefore removed on the guidance



of the authors of the questionnaire. This meant that at discharge and follow-up when participants were starting to move into part-time studying and voluntary work that there was no comparative data from which change could be measured. Given some participants had already been educated to degree level and had held down full-time jobs in the past, this was a potential omission in the data which may have impacted on final QoL scores. The consideration of work, voluntary or paid, is therefore a noticeable gap within this study.

### c) Assessment of Motor and Process Skills

The AMPS, due to the requirement to purchase or gather various items, such as ingredients or a clean shirt to iron, was frequently completed on a different day to the QoL and interview. While this second session of data collection may have added participant burden, anecdotally the participants enjoyed choosing and conducting the two assessment activities and there were no difficulties with gathering the ingredients or equipment, as has previously been noted in clinical practice (Hitch, 2007). However, due to the practicalities of six people sharing a kitchen and bathroom facilities, the only issue was one of timing to ensure other residents at the unit did not require use of the same room at the same time.

Of a total of 66 completed tasks across the 3 phases, a total of 36 different tasks were completed. These offered a variety of challenges across the task hierarchy (Fisher and Bray Jones, 2014) from much easier than average (5), easier than average (6), average (16), harder than average (6) and much harder than average (3) (see Appendix 7.1), suggesting a wide enough variety of tasks for the participants.

Over the course of the study the AMPS software was updated, meaning that it was no longer possible to compare more than two assessments on one graphic report (previously three assessments could be compared at once). While this was not a significant problem it meant that the results for the third phase had to be input onto the graph manually. The remaining features of the software remains the same, producing standardised graphs and tables.

## 7.10 Recommendations

Based on the findings of this research a number of recommendations have been made for rehabilitation services generally, occupational therapists working in a mental health rehabilitation setting, as well as suggestions for further research.

a) Recommendations for the practice of rehabilitation in mental health:

- All potential rehabilitation clients should be involved in the decision to move to a rehabilitation unit and not feel forced or coerced to move. The involvement of previous service users in the very early stages of the referral/assessment process may be beneficial in the shared decision making process to provide an 'insider view' alongside that of the staff.
- Loss and the range of losses should be explored as part of the routine initial rehabilitation assessment process. Consideration should be given as to whether to offer one to one support or a structured sensitive group setting in order to explore personal losses as part of the recovery process. This would depend on client profile at any given time.
- All rehabilitation services should be subject to a recovery-based evaluation or audit on an annual basis to review the attitude of staff, establish a level of hopefulness, and put plans in place to improve year on year. An example of a validated tool is The Hope Agency Opportunity (HAO) Questionnaire (Newman-Taylor, Garner et al. 2017).
- All rehabilitation services should introduce a measure of quality of life as part of their initial assessment process and use the findings to set and review individual rehabilitation goals. An example of a validated tool is the newly developed ReQoL (Keetharuth, Brazier et al. 2018).
- All rehabilitation services should review staff burnout rates on an annual basis, and be proactive to prevent and alleviate it. An example of a validated tool is the Maslach Burnout Scale (Maslach, Jackson 1981).
- All rehabilitation services should consider an outreach function which can support clients after discharge from a rehabilitation unit for the first few of weeks to assist with the transfer of skill from rehabilitation to home.

b) Recommendations for occupational therapists working in a rehabilitation setting:

- Occupational therapists should lead or be active in the assessment and admission process of all potential rehabilitation clients. This would provide a benchmark of the client's day to day functional ability and provide valuable information for future goal setting.
- Occupational therapists should lead or be active in the discharge process, to evaluate and review day to day functional ability and make recommendations for ongoing suitable accommodation and future rehabilitation goals.
- Occupational therapists should consider including group or individual work around loss within the more traditional occupation-based interventions.
- Where trained, occupational therapists should consider embedding the use of AMPS within a rehabilitation setting. This would help with initial intervention plans, discharge planning and becoming an advocate for the client with their ongoing level of need for support. Comparative data could also be fed into a service evaluation or audit to review if rehabilitation is helping to improve clients' ADL skills.

c) Recommendations for further research in order to:

- Establish why, given the prevalence of psychotic illness, the population of rehabilitation units have such a limited ethnic mix.
- Establish if there are personal differences which optimise the commitment to rehabilitation, and whether length of stay impacts on the level of independence at follow-up.
- Further explore the links between quality of life and occupational performance levels.
- Explore staff perception of mental health rehabilitation by means of:
  - focus groups to explore perceptions of rehabilitation, the unit they work in and the requirements of clients
  - longitudinal studies from the perspective of the community mental health teams to explore the ongoing recovery journeys of 'positive dropouts' to understand their trajectory

## 7.11 Chapter summary

This discussion chapter has brought together and triangulated qualitative and quantitative findings to illuminate and draw conclusions on the five key findings of this study. Experiences of loss, the impact of staff attitude on engagement and hope, the tentative links between occupational performance and quality of life, have all been discussed in relation to the individual case studies and within the context of the literature. This critical examination and discussion has highlighted personal reasons and presented possible explanations for the feelings experienced and the decisions made by participants, thereby keeping the individuals at the forefront of the study.

The strengths and weakness of the methodological approach in the study have been critiqued. However this study is unique in addressing an established gap in the literature and adding to the understanding of rehabilitation and this makes it distinctively different from previous research.

The recommendations put forward, in addition to areas for further research, include ways to increase client involvement in key decisions which have an impact on their life, in particular in relation to admission and discharge. Occupational therapy involvement at this time is recommended to ensure occupational performance ability matches with occupational and community demands. Other recommendations include a focus on extending rehabilitation into the community, an audit to review the recovery-orientation of a service and the inclusion of grief work into mainstream rehabilitation practices.

The following final chapter concludes this thesis with a personal reflection.

## **Chapter 8**

### **Reflections and limitations of the study**

#### **8.1 Introduction**

This final chapter offers both personal reflections and a deeper, more personal look at some of the limitations of the study. Researcher reflexivity, the ability of the researcher to '*turn a critical gaze towards themselves*', (Finlay and Gough, 2003, p3) is difficult to achieve - it requires the researcher to take an objective look at themselves and their actions. However this is a central part of qualitative research, enabling researchers to develop an awareness of their role in the research process, and allowing them to understand their own perspective, acknowledge any biases, and understand the impact of conscious and unconscious motivations on research design and results (ibid). I found this particularly important - as an occupational therapist I value the contribution of reflection on my own self-awareness. While I had no clinical involvement with any of the study participants, I was part of the senior management team and provided clinical supervision to the rehabilitation unit staff, thus reflexivity was vital for me in understanding my feelings and role in relation to the whole research process.

In considering reflections and limitations I am responding to both the constructionist and positivist ontologies used to guide a mixed method study, where both qualitative and quantitative data have been used to seek an answer to everyday questions relating to everyday human behaviour (Creswell, 2014; Tashakkori and Teddlie, 2010). This reflexive account highlights the challenges I faced as a researcher in bringing together two different approaches, each with their own research methodologies and terminology, and each with their own presentation of what constitutes a truth. It lays out and challenges some of the assumptions I had held and some of the conflicts I had experienced as both a therapist and researcher. It highlights how I have changed through the process of combining being a therapist and a researcher.

#### **8.2. Some basic assumptions**

My first assumption was that I was embedded within the constructionist ontology and epistemology, with a natural bias towards many truths and qualitative methods. The small

research study I undertook for my master's degree used a phenomenological approach. It therefore seemed natural to me that any further research study would follow the same ontological and epistemological approach. However, I was challenged to move away from this stance, given that I was aware of the tensions between the commissions and clinicians and their disparate views on the value of rehabilitation. I felt I needed to demonstrate the impact of rehabilitation in a way that would be understood by those commissioning and evaluating the service, without losing sight of what was important for those using the service. The literature review confirmed for me how often the voices of people using rehabilitation services go unheard, and I was interested to explore the impact of rehabilitation on skill acquisition and quality of life - two key aspects of rehabilitation. This of course is the second of two assumptions - subconsciously I was of the opinion that rehabilitation was a good thing and that it would impact positively on a person's life.

Through the use of a reflective log, these assumptions were brought to the fore in my thinking. I have been able to see how my values as an occupational therapist, particularly those in relation to client-centred work, kept pulling me to hear the client's perspective. While this is a positive attribute for a therapist, within the context of this enquiry it was felt not to be enough. I needed some objective measure to complement or underpin subjective experiences. As a therapist I fully appreciate the subjectivity of experiences and the social construction of those experiences (Burr, 2003; Finlay and Gough, 2003), however within the wider context of rehabilitation, more tangible, objective measures are required when the future of a service is being considered. Through supervision and engagement in personal reflexivity it transpired that I needed to balance this tension within myself.

I can now see that my desire to find a middle ground, to hear both sides of a story, is reflective of my clinical role at the time and my personality, with a natural position of trying to find balance within a life that is never straightforward and balanced. Through reflection I have concluded that I am much more a pragmatist, and will use whatever method is needed to find that balance, and will represent opposing views fairly in the search of finding an agreed truth in any given situation.

### 8.3 Conflicts and challenges

Over the course of undertaking this research there have been a number of conflicts which have required resolution: from the methodological conflicts mentioned above, to those pertaining to data collection, data analysis and presentation of results. There has been no simple or straightforward resolution to any of these, and each has tested me from a variety of standpoints, including ethically, academically and personally.

#### a) Researcher/ therapist

First and foremost, given my assumption that rehabilitation is a good thing and my awareness of the tensions within the service, I needed to be careful that I did not impose my opinions onto participants or allow them to influence how I worked with the data. This was particularly relevant during data collection and most evident when conducting and analysing the semi-structured interviews. It was much less evident with the quantitative data, although this brought different conflicts.

The data collection was the most enjoyable phase of the research process. However, it was more challenging than I had originally anticipated given my clinical experience, and gave rise to a particular conflict. While I am an experienced therapist I am a novice researcher, and my role with participants is different to my role with clients or patients, with different ethical boundaries. While both roles are about making the person feel comfortable, listening to them and collecting information, I was aware that some of the nuances in my language and the syntax of my sentences made me sound on the recordings very much like a therapist. While the actual words used within my opening question style, for example, '*Can you tell me more about that?*' or '*How did that make you feel?*' may not be very different from the words an experienced researcher interviewer might use, I had to be constantly mindful that my questions were not for the purposes of therapeutic formulation, writing a treatment plan or carrying out interventions.

On reviewing the interview recordings I was aware of probably longer than normal silences and a number of hesitations. On reflection I attribute these to two things: firstly, I am very comfortable with silences in interview settings, and secondly I was holding back from offering insights I had gained from the client through clinical reasoning. This combined approach may have interrupted the flow of conversation somewhat. Withholding the analysis of participants'

conversations with me never really sat comfortably, and while I believe I was empathic, it is possible that this distance I created as a researcher had an impact on the participant's desire to share with me, therefore impacting the overall retention rate.

A further researcher/therapist conflict arose while completing phase 3 of the data collection, and this was particularly apparent with one female participant. The participant had been discharged to her own home and my plan was to meet her there to complete the data collection tools. She was inconsistent in keeping her appointments, often out when I arrived at the agreed time. If I had been working clinically I would have gone and looked for her in places where I knew she might be found, but this felt ethically wrong as a researcher. In total I made three appointments to complete the interview and AMPS with her, and on each occasion she was out. On two occasions I called to rearrange, but by the third time I had to accept that despite her agreeing to see me her behaviour was telling me otherwise. This gave rise to another conflict on whether or not I should alert the community mental health team of her non-attendance at our meetings. Given I was researching as an occupational therapist I still had a duty of care, which meant I had to 'step outside' of my researcher role and act in accordance with my professional code of conduct.

An additional challenge for me arose when the unit's only occupational therapist was on sick leave for approximately six months. During this time there was no occupational therapy cover: no assessments of functioning, no treatment plans to address the occupational aspects of treatment, and very few therapeutic groups were held. Not only did this affect the results of this research, but I felt ethically compromised: had I not been using the unit for research, I could have stood in and offered clinical interventions. The compromise comes from essentially prioritising the longer-term benefits of the research to a wider group of people over the immediate client need. I felt some frustration at this time as had it been a nurse or a doctor who had been off work for such a length of time, I felt confident a temporary replacement would have been sought.

#### b) Data collection and analysis

As the data was collected, the AMPS data was uploaded to the Centre for Innovative OT Solutions (CIOTS) website and the QoL data to a specially designed PASW database. Initially



the transcription of the interviews was commenced within a week of the interview. However as each one was taking approximately 10 hours to transcribe, I decided to outsource some interviews towards the end of the process. While this could be seen as removing myself from the data and possibly compromising the consistency of the transcription process, extra care was taken to listen back to the original recording and check the transcript for accuracy. Having transcribed all of phase 1 and most of phase 2 personally, I felt I had achieved a good understanding of the participants, and this practical approach did not I believe have an impact on the quality or authenticity of the transcription.

Data analysis was always going to pose a challenge, given the three different approaches to data collection and the range of methods used. For this reason I made the decision to wait until all data was collected before starting on analysis in order to gain an understanding of the overall picture and complexity rather than as separate parts. I started with the interviews in order to re-familiarise myself with the participants.

Having read the scripts thoroughly I decided to use Nvivo in the initial stages of thematic analysis. This decision was made because of the volume of data, and Nvivo was thus used for all 19 interviews at phase 1. However, the themes elicited bore too much resemblance to the themes on the semi-structured interview schedule, raising the question of how novel the themes actually were. On reflection, I attributed this to a lack of personal familiarity with the tool and attempting to work with an unfamiliar method of analysis.

I therefore made a difficult choice to abandon the use of Nvivo and restart the thematic analysis by reading the scripts again. Colour coding was used to identify themes, and these themes were grouped together before clear overarching themes emerged from the data. This was a lengthy and painstaking exercise, but one with which I was familiar and comfortable following my masters level research. However, due to the volume of data the process took a very long time. This process was repeated for phase 2 and 3 and continued well into the writing up stage. While I feel the results of phase 1 and 2 were robust, phase 3 with fewer participants felt somewhat thinner. I recognised however that retention of participants can be a challenge with this client group, therefore to have five participants across three phases felt like a minor success.

The AMPS data was relatively straightforward to input and draws down results from the computer-scoring software held on the CIOTS website. However, mid-way through the research there was a system upgrade which would only allow for two, compared to the previous three sets of data to be compared. Despite contacting the UK lead for AMPS and having email correspondence with CIOTS directly, a solution could not be found to allow the results of all three phases to be shown on one graph. While this is not necessarily important on a day to day clinical level, it meant I was obliged to draw in the third position on the motor and process logit graphs.

Unlike the analysis of the AMPS data, which was relatively problem free, the analysis of the QoL data was the most difficult and personally challenging aspect of the research project. With the assistance of one of my supervisors I set up the original spreadsheet using Version 21 on Predictive Analysis Software (PASW). After each completed questionnaire the data was input with care into the software. During the two years of data collection I familiarised myself the functions of the software and became expert at producing descriptive statistics, however this process was challenging in terms of the learning required.

Once all data had been entered, more detailed analysis was required. Due to the small numbers and in order to compare individuals rather than groups over time, it was decided to look at clinically meaningful as opposed to statistically meaningful change. For the next year, I calculated clinically meaningful change (CMC) by determining the reliable change index, effect size and standard error of measure for each of the 37 completed quality of life questionnaires. I had gathered a large amount data and learnt a good deal about statistics, but the data was too detailed to draw meaningful conclusions from. Similarly to the experience with NVivo, I decided following further guidance and supervision to go back and re-analyse the data, this time using changes above or below the minimal detectable change (MDC) threshold. It was at this point I also decided to focus on the three main areas of the QoL questionnaire - perceived quality of life, psychological wellbeing and self-esteem.

However, the multiple ways in which the quality of life data could have been analysed made me question the validity of quantitative research, in much the same way true positivists question the validity of qualitative research.

### c) Presentation of results and discussion

Having analysed the data and arrived at the results, the next challenge was in presenting the results in a way appropriate to a mixed methodological approach. I eventually settled on first presenting the results of the thematic analysis in two separate chapters to account for the volume of findings, with the first chapter containing vignettes of the participants as a reminder that they are central to the research - a nod to my constructionist roots. The presentation of the AMPS and QoL on an individual participant basis highlights that my interest was in personal change rather than group change.

The writing of the discussion chapter posed a major personal challenge. I had gathered a great detail of information but was unsure how to proceed. Throughout my personal journey as a researcher, I had transferred from Cork to Brunel University. This move to a new supervisory team coupled with a computer fire and the loss of work to date was the first point at which I felt my personal and academic resilience was tested. At about the same time I experienced major challenges in my personal life including serious illness and bereavement in the family. Between January and April 2018 I took some time out, this was the second official break to my studies, the first being in May 2016 because of an accident sustained at work leading to a broken arm.

### **8.4 Reflections of the unit**

I found the unit to be an incongruous place to be - neither a hospital nor a home, but some uncomfortable place in the middle. This may be reflective of the nature of rehabilitation, the place in-between hospital and home, the time when clients feel uncomfortable as they are out of their comfort zone, living with people they had not chosen to live with, and having the prospect of an unclear future once they leave the unit. In an attempt to make the unit more homely there were always flowers on the kitchen windowsills, fresh fruit in the fruit bowl on the kitchen table, and well-tended pretty gardens around the unit. However, to me the overall atmosphere felt cold and unloved, the books on the book cases were old and unappealing, the magazines were out of date and the fish in the therapy room at the end of the garden were very unattractive. The locked staff office, the large notices on the doors, and smell of hospital laundry were a constant reminder that it was a hospital site.

Although I had a good working relationship with the staff and they were helpful in the recruitment of participants for the study, I always felt like an outsider to the unit. I often wondered how patients felt having to wait outside in the rain, as frequently did I, while the nurse in the office finished their call before the door was opened to let them in.

To me, the unit was a place that didn't understand its own position or what it was trying to be. At a time when other services closing, the staff on the unit appeared vulnerable and defensive - letting outsiders into their safe place was difficult. As a researcher I was asking their patients to tell me about their experience of being on the unit – this possibly posed a threat to the staff group at a difficult time.

## **8.5 Concluding comments**

As I write this final chapter, I have the luxury of looking back over my life from 2010. Without a doubt it has been a very long journey, with both personal and professional learning. However despite some very sad and painful times I have been determined to continue my studies. Taking time out I have learned is okay - we all need time to recover and start again. The timeout with a broken arm was enforced - I physically was unable to type for six weeks. However, following a close family bereavement I needed time out - I was aware that I was emotionally and physically closed down for a while. I have learned that it is okay to stop for a while, to take the time to balance oneself again and find a way forward in a life that will be different.

It was only when I started to write this final chapter that I realised I had experienced two episodes of rehabilitation, and this lead me to explore my own experience of rehabilitation and compare it with the experiences of those in the study. Like so many of the participants I had experienced loss - loss of function and loss of someone I loved dearly. Through reflection and the natural healing process I have come to realise how important control and hope for the future are for me personally. I knew this professionally, but personal experience is very different. It highlighted how I - someone I wouldn't ordinarily describe as defensively controlling – felt vulnerable when not in control and how hope for the future is essential to move on from the dark days of yesterday, how we need something to focus on and drive us forward, not negating the loss but embracing it into a new normal.

Again I am drawn to think of the participants in this study, why some could move on but others remained stuck. I moved on from being stuck in the writing of my discussion chapter to discover there is a way to bring lots of information together in a way then would make sense to others. But this didn't happen overnight and it didn't happen in the first iteration – so why then do we think rehabilitation for our clients should be successful first time, without recognising or paying attention to the small, very positives steps in a new direction

## 9. Glossary of terms

Activities of Daily Living (ADL): Day to day occupations that can be categorised into personal (teeth cleaning), domestic (cooking) or work (paid, voluntary or home based).

Assessment of Motor and Process Skills: A standardised observational assessment, conducted by a suitably trained occupational therapist to evaluate 22 components of functional performance

Client: A person with a mental health need who uses the care and support offered of primary, secondary or tertiary mental health services. The term is often used interchangeably with patient and service user, with patient often seen in mental health work as paternalistic and outdated while service user is frequently associated with those who access specialist drug or alcohol services.

- In this thesis patient is used pre the emergence of 'Recovery'. In the era of recovery client and service user are used to signify a more equal relationship between two or more parties and are used interchangeably throughout

Functional performance: The ability and effectiveness of carrying out physical and psychological performance components (e.g. lifts, moves and sequences) to complete an activity or occupations.

Inpatient unit: A mental health rehabilitation unit located in the community but regulated by the Care Quality Commission against agreed mental health hospital standards. It is staffed by qualified nurses 24 hours a day, with on call medical support and has the legal framework in place to accommodate people on section of the Mental Health Act.

Occupational Therapy: A registered health profession which draws on a range of bio-pyscho-social sciences alongside occupational science to facilitate personal change to overcome the challenges presented by physical and or mental disability or illness. Everyday meaningful occupations are the treatment medium of choice

- Occupational capacity: The ability to participate in occupations, influenced by a person's physical and psychological performance components, the environment and the demands of the activity or occupation
- Occupational performance: The process of engaging in meaningful, goal-directed and culturally defined actions to achieve a task

Occupational Science: The study of humans as 'occupational beings'

- Occupational alienation: A sense of purposelessness and loss of control that arises from engaging in activities or occupations that have no meaning for the person
- Occupational apartheid: A sense of separation between those can and those who cannot engage in meaningful occupations

- Occupational balance: A sense that arises when a person is satisfactorily engaged in a range of meaningful activities or occupations that are harmonious with their aspirations and values
- Occupational deprivation: A state of being excluded from the opportunities to engage in meaningful activities or occupations
- Occupational Injustice: When the right to engage in diverse and meaningful occupations is not upheld impacting on the individual's needs and potential to develop

Psychotic illness: A transient or persistent, severe and disabling brain disorder that affects a person's thinking, perceptions and behaviour, affecting approximately 1% of the population, with the most common condition being schizophrenia. While many people go on to live rewarding and full lives, some become stigmatised and excluded from the community.

- Negative symptoms of schizophrenia: These symptoms are associated with disruptions to normal emotions and may be primary, because of the illness or secondary as a way of escaping from the distress of the positive symptoms. They can be overlooked, assumed to be laziness or mistaken for other illnesses such as depression.
- Positive symptoms of schizophrenia: Generally recognised as *hallucinations*, (when the person can hear, smell, see or feel things that are 'not real') or *delusions*, when a false belief is held (for example, they believe they have special powers)
- Cognitive impairment: The slowing down of mental processes making processing information and decision making more difficult. Also referred to as psychomotor retardation.

Recovery: A paradigm or worldview whereby it is believed people with a serious mental illness can rebuild and live a life of value, hope and meaning. It originated from a social movement of oppression and clinical evidence, challenging the notion that people with long term serious mental illnesses, such as schizophrenia will never be any different. It is recognised that there are two types of recovery:

- Clinical recovery: A state of being where the symptoms of an illness no longer exist, or have been cured
- Social recovery: A state of being where a person has rebuilt or adjusted their life following an episode of illness (with or without on-going symptoms) so that it has meaning, purpose and hope. For example, a person may need to change job, adjust family routines or develop new relationships which accommodate ongoing symptoms and allow support and facilitate full integration into life and the community they live in. People can have social recovery without clinical recovery.

Recovery- orientated practice: An intervention or range of interventions delivered from a recovery perspective, acknowledging that change is possible and delivered in a way that is in accordance with person- centred working, promoting hope, agency and opportunity.

Rehabilitation: A process, after illness whereby a person regains skills or finds new ways of doing old activities to increase their independence and improve their quality life. Rehabilitation or rehab is usually goal oriented and facilitated by a range of therapies, it traditionally works within the wider framework of the medical model.

Psychiatric rehabilitation: A process whereby people with a serious mental illness are helped to develop the skills to live in the community, as independently as possible. It usually takes place after a long period of hospitalisation. Psychiatric rehabilitation was traditionally associated with the closure of the large psychiatric institutions and the need to ensure people had a range of communication, social and domestic skills to support deinstitutionalisation and to help them be accepted into the community

Psychosocial rehabilitation: A multi-faceted, person centred intervention drawing on knowledge, skills and techniques from a wide range of psychological and social theories. It builds on the principles of psychiatric rehabilitation, acknowledging both the recovery paradigm and advances in a range of therapeutic and pharmacological interventions.



## 10. References

- Aas, I.M. (2011) 'Guidelines for rating global assessment of functioning (GAF)', *Annals of general psychiatry*, 10(1), pp. 2.
- Abshire, M., Dinglas, V.D., Cajita, M.I.A., Eakin, M.N., Needham, D.M. and Himmelfarb, C.D., 2017. Participant retention practices in longitudinal clinical research studies with high retention rates. *BMC medical research methodology*, 17(1), pp. 30.
- Adachi, M., Rohde, C. and Kendle, A. (2000) 'Effects of floral and foliage displays on human emotions', *HortTechnology*, 10(1), pp. 59-63.
- American National Heart, Lung and Blood Institute (2017) *Quality Assessment tool for Before-After (Pre-Post) Studies With No Control Group*. Available at: <https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools> (Accessed: 07/13 2017).
- Anaf, S. and Sheppard, L.A. (2007) 'Mixing Research Methods in Health Professional Degrees: Thoughts for Undergraduate Students and Supervisors', *Qualitative Report*, 12(2), pp. 184-192.
- Anderson, J., Dayson, D., Wills, W. and Gooch, C. (1993) 'The TAPS project: XIII. Clinical and social outcomes of long-stay psychiatric patients after one year in the community', *The British Journal of Psychiatry*, 162 (s19), pp.45-56
- Andreasen, N.C. (1989) 'The Scale for the Assessment of Negative Symptoms (SANS): conceptual and theoretical foundations', *The British Journal of Psychiatry*, 155 (7), pp. 49-58
- Andreasen, N.C. (1982) 'Negative symptoms in schizophrenia. Definition and reliability', *Archives of General Psychiatry*, 39 (7), pp. 784-788.
- Andresen, R., Oades, L.G. and Caputi, P. (2011) 'Measures of individual recovery', *Australian and New Zealand Journal of Psychiatry*, 45(10), pp. 900.
- Andrew, S. and Halcomb, E. (eds) (2009) *Mixed methods research for nursing and the health sciences*. Blackwell Publishing, London
- Andrews, G. and Slade, T. (2001) 'Interpreting scores on the Kessler psychological distress scale (K10)', *Australian and New Zealand Journal of Public Health*, 25 (6), pp. 494-497.
- Anell, A. (2008) 'The health system in Sweden', *Eurohealth, London*, 14 (1), pp. 10.
- Anthony, W.A. (1993) 'Recovery from mental illness: The guiding vision of the mental health service system in the 1990s', *Psychosocial Rehabilitation Journal*, 16, pp. 11
- Anthony, W.A. and Liberman, R.P. (1986) 'The practice of psychiatric rehabilitation: historical, conceptual, and research base.', *Schizophrenia bulletin*, 12 (4), pp. 542.

- Arfken, C.L., Wilson, J.G. and Hegedus, A.M. (2002) 'Challenges encountered in measuring outcome for a rural psychiatric residential program', *International Journal of Rehabilitation Research*, 25 (2), pp. 77-85.
- Åsberg, M., Montgomery, S., Perris, C., Schalling, D. and Sedvall, G. (1978) 'A comprehensive psychopathological rating scale', *Acta Psychiatrica Scandinavica*, 57 (S271), pp. 5-27.
- Ayres, H. and Panickacheril J, A. (2015) 'The Assessment of Motor and Process Skills as a measure of ADL ability in schizophrenia', *Scandinavian Journal of Occupational Therapy*, 22 (6), pp. 470-477.
- Baker, A.E.. and Procter, N.G., 2014. Losses related to everyday occupations for adults affected by mental illness. *Scandinavian Journal of Occupational Therapy*, 21 (4), pp. 287-294.
- Baker, A.E., Procter, N. and Gibbons, T., 2009. Dimensions of loss from mental illness. *J.Soc.& Soc.Welfare*, 36, pp. 25.
- Baker, F. and Intagliata, J. (1982) 'Quality of life in the evaluation of community support systems', *Evaluation and program planning*, 5 (1), pp. 69-79.
- Baker, R. (1988) 'Token economy in a hospital rehabilitation system', *Journal of Advanced Nursing*, 13 (5), pp. 631-639.
- Battersby, L. and Morrow, M. (2012) 'Challenges in Implementing Recovery-Based Mental Health Care Practices in Psychiatric Tertiary Care', *Canadian Journal of Community Mental Health*, 31 (2), pp. 103-117.
- Baumeister, R.F. and Leary, M.R. (1997) 'Writing narrative literature reviews', *Review of General Psychology*, 1 (3), pp. 311-320.
- Baxter, E.A. and Diehl, S., 1998. Emotional stages: Consumers and family members recovering from the trauma of mental illness. *Psychiatric rehabilitation journal*, 21 (4), pp. 349.
- Bebbington, P., Brugha, T., Hill, T., Marsden, L. and Window, S. (1999) 'Validation of the Health of the Nation Outcome Scales', *The British Journal of Psychiatry : The Journal of Mental Science*, 174, pp. 389-394.
- Beck, A.T., Steer, R.A. and Carbin, M.G. (1988) 'Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation', *Clinical Psychology Review*, 8 (1), pp. 77-100.
- Beck, A.T., Ward, C.H., Mendelson, M., Mock, J. and Erbaugh, J. (1961) 'An inventory for measuring depression', *Archives of General Psychiatry*, 4 (6), pp. 561-571.
- Bell, A. and Lindley, P. (ed.) (2005) *Beyond the Water Towers: The unfinished revolution in mental health services 1985-2005*. London: The Sainsbury Centre for Mental Health.

- Bell, M., Milstein, R., Beam-Goulet, J., Lysaker, P. and Cicchetti, D. (1992) 'The Positive and Negative Syndrome Scale and the Brief Psychiatric Rating Scale: reliability, comparability, and predictive validity', *The Journal of nervous and mental disease*, 180 (11), pp. 723-728.
- Bellack, A.S., Gold, J.M. and Buchanan, R.W. (1999) 'Cognitive Rehabilitation for Schizophrenia', *Schizophrenia bulletin*, 25 (2), pp. 257-274.
- Bellack, A.S. (2004) 'Skills training for people with severe mental illness', *Psychiatric Rehabilitation Journal*, 27 (4), pp. 375-391.
- Benavides, C., Brucato, G. and Kimhy, D. (2018) 'F36. Self-esteem And Symptoms In Individuals At Clinical High-risk For Psychosis', *Schizophrenia Bulletin*, 44 (Suppl 1), pp. 233.
- Berry, K. (2007) 'Psychology services in psychiatric rehabilitation: Service user needs and staff perceptions', *Clinical Psychology and Psychotherapy*, 14 (3), pp. 244-248.
- Beutel, M.E., Zwerenz, R., Bleichner, F., Vorndran, A., Gustson, D. and Knickenberg, R.J. (2005) 'Vocational training integrated into inpatient psychosomatic rehabilitation; short and long-term results from a controlled study', *Disability & Rehabilitation*, 27 (15), pp. 891-900.
- Boardman J (2005). 'New services for old – an overview of mental health policy' in Bell A, Lindley P (eds), *Beyond the Water Towers: The unfinished revolution in mental health services 1985–2005*, pp 27–36. London: Sainsbury Centre for Mental Health.
- Boardman, J., Craig, T., Goddard, C., Henderson, C., McCarthy, J. and McInerney, T. (2010) 'Recovery is for all: hope, agency and opportunity in psychiatry: a position statement by consultant psychiatrists',
- Bond, G., Drake, R. and Luciano, A. (2015) 'Employment and educational outcomes in early intervention programmes for early psychosis: a systematic review', *Epidemiology and psychiatric sciences*, 24 (5), pp. 446-457.
- Borg, M., Karlsson, B., Tondora, J. and Davidson, L. (2009) 'Implementing person-centered care in psychiatric rehabilitation: What does this involve?', *Israel Journal of Psychiatry and Related Sciences*, 46 (2), pp. 84-93.
- Braun, V. and Clarke, V. (2013) *Successful qualitative research: A practical guide for beginners*. Sage.
- Brazier, J., Keetharuth, A., Connell, J., Barkham, M., Carlton, J., Ricketts, T. and Taylor-Buck, L. (2016) 'Constructing Classification System For A New Qaly Measure In Mental Health: Recovering Quality Of Life (Reqol)', *Value in Health*, 19(3), pp. A190.
- Bridges, K., Huxley, P. and Oliver, J. (1994) 'Psychiatric rehabilitation: Redefined for the 1990s.', *International journal of social psychiatry*, (40) 1 pp.1-16

- Brohan, E., Slade, M., Clement, S. and Thornicroft, G. (2010) 'Experiences of mental illness stigma, prejudice and discrimination: A review of measures', *BMC Health Services Research*, pp.10-80
- Brown, C. (2009) 'Functional assessment and intervention in occupational therapy', *Psychiatric rehabilitation journal*, 32 (3), pp. 162 - 170
- Browne, S. (1999) 'Rehabilitation programmes and quality of life in severe mental illness', *International Journal of Social Psychiatry*, 45 (4), pp. 302-309.
- Bruseker, R. and O'Halloran, P. (1999) 'Preliminary results from an Australian psychosocial rehabilitation program for people with serious mental illness', *Australian & New Zealand Journal of Mental Health Nursing*, 8 (2), pp. 58-64.
- Bryant, W., Craik, C. and McKay, E.A. (2004) 'Living in a glasshouse: exploring occupational alienation', *Canadian Journal of Occupational Therapy*, 71 (5), pp. 282-289.
- Bunyan, M., Crowley, J., Cashen, A. and Mutti, M. (2017) 'A look at inpatients' experience of mental health rehabilitation wards', *Mental Health Practice*, 20(6), pp. 17-23.
- Bunyan, M., Ganeshalingam, Y., Morgan, E., Thompson-Boy, D., Wigton, R., Holloway, F. and Tracy, D. (2016) 'In-patient rehabilitation: clinical outcomes and cost implications', *British Journal of Psychiatry; Bulletin*, (40), pp. 24-28.
- Burr, V. (2015) *Social constructionism*. Routledge.
- Campagne, D.M. (2012) 'When therapists run out of steam: Professional boredom or burnout?', *Revista de Psicopatologia y Psicologia Clinica*, 17 (1), pp. 75-85.
- Carroll, A., Pantelis, C. and Harvey, C. (2004) 'Insight and hopelessness in forensic patients with schizophrenia', *Australian and New Zealand Journal of Psychiatry*, 38 (3), pp. 169-173.
- CASP (2018a) *Cohort Study Checklist*. Available at: <https://casp-uk.net/casp-tools-checklists/> (Accessed: 07/13 2018).
- CASP (2018b) *Qualitative Checklist*. Available at: <https://casp-uk.net/casp-tools-checklists/> (Accessed: 07/13 2018).
- Chopra, P., Harvey, C. and Herrman, H. (2011) 'Continuing accommodation and support needs of long-term patients with severe mental illness in the era of community care', *Current Psychiatry Reviews*, 7(1), pp. 67-83.
- Christiansen, C., Baum, C. and Bass-Haugen, J. (2005) 'Person-environment-occupation-performance: An occupation-based framework for practice', *Occupational Therapy: Performance, Participation, Well-Being*, pp. 242-267.
- Clarke, S.P., Crowe, T.P., Oades, L.G. and Deane, F.P. (2009) 'Do goal-setting interventions improve the quality of goals in mental health services?', *Psychiatric Rehabilitation Journal*, 32 (4), pp. 292-299.

- Coffman, J.M., Bloom, J. and Wallace, N. (2004) 'Assessing the validity of the Colorado Client Assessment Record for measurement of mental health status and outcomes', *Poster presented at the annual meeting of the American Public Health Association, Philadelphia.*
- Cold, J.W. (1994) 'The Christopher Clunis enquiry', *Psychiatric Bulletin*, 18, pp. 449-452.
- College of Occupational Therapists (2006) *Recovering Ordinary Lives: The Strategy for Occupational Therapy in Mental Health Services 2007-2017. Literature Review. Core.* College of Occupational Therapists.
- Conrad-Garrisi, D. (2012) *Inter/intrapersonal variables and readiness for change on achieving recovery*, Wayne State University, Detroit, Michigan
- Cook, S., Mundy, T., Killaspy, H., Taylor, D., Freeman, L., Craig, T. and King, M. (2016) 'Development of a staff training intervention for inpatient mental health rehabilitation units to increase service users' engagement in activities', *British Journal of Occupational Therapy*, 79(3), pp. 144-152.
- Copeland, M.E. (2000) *Wellness recovery action plan*. Peach Press Dunnerston, VT.
- Corcoran, R., Mercer, G. and Frith, C.D. (1995) 'Schizophrenia, symptomatology and social inference: investigating "theory of mind" in people with schizophrenia', *Schizophrenia research*, 17(1), pp. 5-13.
- Cordella, B., Greco, F., Elia, P. and Varaza, M., 2017. Lifelong maintenance treatment or "positive" dropout? *Journal of Substance Use*, 22(4), pp. 372-376.
- Costello, L (2016) 'Patient dropout: Why it happens and how to prevent it' Available at; <https://www.gopraxis.com/patient-dropout-why-it-happens-and-how-to-prevent-it/> accessed 15<sup>th</sup> April 2019
- Costantino, G., Montano, N. and Casazza, G. (2015) 'When should we change our clinical practice based on the results of a clinical study? Searching for evidence: PICOS and PubMed', *Internal and emergency medicine*, 10(4), pp. 525.
- Corrigan, P.W. and Mueser, K.T. (2012) *Principles and practice of psychiatric rehabilitation: An empirical approach*. Guilford Press.
- Corrigan, P.W. and Wassel, A. (2008) 'Understanding and influencing the stigma of mental illness', *Journal of psychosocial nursing and mental health services*, 46(1), pp. 42-48.
- Creswell, J.W. (2014) *Research design: Qualitative, quantitative, and mixed methods approaches*. 4th edn. Sage publications.
- Creswell, J.W. (2013) *Qualitative inquiry and research design: Choosing among five approaches*. 3rd edn. Sage publications
- Creswell, J. and Plano Clark, V. (2011) 'Designing and conducting mixed methods research', 2<sup>nd</sup> edn. Sage publications

- Critten, D.R., Bezyak, J.L. and Fried, J.H. (2013) 'The importance of positive client-staff social interactions in inpatient psychiatric rehabilitation programs', *Journal of Applied Rehabilitation Counseling*, 44 (2), pp. 29-34.
- Crotty, M., (2012). *The Foundations of Social Research*. 3rd edn. London: Sage.
- Crouch, R. and Alers, V. (2014) *Occupational therapy in psychiatry and mental health*. John Wiley & Sons.
- Davidson, L. (2008) 'Recovery' as a response to oppressive social structures', *Chronic Illness*, 4( 4), pp. 305-306.
- Davidson, L. and Stayner, D. (1997) 'Loss, loneliness, and the desire for love: Perspectives on the social lives of people with schizophrenia.', *Psychiatric Rehabilitation Journal*, 20 (3), pp. 3 -12
- Davidson, M., Kapara, O., Goldberg, S., Yoffe, R., Noy, S. and Weiser, M. (2015) 'A nation-wide study on the percentage of schizophrenia and bipolar disorder patients who earn minimum wage or above', *Schizophrenia Bulletin*, 42 (2), pp. 443-447.
- Davidson, L. (2008) 'Recovery' as a response to oppressive social structures', *Chronic Illness*, 4 (4), pp. 305-306.
- Davydov, D.M., Stewart, R., Ritchie, K. and Chaudieu, I. (2010) 'Resilience and mental health', *Clinical Psychology Review*, 30 (5), pp. 479-495.
- Deegan, G. (2003) 'Discovering recovery.', *Psychiatric Rehabilitation Journal*, 26 (4), pp. 368-376
- Deegan, P. (1992) *Recovery, rehabilitation and the conspiracy of hope*. National Empowerment Center.
- Deegan, P.E. (1988) 'Recovery: The lived experience of rehabilitation', *Psychosocial Rehabilitation Journal*, 11 (4), pp. 11-19.
- Denzin NK (1978) *The Research Act: A Theoretical Introduction to Sociological Methods* Second edition. McGraw-Hill, New York NY
- Denzin, N.K. and Lincoln, Y.S. (2013) *The landscape of qualitative research. 4th Ed.* Sage.
- Department of Health (1999) *A national service framework for mental health*. London: Department of Health.
- Department of Health (2001) *The journey to recovery The government's vision for mental health care*. London: DoH.
- Department of Health and Social Security (DHSS) (1971) *Hospital Services for the Mentally Ill*. London: HMSO.

- Derogatis, L.R. and Cleary, P.A. (1977) 'Confirmation of the dimensional structure of the SCL-90: a study in construct validation', *Journal of clinical psychology*, 33 (4), pp. 981-989.
- Derogatis, L.R. and Savitz, K.L. (1999) 'The SCL-90-R, *Brief Symptom Inventory, and Matching Clinical Rating Scales*'. Lawrence Erlbaum Associates Publishers
- Dick, P.H. (1990) 'Psychiatric inpatient rehabilitation: is there a future?', *International journal of rehabilitation research*. 13 (2), pp. 119-126.
- Dimakos, C., Kamenetsky, S.B., Condeluci, A., Curran, J., Flaherty, P., Fromknecht, J., Howard, M. and Williams, J. (2016) 'Somewhere to live, something to do, someone to love: Examining levels and sources of social capital among people with disabilities', *Canadian Journal of Disability Studies*, 5 (4), pp. 130-180.
- Dingemans, P.M., Winter, M.F., Bleeker, J.A. and Rathod, P. (1983) 'A cross-cultural study of the reliability and factorial dimensions of the Brief Psychiatric Rating Scale (BPRS)', *Psychopharmacology*, 80 (2), pp. 190-191.
- Donoghue, D. and Stokes, E.K. (2009) 'How much change is true change? The minimum detectable change of the Berg Balance Scale in elderly people', *Journal of Rehabilitation Medicine*, 41 (5), pp. 343-346.
- Doyle, C., Lennox, L. and Bell, D. (2013) 'A systematic review of evidence on the links between patient experience and clinical safety and effectiveness', *BMJ open*, 3(1).
- Drake, R., Mueser, K. and McHugo, G. (1996) 'Clinician rating scales: alcohol use scale (AUS), drug use scale (DUS), and substance abuse treatment scale (SATS)', *Outcomes assessment in clinical practice*. Baltimore: Williams & Wilkins, pp. 113-116.
- Edgar, K., O'Donnell, I., Martin, C. and Martin, C. (2003) *Prison violence: The dynamics of conflict, fear and power*. Willan Cullompton.
- Eisen, S.V. and Grob, M.C. (1982) 'Clients' rehabilitation goals and outcome', *Psychological Reports*, 50 (3), pp. 763-767.
- Eisenhart, M. (1998) 'On the Subject of Interpretative Reviews', *Review of Educational Research*, 68 (4), pp. 391-399.
- Elliot, A.J. and Harackiewicz, J.M. (1994) 'Goal setting, achievement orientation, and intrinsic motivation: A mediational analysis.', *Journal of personality and social psychology*, 66 (5), pp. 968-980
- Ellis, R.H., Wackwitz, J.H. and Foster, M. (1991) 'Uses of an empirically derived client typology based on level of functioning: Twelve years of the CCAR', *The Journal of Behavioral Health Services and Research*, 18(2), pp. 88-100.
- Ellis, T.J. and Levy, Y. (2008) 'Framework of problem-based research: A guide for novice researchers on the development of a research-worthy problem', *Informing Science: International Journal of an Emerging Transdiscipline*, 11, pp. 17-33.

- Fallatah, R.H.M. and Syed, J. (2018) 'A Critical Review of Maslow's Hierarchy of Needs', in *Employee Motivation in Saudi Arabia*. Springer, pp. 19-59.
- Farnworth, L. (1998) 'Doing, being, and boredom', *Journal of Occupational Science*, 5 (3), pp. 140-146.
- Farnworth, L. and Muñoz, J.P. (2009) 'An occupational and rehabilitation perspective for institutional practice', *Psychiatric Rehabilitation Journal*, 32 (3), pp. 192-198.
- Field, B.I. and Reed, K. (2016) 'The Rise and Fall of the Mental Health Recovery Model.', *International Journal of Psychosocial Rehabilitation*, 20 (2), pp. 86-95.
- Finlay, L. (2011) *Phenomenology for therapists: Researching the lived world*. Wiley-Blackwell.
- Finlay, L. and Gough, B. (2003) 'Reflexivity a Practical Guide for Researchers in Health and Social Sciences', Wiley-Blackwell
- Fischl, C. and Fisher, A.G. (2007) 'Development and Rasch analysis of the assessment of computer-related skills', *Scandinavian Journal of Occupational Therapy*, 14 (2), pp. 126-135.
- Fisher, A. (2009) 'Occupational therapy intervention process model', *Fort Collins, CO: Three Star Press Inc, .*
- Fisher, A.G., (1993) The assessment of IADL motor skills: an application of many-faceted Rasch analysis. *The American journal of occupational therapy: official publication of the American Occupational Therapy Association*, 47 (4), pp. 319-329.
- Fisher, A.G. and Bray Jones, K. (2012) *Assessment of Motor and Process Skills: Volume I: Development, Standardization and Administration Manual*. 7 revised edn. Fort Collins, Colorado: Three Star Press. Inc.
- Fisher, A.G. and Bray Jones, K. (2014) *Assessment of Motor and Process Skills: Volume II: User Manual*. 8th edn. Fort Collins, Colorado: Three Star Press. Inc.
- Fisher, A.G., Liu, Y., Velozo, C.A. and Pan, A.W. (1992) 'Cross-cultural assessment of process skills', *The American journal of occupational therapy.: official publication of the American Occupational Therapy Association*, 46 (10), pp. 876-885.
- Fisher, A.G., Short, M.A. and Duran, L. (1999) 'Occupational performance differences between psychiatric groups', *Scandinavian Journal of Occupational Therapy*, 6 (3), pp. 119-126.
- Fitzpatrick, R., Fletcher, A., Gore, S., Jones, D., Spiegelhalter, D. and Cox, D. (1992) 'Quality of life measures in health care: Applications and issues in assessment', *BMJ (Clinical research ed.)*, 305 (6861), pp. 1074-1077.
- Foruzandeh, N. and Parvin, N. (2013) 'Occupational therapy for inpatients with chronic schizophrenia: A pilot randomized controlled trial', *Japan Journal of Nursing Science*, 10 (1), pp. 136-141.



- Gaarder, J. (1994) *Sophie's world: A novel about the history of philosophy*. Macmillan.
- Gaber, J. and Overacker, T. (2012) 'Establishing mixed method research design guidelines in health impact assessment investigations', *Impact Assessment and Project Appraisal*, 30 (4), pp. 275-283.
- Gaite, L., Vázquez-Barquero, J.L., and Arrizabalaga. et al. (2000) 'Quality of life in schizophrenia: development, reliability and internal consistency of the Lancashire Quality of Life Profile-European Version EPSILON Study 8', *The British Journal of Psychiatry*, 177(39), pp. 49-54.
- Gantschnig, B.E., Page, J. and Fisher, A.G. (2012) 'Cross-regional validity of the Assessment of Motor and Process Skills for use in Middle Europe', *Journal of Rehabilitation Medicine*, 44 (2), pp. 151-157.
- Galvin, E.C., Wills, T. and Coffey, A. (2017) 'Readiness for hospital discharge: A concept analysis', *Journal of advanced nursing*, 73 (11), pp. 2547-2557.
- Gigantesco, A. and Giuliani, M. (2011) 'Quality of life in mental health services with a focus on psychiatric rehabilitation practice', *Annali dell'Istituto superiore di sanità*, 47 (4), pp. 363-372.
- Goldman, S.L. and Fisher, A.G. (1997) 'Cross-Cultural Validation of the Assessment of Motor and Process Skills (AMPS)', *British Journal of Occupational Therapy*, 60 (2), pp. 77-85.
- Gonda, T., Deane, F. and Murugesan, G. (2012) 'Predicting clinically significant change in an inpatient program for people with severe mental illness', *Australian & New Zealand Journal of Psychiatry*, 46 (7), pp. 651-658.
- Gooch, C. and Leff, J. (1996) 'Factors affecting the success of community placement: The TAPS Project 26', *Psychological Medicine*, 26 (3), pp. 511-520.
- Gould, A., DeSouza, S. and Rebeiro-Gruhl, K.L. (2005) 'And then I lost that life: A shared narrative of four young men with schizophrenia', *British Journal of Occupational Therapy*, 68 (10), pp. 467-473.
- Gray, D.E. (2014) *Doing research in the real world*. Sage.
- Greene, J.C., Caracelli, V. J., and Graham, W.F. (1989) 'Toward a Conceptual Framework for Mixed-Method Evaluation Designs', *Education Evaluation and Policy Analysis* 11 (3) 255-274
- Greenacre, K. and Palmer, E. (2018) 'Exploring forensic environments: how do environmental factors influence individual outcomes for residents and staff? A systematic review', *Mental Health and Social Inclusion*, 22 (4), pp. 203-217.
- Griffith, A. (2010) 'SPSS For Dummies', 2<sup>nd</sup> edn Wiley

- Grundy, A., Bee, P., Meade, O., Callaghan, P., Beatty, S., Olleveant, N. and Lovell, K. (2016) 'Bringing meaning to user involvement in mental health care planning: a qualitative exploration of service user perspectives', *Journal of Psychiatric and Mental Health Nursing*, 23 (1), pp. 12-21.
- Hagedorn, R. (2000) *Tools for practice in occupational therapy: A structured approach to core skills and processes*. Churchill Livingstone.
- Hamann, J., Kohl, S., McCabe, R., Bühner, M., Mendel, R., Albus, M. and Bernd, J. (2016) 'What can patients do to facilitate shared decision making? A qualitative study of patients with depression or schizophrenia and psychiatrists', *Social Psychiatry and Psychiatric Epidemiology*, 51 (4), pp. 617-625.
- Harding, C.M., Brooks, G.W., Ashikaga, T., Strauss, J.S. and Breier, A. (1987) 'The Vermont Longitudinal Study of persons with severe mental illness, I: Methodology, study sample, and overall status 32 years later', *American Journal of Psychiatry*, 144 (6), pp. 718-726.
- Harper D. and Speed, E., 2012. Uncovering recovery: The resistible rise of recovery and resilience; *Studies in Social Justice* (6) 1, 9-25
- Harper, D. and Thompson, A.R. (2011) *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. John Wiley & Sons.
- Haslam, J., Pépin, G., Bourbonnais, R. and Grignon, S. (2010) 'Processes of task performance as measured by the Assessment of Motor and Process Skills (AMPS): A predictor of work-related outcomes for adults with schizophrenia?', *Work*, 37(1), pp. 53-64.
- Heinrichs, D.W., Hanlon, T.E. and Carpenter Jr, W.T. (1984) 'The Quality of Life Scale: an instrument for rating the schizophrenic deficit syndrome', *Schizophrenia Bulletin*, 10(3), pp. 388-398.
- Hinojosa, J. (2013) 'The Evidence-Based Paradox', *The American Journal of Occupational Therapy*, 67 (2), pp. e18-e23.
- Hitch, D. (2007) 'A critique of the assessment of motor and process skills (AMPS) in mental health practice', *Mental Health Occupational Therapy*, 12 (1), pp. 4-13.
- Hjorthøj, C., Østergaard, M.L.D., Benros, M.E., Toftdahl, N.G., Erlangsen, A., Andersen, J.T. and Nordentoft, M. (2015) 'Association between alcohol and substance use disorders and all-cause and cause-specific mortality in schizophrenia, bipolar disorder, and unipolar depression: a nationwide, prospective, register-based study', *The Lancet Psychiatry*, 2 (9), pp. 801-808.
- HM Government (2011) *No health without mental health: A cross government mental health outcome strategy for people of all ages*. London: HM Government.
- Hochman, K.M., Fritz, E. and Lewine, R.R. (2005) 'Overcome by or overcoming loss: A call for the development of therapy for individuals mourning vocational loss in schizophrenia', *Illness, Crisis & Loss*, 13 (4), pp. 279-291.

- Honigfeld, G., Gillis, R.D. and Klett, C.J. (1966) 'NOSIE-30: A treatment-sensitive ward behavior scale', *Psychological Reports*, 19 (1), pp. 180-182.
- Holkar, I.M. (1972) 'Rehabilitation of long stay psychiatric patients', *The Nursing Journal of India*, 63(2), pp. 47
- Hollis, C., Kendall, T. and Birchwood, M. (2013) 'Psychosis and schizophrenia in children and young people', *Clinical Guideline*, 155, pp. 1-51.
- Holloway, F. (2005) 'The Forgotten Need for Rehabilitation in Contemporary Mental Health Services', *A Position Statement from the Executive Committee of the Faculty of Rehabilitation and Social Psychiatry, Royal College of Psychiatrists, London*, .
- Holloway, F. (2010) 'Rehabilitation psychiatry in an era of austerity', *Journal of Mental Health*, 19(1), pp. 1-7.
- House of Commons (1985) *Social Services Committee Report 1984/85. Community Care with Special Reference to Mentally Ill and Mentally Handicapped People*. London: HMSO.
- Hughes, H. (2015) *Criticisms of the recovery\_model*. Available at: <http://studymore.org.uk/binrec.htm> (Accessed: 07/22 2018).
- Hume, C. and Pullen, I.M. (1993) *Rehabilitation for mental health problems: an introductory handbook*. Churchill Livingstone.
- Humphries, M. (2013) 'Missing Data & How to Deal: An overview of missing data', *Population Research Center. University of Texas. Recuperado*
- Hyde, P. (2004) 'Fools gold: Examining the use of gold standards in the production of research evidence', *The British Journal of Occupational Therapy*, 67 (2), pp. 89-94.
- Ivankova, N.V., Creswell, J.W. and Stick, S.L. (2006) 'Using mixed-methods sequential explanatory design: From theory to practice', *Field Methods*, 18 (1), pp. 3-20.
- JCPMH (2016) 'Guidance for commissioning public mental health services', *Joint Commissioning Panel for Mental Health*, .London
- Jenkins, J.H. and Carpenter-Song, E.A. (2009) 'Awareness of stigma among persons with schizophrenia: marking the contexts of lived experience', *The Journal of nervous and mental disease*, 197 (7), pp. 520-529.
- Jenkinson, C., Wright, L. and Coulter, A. (1994) 'Criterion validity and reliability of the SF-36 in a population sample', *Quality of Life Research*, 3 (1), pp. 7-12.
- Johansson, R., Nyström, M. and Dahlheim–Englund, A. (2017) 'Reflective team and process-oriented supervision—a case study on differences', *Reflective Practice*, 18 (6), pp. 737-749

- Jolley, S., Garety, P.A., Ellett, L., Kuipers, E., Freeman, D., Bebbington, P.E., Fowler, D.G. and Dunn, G. (2006) 'A validation of a new measure of activity in psychosis', *Schizophrenia research*, 85(1), pp. 288-295.
- Jones, S.H., Thornicroft, G., Coffey, M. and Dunn, G. (1995) 'A brief mental health outcome scale-reliability and validity of the Global Assessment of Functioning (GAF)', *The British journal of psychiatry: the journal of mental science*, 166 (5), pp. 654-659.
- Kaite, C.P., Karanikola, M., Merkouris, A. and Papathanassoglou, E.D. (2015) "An Ongoing Struggle With the Self and Illness": A Meta-Synthesis of the Studies of the Lived Experience of Severe Mental Illness', *Archives of Psychiatric Nursing*, 29 (6), pp.458-473.
- Kajandi M. (1994) A Psychiatric and Interactional Perspective on Quality of Life. In: Nordenfelt L. (eds) *Concepts and Measurement of Quality of Life in Health Care. European Studies in Philosophy of Medicine* 1(47), pp 257-276. Springer, Dordrecht
- Kavanagh, A., Nkire, N. and Lavelle, E. (2009) 'Characteristics and progress of patients who receive inpatient rehabilitation services', *Irish Journal of Psychological Medicine*, 26 (2), pp. 64.
- Keetharuth, D., Brazier, J., Connell, J., Bjorner, J., Carlton, J., Taylor Buck, E., Ricketts, T., McKendrick, K., Browne, J. and Croudace, T. (2017) 'Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people experiencing mental health difficulties', *The British Journal of Psychiatry*, 212 (1), pp. 42-49
- Kessler, R.C., Andrews, G., Colpe, L.J., Hiripi, E., Mroczek, D.K., Normand, S., Walters, E.E. and Zaslavsky, A.M. (2002) 'Short screening scales to monitor population prevalences and trends in non-specific psychological distress', *Psychological medicine*, 32 (06), pp. 959-976.
- Kielhofner, G. (2008) *Model of Human Occupation: Theory and application*. Lippincott Williams & Wilkins.
- Killaspy, H. (2014) 'Contemporary mental health rehabilitation', *East Asian Archives of Psychiatry*, 24 (3), pp. 89.
- Killaspy, H., Harden, C., Holloway, F. and King, M. (2005) 'What do mental health rehabilitation services do and what are they for? A national survey in England', *Journal of Mental Health*, 14 (2), pp. 157-165.
- Killaspy, H., Marston, L., Green, N., Harrison, I., Lean, M., Holloway, F., Craig, T., Leavey, G., Arbuthnott, M. and Koeser, L. (2016) 'Clinical outcomes and costs for people with complex psychosis; a naturalistic prospective cohort study of mental health rehabilitation service users in England', *BMC psychiatry*, 16(1), pp. 1.
- Killaspy, H., Marston, L., Omar, R.Z., Green, N., Harrison, I., Lean, M., Holloway, F., Craig, T., Leavey, G. and King, M. (2013a) 'Service quality and clinical outcomes: an example from

- mental health rehabilitation services in England', *The British Journal of Psychiatry*, 202 (1), pp. 28-34.
- Killaspy, H. and Meier, R. (2010) 'A Fair Deal for mental health includes local rehabilitation services', *The Psychiatrist*, 34 (7), pp. 265-267.
- Killaspy, H., Rambarran, D., Harden, C., Fearon, D., Caren, G. and McClinton, K. (2009) 'A comparison of service users placed out of their local area and local rehabilitation service users', *Journal of Mental Health*, 18 (2), pp. 111-120.
- Killaspy, H., White, S., Wright, C., Taylor, T.L., Turton, P., Schützwohl, M., Schuster, M., Cervilla, J.A., Brangier, P. and Raboch, J. (2011) 'The development of the Quality Indicator for Rehabilitative Care (QulRC): a measure of best practice for facilities for people with longer term mental health problems', *BMC psychiatry*, 11 (1), pp. 35.
- Killaspy, H., King, M., Holloway, F., Craig, T.J., Cook, S., Mundy, T., Leavey, G., McCrone, P., Koeser, L., Omar, R., Marston, L., Arbuthnott, M., Green, N., Harrison, I., Lean, M., Gee, M. and Bhanbhro, S. (2017) 'The Rehabilitation Effectiveness of Activities for Life (REAL) study. A national programme of research into NHS inpatient mental health rehabilitation services across England', *Programme Grants Appl Res*, 5 (2).
- Killaspy, H., Cook, S., Mundy, T., Craig, T., Holloway, F., Leavey, G., Marston, L., McCrone, P., Koeser, L., Arbuthnott, M., Omar, R.Z. and King, M. (2013b) 'Study protocol: cluster randomised controlled trial to assess the clinical and cost effectiveness of a staff training intervention in inpatient mental health rehabilitation units in increasing service users' engagement in activities', *BMC Psychiatry*, 13 (1), pp. 216-216.
- Killaspy, H. and Zis, P. (2013) 'Predictors of outcomes for users of mental health rehabilitation services: A 5-year retrospective cohort study in inner London, UK', *Social Psychiatry and Psychiatric Epidemiology*, 48 (6), pp. 1005-1012.
- Knapp, M., Andrew, A., McDaid, D., Lemmi, V., McCrone, P., Park, A., Parsonage, M., Boardman, J. and Shepherd, G. (2014) '*Investing in recovery: making the business case for effective interventions for people with schizophrenia and psychosis*', Rethink, London
- Kogstad, R.E., Ekeland, T. and Hummelvoll, J.K. (2011) 'In defence of a humanistic approach to mental health care: recovery processes investigated with the help of clients' narratives on turning points and processes of gradual change', *Journal of Psychiatric and Mental Health Nursing*, 18 (6), pp. 479-486.
- Kristensen, H.K. and Petersen, K.S. (2016) 'Occupational science: An important contributor to occupational therapists' clinical reasoning', *Scandinavian Journal of Occupational Therapy*, 23 (3), pp. 240-243.
- Krupa, T., Fossey, E., Anthony, W.A., Brown, C. and Pitts, D.B. (2009) 'Doing daily life: How occupational therapy can inform psychiatric rehabilitation practice.', *Psychiatric Rehabilitation Journal*, 32 (3), pp. 155.
- Kubler-Ross, E. and Kessler, D., (2005). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. Simon and Schuster.

- Kuhn, T.S. (1970) 'The structure of scientific revolutions', *Chicago and London*, .
- Kumar, R. (2005) 'Research methodology: A step-by-step guide for beginners: 4<sup>th</sup> edn. Pearson Education' .
- Kurtz, M.M., Bronfeld, M. and Rose, J. (2012) 'Cognitive and social cognitive predictors of change in objective versus subjective quality-of-life in rehabilitation for schizophrenia', *Psychiatry Research*, 200 (2), pp. 102-107.
- Kurzban, S., Davis, L. and Brekke, J.S. (2010) 'Vocational, social, and cognitive rehabilitation for individuals diagnosed with schizophrenia: a review of recent research and trends', *Current Psychiatry Reports*, 12 (4), pp. 345-355.
- Lane, R.D., Glazer, W.M., Hansen, T.E., Berman, W.H. and Kramer, S.I. (1985) 'Assessment of tardive dyskinesia using the Abnormal Involuntary Movement Scale', *The Journal of Nervous and Mental Disease*, 173 (6), pp. 353-357.
- Law, M. (2002) 'Participation in the occupations of everyday life', *The American Journal of Occupational Therapy*, 56 (6), pp. 640-649.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P. and Letts, L. (1996) 'The person-environment-occupation model: A transactive approach to occupational performance', *Canadian Journal of Occupational Therapy*, 63 (1), pp. 9-23.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J. and Slade, M. (2011) 'Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis', *The British journal of psychiatry*, 199 (6), pp. 445-452.
- Lecomte, T., Leclerc, C. and Wykes, T., 2016. *Group CBT for psychosis: A guidebook for clinicians*. Oxford University Press.
- Lee, S.W., Forsyth, K., Morley, M., Garnham, M., Heasman, D. and Taylor, R.R. (2013) 'Mental Health Payment-by-Results Clusters and the Model of Human Occupation Screening Tool', *OTJR: Occupation, Participation and Health*, 33 (1), pp. 40-49.
- Leff, J. (2001) 'Why is care in the community perceived as a failure?', *The British Journal of Psychiatry*, 179 (5), pp. 381-383.
- Leff, J. and Szmidla, A. (2002) 'Evaluation of a special rehabilitation programme for patients who are difficult to place', *Social Psychiatry and Psychiatric Epidemiology*, 37 (11), pp. 532-536.
- Leff, J. and Trieman, N. (2000) 'Long-stay patients discharged from psychiatric hospitals. Social and clinical outcomes after five years in the community. The TAPS Project 46', *The British Journal of Psychiatry*, 176 (3), pp. 217-223.
- Leff, J., Trieman, N. and Gooch, C. (1996) 'Team for the Assessment of Psychiatric Services (TAPS) Project 33: prospective follow-up study of long-stay patients discharged from two psychiatric hospitals', *The American Journal of Psychiatry*, 153 (10), pp. 1318-1324.

- Leff, J., Trieman, N., Knapp, M. and Hallam, A. (2000) 'The TAPS Project A report on 13 years of research, 1985-1998', *Psychiatric Bulletin*, 24 (5), pp. 165-168.
- Leff, J. and Warner, R. (2006) *Social inclusion of people with mental illness*. Cambridge University Press.
- Legault, E. and Rebeiro, K.L. (2001) 'Occupation as means to mental health: A single-case study', *American Journal of Occupational Therapy*, 55 (1), pp. 90-96.
- Lehman, A.F. (1988) 'A quality of life interview for the chronically mentally ill', *Evaluation and Program Planning*, 11 (1), pp. 51-62.
- Lelliott, P., Wing, J. and Clifford, P. (1994) 'A national audit of new long-stay psychiatric patients. I: Method and description of the cohort', *The British journal of psychiatry*, 165 (2), pp. 160-169.
- Levenson, H. (1973) 'Multidimensional locus of control in psychiatric patients.', *Journal of Consulting and Clinical Psychology*, 41 (3), pp. 397.
- Lin, K., Fu, T., Wu, C., Wang, Y., Liu, J., Hsieh, C. and Lin, S. (2010) 'Minimal detectable change and clinically important difference of the Stroke Impact Scale in stroke patients', *Neurorehabilitation and Neural Repair*, 24 (5), pp. 486-492.
- Lindström, M., Hariz, G. and Bernspång, B. (2012) 'Dealing with real-life challenges: Outcome of a home-based occupational therapy intervention for people with severe psychiatric disability', *OTJR: Occupation, Participation and Health*, 32 (2), pp. 5-14.
- Lindström, M., Sjöström, S. and Lindberg, M. (2013) 'Stories of rediscovering agency: home-based occupational therapy for people with severe psychiatric disability', *Qualitative Health Research*, 23 (6), pp. 728-740.
- Link, B.G., Struening, E.L., Neese-Todd, S., Asmussen, S. and Phelan, J.C. (2001) 'Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses', *Psychiatric Services*, 52 (12), pp. 1621-1626.
- Liu, N.H., Choi, K., Reddy, F. and Spaulding, W.D. (2011) 'Heterogeneity and the longitudinal recovery of functioning during inpatient psychiatric rehabilitation for treatment-refractory severe mental illness', *American Journal of Psychiatric Rehabilitation*, 14 (1), pp. 55-75.
- Luk, A., L. (2011) 'Investigating the long-term effects of a psychiatric rehabilitation programme for persons with serious mental illness in the community: a follow-up study', *Journal of Clinical Nursing*, 20 (19), pp. 2712-2720.
- Lukoff, D., Liberman, R.P. and Nuechterlein, K.H. (1986) 'Symptom monitoring in the rehabilitation of schizophrenic patients', *Schizophrenia Bulletin*, 12 (4), pp. 578-602.
- Lyall, D., Hawley, C. and Scott, K. (2004) 'Nurses' observation scale for inpatient evaluation: reliability update', *Journal of Advanced Nursing*, 46 (4), pp. 390-394.

- Lysaker, P.H. and Leonhardt, B.L. (2012) 'Agency: its nature and role in recovery from severe mental illness', *World Psychiatry*, 11 (3), pp. 165-166.
- MacDonald-Wilson, K.L. and Nemece, P.B. (2005) 'The International Classification of Functioning, Disability and Health (ICF) in Psychiatric Rehabilitation.', *Rehabilitation Education*, 19 (2-3) 159-176
- Magalhães, L.C., Fisher, A.G., Bernspång, B. and Linacre, J.M. (1996) 'Cross-cultural assessment of functional ability', *Occupational Therapy Journal of Research*, 16 (1), pp. 45-63
- Mann, S. and Cree, W. (1976) 'New long-stay psychiatric patients. A national survey of 15 mental hospitals in England and Wales 1972/73', *Psychological Medicine*, 6, pp. 603-616.
- Marks, I.M., Connolly, J., Muijen, M., Audini, B., McNamee, G. and Lawrence, R. (1994) 'Home-based versus hospital-based care for people with serious mental illness', *The British Journal of Psychiatry*, 165 (2), pp. 179-194.
- Martin, M., Sadlo, G. and Stew, G. (2012) 'Rethinking occupational deprivation and boredom', *Journal of Occupational Science*, 19 (1), pp. 54-61.
- Maslach, C. and Jackson, S.E. (1981) 'The measurement of experienced burnout', *Journal of occupational behavior*, 2 (2), pp. 99-113.
- Maslow, A.H. (1943) 'A theory of human motivation', *Psychological Review*, 50 (4), pp. 370.
- Mauritz, M. and van Meijel, B. (2009) 'Loss and grief in patients with schizophrenia: on living in another world', *Archives of Psychiatric Nursing*, 23 (3), pp. 251-260.
- Mazor, K.M., Clauser, B.E., Field, T., Yood, R.A. and Gurwitz, J.H. (2002) 'A demonstration of the impact of response bias on the results of patient satisfaction surveys', *Health services research*, 37 (5), pp. 1403-1417.
- McCloughen, A., O'Brien, L., Gillies, D. and McSherry, C. (2008) 'Nursing handover within mental health rehabilitation: An exploratory study of practice and perception', *International Journal of Mental Health Nursing*, 17 (4), pp. 287-295.
- McNulty, M.C. and Fisher, A.G. (2001) 'Validity of using the assessment of motor and process skills to estimate overall home safety in persons with psychiatric conditions', *American Journal of Occupational Therapy*, 55 (6), pp. 649-655.
- Meddings, S. and Perkins, R. (2002) 'What 'getting better' means to staff and users of a rehabilitation service: an exploratory study', *Journal of Mental Health*, 11 (3), pp. 319-325.
- Meddings, S. and Perkins, R. (1999) 'Service user perspectives on the 'rehabilitation team' and roles of professionals within it', *Journal of Mental Health*, 8 (1), pp. 87-94.



- Meeks, S., Carstensen, L.L., Stafford, P.B., Brenner, L.L., Weathers, F., Welch, R. and Oltmanns, T.F. (1990) 'Mental health needs of the chronically mentally ill elderly.', *Psychology and Aging*, 5 (2), pp. 163.
- Mental Health Foundation (2016) *Fundamental Facts About Mental Health 2016*. Mental Health Foundation: London.
- Mental Health Foundation (2016) *Mental Health Statistics: Homelessness*. Available at: <https://www.mentalhealth.org.uk/statistics/mental-health-statistics-homelessness> (Accessed: 10/20 2018).
- Mental Health Network, N.C. (2011) '*Housing and mental health*', NHS Confederation (Dec), 233.
- Merritt, B.K. (2011) 'Validity of using the Assessment of Motor and Process Skills to determine the need for assistance', *American Journal of Occupational Therapy*, 65 (6), pp. 643-650.
- Merritt, B.K. (2010) 'Utilizing AMPS ability measures to predict level of community dependence', *Scandinavian Journal of Occupational Therapy*, 17 (1), pp. 70-76.
- Merritt, B., Gahagan, J. and Kottorp, A. (2013) 'HIV and disability: a pilot study exploring the use of the Assessment of Motor and Process Skills to measure daily life performance', *Journal of the International AIDS Society*, 16, pp. 17339.
- Meyer, A. (1977) 'The philosophy of occupation therapy. Reprinted from the Archives of Occupational Therapy, Volume 1, pp. 1-10, 1922', *The American Journal of Occupational Therapy*, 31(10), pp. 639-642.
- MIND (2017) *Leaving Hospital: Briefing on discharge from mental health inpatient services*. MIND. London
- Mjøsund, N.H., Eriksson, M., Espnes, G.A., Haaland-Øverby, M., Jensen, S.L., Norheim, I., Kjus, S.H.H., Portaasen, I. and Vinje, H.F. (2017) 'Service user involvement enhanced the research quality in a study using interpretative phenomenological analysis—the power of multiple perspectives', *Journal of Advanced Nursing*, 73 (1), pp. 265-278.
- Monroe, L. (2015) 'Horticulture Therapy Improves the Body, Mind and Spirit.', *Journal of Therapeutic Horticulture*, 25 (2).
- Montgomery, S.A. and Asberg, M. (1979) 'A new depression scale designed to be sensitive to change', *The British journal of psychiatry*, 134, pp. 382-389.
- Murray, R. (2011) *How to write a thesis*. McGraw-Hill Education (UK)
- Murugesan, G., Jeffrey, R., Amey, C.G., Deane, F.P., Kelly, B. and Stain, H. (2007) 'Inpatient psychosocial rehabilitation in rural NSW: assessment of clinically significant change for people with severe mental illness', *Australian & New Zealand Journal of Psychiatry*, 41 (4), pp. 343-350.

- National Institute for Health and Care Excellence (2014) *Psychosis and Schizophrenia in adults: The NICE guideline on treatment and management*. [CG178], NIHC: London
- Neher, A. (1991) 'Maslow's theory of motivation: A critique', *Journal of Humanistic Psychology*, 31 (3), pp. 89-112.
- Newman-Taylor, K., Garner, C., Vernon-Wilson, E., Paas, K.H., Herbert, L. and Au-Yeung, S.K. (2017) 'Psychometric evaluation of the hope, agency and opportunity (HAO); a brief measure of mental health recovery', *Journal of Mental Health*, 26 (6), pp. 562-568.
- NHS England (2016a) 'Commissioning Guidance for Rehabilitation', *Commissioning Guidance for Rehabilitation*, NHS England, London
- NHS England (2016b) *The Five Year Forward View for Mental Health*. Available at: <https://www.england.nhs.uk/wp-content/.../Mental-Health-Taskforce-FYFV-final.pdf> (Accessed: 07/31 2018).
- National Institute for Health and Care Excellence (2016) *Transition between inpatient mental health settings and community or care home settings*. NICE .London
- Nordentoft, M., Rasmussen, J.Ø, Melau, M., Hjorthøj, C.R. and Thorup, A.A. (2014) 'How successful are first episode programs? A review of the evidence for specialized assertive early intervention', *Current Opinion in Psychiatry*, 27 (3), pp. 167-172.
- Norman, I. and Parker, F. (1990) 'Psychiatric patients' views of their lives before and after moving to a hostel: a qualitative study', *Journal of Advanced Nursing*, 15 (9), pp. 1036-1044.
- Notley, J., Pell, H., Bryant, W., Grove, M., Croucher, A., Cordingley, K. and Blank, A. (2012) 'I know how to look after myself a lot better now': Service user perspectives on mental health in-patient rehabilitation', *International Journal of Therapy and Rehabilitation*, 19(5), pp. 288-298.
- O'Driscoll, C. and Leff, J. (1993) 'The TAPS project: VIII. Design of the research study on the long-stay patients.', *The British Journal of Psychiatry*, April (19) 18-24.
- Oliver, J., Huxley, P., Priebe, S. and Kaiser, W. (1997) 'Measuring the quality of life of severely mentally ill people using the Lancashire Quality of Life Profile', *Social Psychiatry and Psychiatric Epidemiology*, 32 (2), pp. 76-83.
- Overall, J.E. and Gorham, D.R. (1962) 'The brief psychiatric rating scale', *Psychological Reports*, 10 (3), pp. 799-812.
- Owen, P.R. (2012) 'Portrayals of schizophrenia by entertainment media: a content analysis of contemporary movies', *Psychiatric Services*, 63 (7), pp. 655-659.
- Panksepp, J. (2003) 'Neuroscience. Feeling the pain of social loss', *Science (New York, N.Y.)*, 302 (5643), pp. 237-239.

- Palinkas, L.A., Aarons, G.A., Horwitz, S., Chamberlain, P., Hurlburt, M. and Landsverk, J. (2011) 'Mixed method designs in implementation research', *Administration and Policy in Mental Health and Mental Health Services Research*, 38 (1), pp. 44-53.
- Pan, A.W. and Fisher, A.G. (1994) 'The Assessment of Motor and Process Skills of persons with psychiatric disorders.', *The American journal of occupational therapy*. 48(9), pp. 775-780.
- Parahoo, K. (1997) 'Nursing Research: Principles, Process and Issues.', Macmillan
- Parker, G., Rosen, A., Emdur, N. and Hadzi-Pavlov, D. (1991) 'The Life Skills Profile: psychometric properties of a measure assessing function and disability in schizophrenia', *Acta Psychiatrica Scandinavica*, 83 (2), pp. 145-152.
- Patterson, D.A. and Lee, M. (1995) 'Field trial of the global assessment of functioning scale-modified', *The American Journal of Psychiatry*, 152 (9), pp. 1386.
- Peer, J.E. and Spaulding, W.D. (2007) 'Heterogeneity in recovery of psychosocial functioning during psychiatric rehabilitation: An exploratory study using latent growth mixture modelling', *Schizophrenia Research*, 93 (1-3), pp. 186-193.
- Pejlert, A., Asplund, K. and Norberg, A. (1999) 'Towards recovery: living in a home-like setting after the move from a hospital ward', *Journal of Clinical Nursing*, 8 (6), pp. 663-674.
- Perkins, R., Repper, J., Rinaldi, M. and Brown, H. (2012) '*Recovery Colleges: Implementing Recovery through Organisational Change (ImROC) briefing paper*', Centre for Mental Health, London
- Perkins, R. and Slade, M. (2012) 'Recovery in England: Transforming statutory services?', *International Review of Psychiatry*, 24 (1), pp. 29-39.
- Petersen, K., Hounsgaard, L., Borg, T. and Nielsen, C.V. (2012) 'User involvement in mental health rehabilitation: a struggle for self-determination and recognition', *Scandinavian Journal of Occupational Therapy*, 19 (1), pp. 59-67.
- Petrie, R.X.A. and Mountain, D.A. (2009) 'An observational study of the impact of a rehabilitation admission on readmission data', *Scottish Medical Journal*, 54 (1), pp. 32-34.
- Phelan, M., Slade, M., Thornicroft, G., Dunn, G., Holloway, F., Wykes, T., Strathdee, G., Loftus, L., McCrone, P. and Hayward, P. (1995) 'The Camberwell Assessment of Need: the validity and reliability of an instrument to assess the needs of people with severe mental illness', *The British Journal of Psychiatry*, 167 (5), pp. 589-595.
- Pinto, R., Ashworth, M. and Jones, R. (2008) 'Schizophrenia in black Caribbeans living in the UK: an exploration of underlying causes of the high incidence rate', *The British Journal of General Practice* 58(551), pp. 429-434.
- Pirkis, J.E., Burgess, P.M., Kirk, P.K., Dodson, S., Coombs, T.J. and Williamson, M.K. (2005) 'A review of the psychometric properties of the Health of the Nation Outcome Scales (HoNOS) family of measures', *Health and quality of life outcomes*, 3 (1), pp. 76.

- Pitkänen, A., Välimäki, M., Kuosmanen, L., Katajisto, J., Koivunen, M., Hätönen, H., Patel, A. and Knapp, M. (2012) 'Patient education methods to support quality of life and functional ability among patients with schizophrenia: A randomised clinical trial', *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 21 (2), pp. 247-256.
- Playford, E., Dawson, L., Limbert, V., Smith, M., Ward, C. and Wells, R. (2000a) 'Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting', *Clinical Rehabilitation*, 14 (5), pp. 491-496.
- Powell, E. (1961) '*Water tower speech*', Annual Conference: National Association for Mental Health, Brighton.
- Pratt, C.W., Gill, K.J., Barrett, N.M. and Roberts, M.M. (2006) *Psychiatric Rehabilitation* (2nd edn). Academic Press.
- Price-Robertson, R., Obradovic, A. and Morgan, B. (2017) 'Relational recovery: beyond individualism in the recovery approach', *Advances in Mental Health*, 15 (2), pp. 108-120.
- Priebe, S., Huxley, P., Knight, S. and Evans, S. (1999) 'Application and results of the Manchester Short Assessment of Quality of Life (MANSA)', *International Journal of Social Psychiatry*, 45( 1), pp. 7-12.
- Rebeiro, K.L. (2000) 'Client perspectives on occupational therapy practice: Are we truly client-centred?', *Canadian Journal of Occupational Therapy*, 67(1), pp. 7-14.
- Repper, J. and Perkins, R. (2006) 'Looking through users' eyes.', *Mental Health Today* Jan, pp. 25-28.
- Repper, J. and Perkins, R. (2003) *Social inclusion and recovery: a model for mental health practice*. Edinburgh ; London: Baillière Tindall.
- Richards, V., Parry, A., Emery, L. and Sanderson, C. (2016) 'Useful Groups Like this don't Usually Happen in Places Like These: An Evaluation of Psychoeducational and Skills Workshops Within Inpatient Rehabilitation Services', *Journal of Psychosocial Rehabilitation and Mental Health*, 3 (2), pp. 119-123.
- Richter, M., Schmid-Ott, G. and Muthny, F.A. (2011) 'Goals, goal attainment, and patient satisfaction in psychosomatic rehabilitation', *Zeitschrift Für Psychosomatische Medizin Und Psychotherapie*, 57 (1), pp. 91-99.
- Ritchie, J.H. (1994) *The report of the inquiry into the care and treatment of Christopher Clunis: presented to the Chairman of North East Thames and South East Thames Regional Health Authorities, February 1994*. HM Stationery Office.
- Rogers, C.R. (1961) '*On becoming a person: A therapist's view of psychology*', Constable, London:

- Rojo-Mota, G., Pedrero-Pérez, E.J., Ruiz-Sánchez de León, José María and Miangolarra Page, J.C. (2014) 'Assessment of motor and process skills in daily life activities of treated substance addicts', *Scandinavian Journal of Occupational Therapy*, 21 (6), pp. 458-464.
- Rose, D. (2014) 'The mainstreaming of recovery', *Journal of Mental Health*, 23(5), pp. 217-218.
- Rosen, A., Hadzi-Pavlovic, D. and Parker, G. (1989) 'The life skills profile: a measure assessing function and disability in schizophrenia', *Schizophrenia bulletin*, 15 (2), pp. 325-337.
- Roy, L., Rousseau, J., Fortier, P. and Mottard, J. (2016) 'Postsecondary academic achievement and first-episode psychosis: A mixed-methods study', *Canadian Journal of Occupational Therapy*, 83 (1), pp. 42-52.
- Rozas, L.W. and Klein, W.C. (2010) 'The value and purpose of the traditional qualitative literature review', *Journal of Evidence-Based Social Work*, 7 (5), pp. 387-399.
- Rudnick, A. and Eastwood, D. (2013) 'Psychiatric rehabilitation education for physicians.', *Psychiatric Rehabilitation Journal*, 36 (2), pp. 126.
- Rugkåsa, J. and Burns, T. (2009) 'Community treatment orders', *Psychiatry*, 8 (12), pp. 493-495.
- Ryan, T., Carden, J., Higgo, R., Poole, R. and Robinson, C.A. (2016) 'An assessment of need for mental health rehabilitation amongst in-patients in a Welsh region', *Social Psychiatry and Psychiatric Epidemiology*, , pp. 1-7.
- Salgado, J.D., Deane, F.P., Crowe, T.P. and Oades, L.G. (2010) 'Hope and improvements in mental health service providers' recovery attitudes following training', *Journal of Mental Health*, 19 (3), pp. 243-248.
- Salzmann-Erikson, M. (2013) 'An integrative review of what contributes to personal recovery in psychiatric disabilities', *Issues in Mental Health Nursing*, 34 (3), pp. 185-191.
- Samara, M.T., Engel, R.R., Millier, A., Kandenwein, J., Toumi, M. and Leucht, S. (2014) 'Equipercntile linking of scales measuring functioning and symptoms: examining the GAF, SOFAS, CGI-S, and PANSS', *European Neuropsychopharmacology*, 24 (11), pp. 1767-1772.
- Samsudin, E.Z., Isahak, M. and Rampal, S. (2018) 'The prevalence, risk factors and outcomes of workplace bullying among junior doctors: a systematic review', *European Journal of Work and Organizational Psychology*, 27(6) pp. 700-718..
- Schmidt, LJ, Garratt, AM, Fitzpatrick, R. (2000) *Instruments for Mental Health: a Review Report from the Patient reported Health Instruments Group '(formerly the Patient-assessed Health Outcomes Programme) to the Department of Health'*, Department of Health, London
- Schmidt, M. (1996) *Rey auditory verbal learning test: A handbook*. Western Psychological Services Los Angeles, CA

- Schneider, J., Carpenter, J. and Brandon, T. (1999) 'Operation and organisation of services for people with severe mental illness in the UK. A survey of the Care Programme Approach', *The British Journal of Psychiatry*, 175, pp. 422-425.
- Schwartz, R.C. (2007) 'Concurrent validity of the Global Assessment of Functioning Scale for clients with schizophrenia', *Psychological Reports*, 100(2), pp. 571-574.
- Semkovska, M., Bédard, M., Godbout, L., Limoge, F. and Stip, E. (2004) Assessment of executive dysfunction during activities of daily living in schizophrenia. *Schizophrenia Research*, 69 (2-3), 289-300.
- Sensky, T., Turkington, D., Kingdon, D., Scott, J.L., Scott, J., Siddle, R., O'Carroll, M. and Barnes, T.R. (2000) 'A randomized controlled trial of cognitive-behavioral therapy for persistent symptoms in schizophrenia resistant to medication', *Archives of General Psychiatry*, 57 (2), pp. 165-172.
- Shepherd, G., Boardman, J. and Burns, M. (2008) *'Implementing Recovery'*, Sainsbury Centre for Mental Health, London .
- Shepherd, G., Boardman, J. and Slade, M. (2008) *'Making recovery a reality'*, Sainsbury Centre for Mental Health, London.
- Shepherd, G. (1995) 'The 'ward-in-a-house': residential care for the severely disabled', *Community Mental Health Journal*, 31 (1), pp. 53-69.
- Siu, B.W.-., Ng, B.F.L., Li, V.C.K., Yeung, Y.M., Lee, M.K.L. and Leung, A.Y.H. (2012) 'Mental health recovery for psychiatric inpatient services: Perceived importance of the elements of recovery', *East Asian Archives of Psychiatry*, 22 (2), pp. 39-48.
- Skevington, S.M. (1999) 'Measuring quality of life in Britain: introducing the WHOQOL-100', *Journal of Psychosomatic Research*, 47 (5), pp. 449-459.
- Skevington, S.M., Lotfy, M. and O'Connell, K.A. (2004) 'The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group', *Quality of Life Research*, 13 (2), pp. 299-310.
- Skevington, S.M. and McCrate, F.M. (2012) 'Expecting a good quality of life in health: assessing people with diverse diseases and conditions using the WHOQOL-BREF', *Health Expectations*, 15 (1), pp. 49-62.
- Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., Perkins, R., Shepherd, G., Tse, S. and Whitley, R. (2014) 'Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems', *World Psychiatry*, 13 (1), pp. 12-20.
- Slade, M., Beck, A., Bindman, J., Thornicroft, G. and Wright, S. (1999) 'Routine clinical outcome measures for patients with severe mental illness: CANSAS and HoNOS', *The British Journal of Psychiatry*, 174, pp. 404-408.

- SLAM (2010) *Hope, Agency and Opportunity in Psychiaity. A Position Statement by Consultant Psychiatrists*. South London and Maudsley NHS Trust: Royal College of Psychiatrists.
- Smith, J.A. (2008) *Qualitative Psychology: A Practical Guide to Research Methods* (2edn). Sage Publications
- Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative phenomenological analysis: Theory, method and research*. Sage Publications.
- Snyder, C.R., 1996. 'To hope, to lose, and to hope again', *Journal of Loss & Trauma*, 1 (1), pp. 1-16.
- Snyder, C.R., Lehman, K.A., Kluck, B. and Monsson, Y. (2006) 'Hope for rehabilitation and vice versa', *Rehabilitation Psychology*, 51 (2), pp. 89-112.
- Sook Hee, J. and Hyun Jeong, K. (2012) 'Perceived Stigma and Quality of Life of Individuals Diagnosed With Schizophrenia and Receiving Psychiatric Rehabilitation Services: A Comparison Between the Clubhouse Model and a Rehabilitation Skills Training Model in South Korea', *Psychiatric Rehabilitation Journal*, 35 (6), pp. 460-465.
- Spaulding, W.D., Fleming, S.K., Reed, D., Sullivan, M., Storzbach, D. and Lam, M. (1999) 'Cognitive functioning in schizophrenia: implications for psychiatric rehabilitation.', *Schizophrenia Bulletin*, 25 (2), pp. 275.
- Spaulding, W., Garbin, C.P. and Dras, S.R. (1989) 'Cognitive abnormalities in schizophrenic patients and schizotypal college students.', *The Journal of Nervous and Mental Disease*, 177 (12), pp. 717-728.
- Speak, B.L., Hay, P. and Muncer, S.J. (2015) 'HoNOS—their utility for payment by results in mental health', *International Journal of Health Care Quality Assurance*, 28(2), pp. 115-128.
- Srisurapanont, M., Suttajit, S., Maneeton, N. and Maneeton, B. (2015) 'Efficacy and safety of aripiprazole augmentation of clozapine in schizophrenia: A systematic review and meta-analysis of randomized-controlled trials', *Journal of Psychiatric Research*, 62, pp. 38-47.
- Sterne, J.A., White, I.R., Carlin, J.B., Spratt, M., Royston, P., Kenward, M.G., Wood, A.M. and Carpenter, J.R. (2009) 'Multiple imputation for missing data in epidemiological and clinical research: potential and pitfalls', *British Medical Journal* Accessed via <https://doi.org/10.1136/bmj.b2393>
- Stickley, T. and Felton, A, 2006. Promoting recovery through therapeutic risk taking. *Mental Health Practice*, 9 (8),
- Strauss, J.S. and Carpenter, W.T. (1972) 'The prediction of outcome in schizophrenia: I. Characteristics of outcome', *Archives of General Psychiatry*, 27 (6), pp. 739-746.
- Strauss, J.S. and Carpenter, W.T. (1977) 'Prediction of Outcome in Schizophrenia: III. Five-Year Outcome and Its Predictors', *Archives of General Psychiatry*, 34 (2), pp. 159-163.

- Svensson, B. and Hansson, L. (1999) 'Rehabilitation of schizophrenic and other long-term mentally ill patients. Results from a prospective study of a comprehensive inpatient treatment program based on cognitive therapy', *European Psychiatry*, 14 (6), pp. 325-332.
- Svensson, B., Hansson, L. and Nyman, K. (2000) 'Stability of outcome in a comprehensive, cognitive therapy based treatment programme for long-term mentally ill patients. A 2-year follow-up study', *Journal of Mental Health*, 9 (1), pp. 51-61.
- Szmidla, A. and Leff, J. (2006) 'Differentiating the effects of pharmacological and psychosocial interventions in an intensive rehabilitation programme', *Social Psychiatry and Psychiatric Epidemiology*, 41 (9), pp. 734-737.
- Tashakkori, A. and Teddlie, C. (1998) *Mixed methodology: Combining qualitative and quantitative approaches*. Sage Publications,
- Tashakkori, A. and Teddlie, C. (2010a) 'Putting the human back in "human research methodology": The researcher in mixed methods research', *Journal of Mixed Methods Research*, 4 (4), pp. 271-277.
- Tashakkori, A. and Teddlie, C. (2010b) *Sage handbook of mixed methods in social & behavioral research*. Sage Publications.
- Taylor, K.E. and Perkins, R.E. (1991) 'Identity and coping with mental illness in long-stay psychiatric rehabilitation', *British Journal of Clinical Psychology*, 30(1), pp. 73-85.
- Taylor, P.J. and Gunn, J. (1999) 'Homicides by people with mental illness: myth and reality', *The British Journal of Psychiatry*, 174, pp. 9-14.
- Thomas, K.A. and Rickwood, D.J. (2016) 'One woman's journey of recovery from mental illness; hopes, back-up plans, rebuilding self and service support', *Qualitative Social Work*, 15( 4), pp. 501-517.
- Thornicroft, G. and Tansella, M. (2005) 'Growing recognition of the importance of service user involvement in mental health service planning and evaluation', *Epidemiology and Psychiatric Sciences*, 14 (1), pp. 1-3.
- Thornicroft, G. and et al (2006) *International outcome measures in mental health. Quality of life, needs, service satisfaction, costs and impact on carers*. Royal College of Psychiatrists, London.
- Townsend, E. and A. Wilcock, A. (2004) 'Occupational justice and client-centred practice: A dialogue in progress', *Canadian Journal of Occupational Therapy*, 71 (2), pp. 75-87.
- Trauer, T., Duckmanton, R.A. and Chiu, E. (1995) 'The Life Skills Profile: a study of its psychometric properties', *Australian & New Zealand Journal of Psychiatry*, 29 (3), pp. 492-499.



- Tregoweth, J., Walton, J.A. and Reed, K. (2012) 'The experiences of people who re-enter the workforce following discharge from a forensic hospital', *Journal of Vocational Rehabilitation*, 37 (1), pp. 49-62.
- Trieman, N. and Leff, J. (1996) 'Difficult to place patients in a psychiatric hospital closure programme: the TAPS project 24', *Psychological Medicine*, 26 (04), pp. 765-774.
- Trieman, N. and Leff, J. (2002) 'Long-term outcome of long-stay psychiatric in-patients considered unsuitable to live in the community: TAPS Project 44', *The British Journal of Psychiatry*, 181 (5), pp. 428-432.
- Trieman, N., Smith, H.E., Kendal, R. and Leff, J. (1998) 'The TAPS project 41: homes for life? Residential stability five years after hospital discharge', *Community Mental Health Journal*, 34 (4), pp. 407-417.
- Tsai, J., Salyers, M.P. and Lobb, A.L. (2010) 'Recovery-oriented training and staff attitudes over time in two state hospitals', *Psychiatric Quarterly*, 81 (4), pp. 335-347.
- Tufford, L. and Newman, P. (2012) 'Bracketing in qualitative research', *Qualitative Social Work*, 11 (1), pp. 80-96.
- Van Busschbach, J. and Wiersma, D. (2002) 'Does rehabilitation meet the needs of care and improve the quality of life of patients with schizophrenia or other chronic mental disorders?', *Community Mental Health Journal*, 38 (1), pp. 61-70.
- Van, D.P., Hoek, H.W., Van Hoeken, D., Valencia, E. and Van Hemert, A.M. (2012) 'Perceptions of quality of life and disability in homeless persons with schizophrenia and persons with schizophrenia living in non-institutional housing', *International Journal of Social Psychiatry*, 58 (6), pp. 629-634.
- Van Wel, T., Felling, A. and Persoon, J. (2003) 'The effect of psychiatric rehabilitation on the activity and participation level of clients with long-term psychiatric disabilities', *Community Mental Health Journal*, 39 (6), pp. 535-546.
- Vandevooren, J., Miller, L. and O'Reilly, R. (2007) 'Outcomes in community-based residential treatment and rehabilitation for individuals with psychiatric disabilities: a retrospective study', *Psychiatric Rehabilitation Journal*, 30 (3), pp. 215-217.
- Velligan, D.I., Kern, R.S. and Gold, J.M. (2006) 'Cognitive Rehabilitation for Schizophrenia and the Putative Role of Motivation and Expectancies', *Schizophrenia Bulletin*, 32(3), pp. 474-485.
- Veseth, M., Binder, P., Borg, M. and Davidson, L. (2017) 'Collaborating to stay open and aware: Service user involvement in mental health research as an aid in reflexivity', *Nordic Psychology*, pp. 1-8.
- Waghorn, G., Lloyd, C. and Clune, A. (2009) 'Reviewing the theory and practice of occupational therapy in mental health rehabilitation', *The British Journal of Occupational Therapy*, 72 (7), pp. 314-323.

- Walid, M.S. and Zaytseva, N.V. (2011) 'Which Neuropsychiatric Disorder Is More Associated With Divorce?', *Journal of Divorce & Remarriage*, 52 (4), pp. 220-224.
- Ware Jr, J.E. and Sherbourne, C.D. (1992) 'The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection', *Medical Care*, 30(6), pp. 473-483.
- Wechsler, D. (1997) '*Wechsler Adult Intelligence Scale—version III (WAIS-III)*. Psychological Corporation' .
- Wilkinson, H., Whittington, R., Perry, L. and Eames, C. (2017) 'Examining the relationship between burnout and empathy in healthcare professionals: A systematic review', *Burnout Research*, 6, pp. 18-29.
- Willig, C. (2008) *Introducing qualitative research in psychology*. 2nd edn. McGraw-Hill Education (UK).
- Wing, J.K., Curtis, R. and Beevor, A. (1996) *HoNOS: Health of the Nation Outcome Scales: Report on Research and Development July 1993-December 1995*. Royal College of Psychiatrists, London.
- Wing, J. and Morris, B. (eds.) (1981) *Handbook of Psychiatric Rehabilitation Practice*. Oxford University Press, Oxford.
- Wittman, D., Smith, P., Rajarethinam, R., Foley, S., Vanbrusse, A., Phillip, B. and Keshavan, M., 2010. 'Do patients with psychosis experience loss and grief as a result of their illness?' *Psychoanalytic Social Work*, 17 (1), pp. 30-39.
- Wright, E. (2017) '*Long-stay rehabilitation services*', Briefing 51, Centre for Mental Health, London .
- Wykes, T. and Sturt, E. (1986) 'The measurement of social behaviour in psychiatric patients: an assessment of the reliability and validity of the SBS schedule', *The British Journal of Psychiatry*, 148, pp. 1-11.
- Yanos, P.T., Roe, D. and Lysaker, P.H. (2010) 'The impact of illness identity on recovery from severe mental illness', *American Journal of Psychiatric Rehabilitation*, 13 (2), pp. 73-93.
- Yerxa, E.J. (1990) 'An introduction to occupational science, a foundation for occupational therapy in the 21st century', *Occupational Therapy in Health Care*, 6 (4), pp. 1-17.

## Appendix 2.1: Rationale for exclusion from main literature review

Reason for exclusion	Reference
client need	Killaspy, Rambarran et al. 2008, Killaspy, Rambarran et al. 2009, Power, Dragović et al. 2012, Ryan, Carden et al. 2016
deinstitutionalisation	King, Singh et al. 2000, Chan, Inoue et al. 2007, Grinshpoon, Naisberg et al. 2006, Trieman, Leff 2002
characteristics of the patients who had used a rehabilitation service	Kavanagh, Nkire et al. 2009, Killaspy, Harden et al. 2005
groups specifically for woman	Taylor, Dorer et al. 2010
military personal experiencing post-traumatic stress disorder	Fagan-Pryor, Haber et al. 2009
effect of legal detention on readmission rates	Grinshpoon, Abramowitz et al. 2007
behavioural techniques	(Silverstein, Hatashita-Wong et al. 2006)
rehabilitation within a secure setting	Murugesan, Jeffrey et al. 2007
staff stress experienced while working in a rehabilitation setting	Brooker, Molyneux et al. 1999
Psychiatrist's opinions regard service changes	Mountain, Killaspy et al. 2009
clinical outcome measures as part of routine practice in a rehabilitation unit	Berry & Poorhady 2007
The REAL studies (Rehabilitation Effectiveness for Activities of Life)	Killaspy, White et al. 2011 Killaspy, Marston et al. 2013 Cook, Mundy et al. 2016

## Appendix 2.2: Summary of studies included in the literature review in date order

Citation	Journal	Country	Type of study	Aim of study	Measures	Population	Time scale	Quality assessment
Bunyan et al (2016)	British Journal of Psychiatry Bulletin	UK	Retrospective cohort using client notes	Evaluation of clinical and economic effectiveness of 3 inpatient units	Occupied bed days  Functioning information gathered from notes	N =22	2 years before and 2 years after rehabilitation	Fair  Selection criteria not clear. Not blind to participants
Killaspy et al (2016)	BMC Psychiatry	UK	Naturalistic prospective cohort from 50 rehab units in England	Evaluation of longitudinal outcomes and costs for patients and predictor indicators for better outcomes	Length of admission  Clinicians Alcohol and Drug use Scales <sup>19</sup>  Life Skills Profile <sup>20</sup>  Time Use Diary <sup>21</sup>  Global assessment of Functioning <sup>22</sup>  Special Problems Rating Scale <sup>23</sup>	N = 329	12 months	Good to fair  Robust representation of population and follow up

<sup>19</sup> Clinicians Alcohol and Drug use Scales (Drake, Mueser and McHugo, 1996) A clinicians view of use and addiction

<sup>20</sup> Life skills Profile (Parker *et al.*, 1991) A general, clinicians view of function and disability

<sup>21</sup> Time use Diary (Jolley *et al.*, 2006) Assesses activity levels at 4 time periods during the day for a week

<sup>22</sup> Global assessment of Functioning (Jones *et al.*, 1995) A clinicians view of functioning across social, occupational and psychological domains

<sup>23</sup> Special Problems Rating Scale (Trieman and Leff, 1996) A clinicians view of challenging behaviours

Citation	Journal	Country	Type of study	Aim of study	Measures	Population	Time scale	Quality assessment
Killaspy and Zis (2013)	Social Psychiatry and Psychiatric Epidemiology	UK	Retrospective cohort study – 5 year comparison of within groups	To investigate outcomes relating to accommodation and factors associated with outcome	Success of community living Clinicians Alcohol and Drug use Scales Psychotropic medication Life Skills Profile Special Problems Rating Scale Camberwell Assessments of Need <sup>24</sup>	N= 141	5 years	Good to fair  Possible recall bias and possible issues with data collection
Gonda et al (2012)	Australian and New Zealand Journal of Psychiatry	Australia	Retrospective cohort design - purpose sampling from archival data	To investigate reliable and clinically significant change and determine factors associated with outcome	Brief Psychiatric Rating Scale <sup>25</sup> Kessler 10 <sup>26</sup> Health of the Nation Outcome Score <sup>27</sup>	N = 371	Repeated measures – admission , 3-month review and discharge	Good  Clear methodology  Intervention generalised

<sup>24</sup> Camberwell Assessment of Need A subjective and objective view of need across 22 domains including symptoms, activities and relationships

<sup>25</sup> Brief Psychiatric Rating Scale (Overall and Gorham, 1962) a semi structured interview to measure a range of psychiatric symptoms

<sup>26</sup> Kessler 10(Kessler *et al.*, 2002) Assesses a clients perceptions of symptom and distress

<sup>27</sup> Health of the Nation Outcome Score (Wing, Curtis and Beevor, 1996) a brief, clinician rated measure of clinical change. Designed as a service measure

Citation	Journal	Country	Type of study	Aim of study	Measures	Population	Time scale	Quality assessment
Notley et al (2012)	International Journal of Therapy and Rehabilitation	United Kingdom	Qualitative study. Semi structured interview using photo – elicitation	To explore patients experience of rehabilitation	One to one semi structured interview with photos to trigger memories and encourage responses	N=10	1 year post discharge	Good Recruitment, aims and methodology explicit findings relevant <sup>28</sup>
Liu et al (2011)	American Journal of psychiatric rehab	USA	Retrospective cohort design using archival data	To explore longitudinal recovery across key functional domains	Brief Psychiatric Rating Scale Wechsler Adult Intelligence Scale <sup>29</sup> Hinting Task <sup>30</sup> Nurses' Observation Scale for Inpatient Evaluation <sup>31</sup>	N =10	10 years	Good to Fair  Possible variations in recording and obtaining data
Petrie and Mountain (2009)	Scottish Medical Journal	UK	Retrospective observational study using case notes	To explore outcomes in terms of re-hospitalisation	Number of occupied bed days Frequency of use of the Mental Health Act	N = 35	4 years (2 years before and 2 years after admission)	Fair  Nature of service and interventions offered not clear  No inclusion / exclusion or how subjects were selected

<sup>28</sup> CASP quality assessment used on this study due to qualitative nature of the study

<sup>29</sup> Wechsler Adult Intelligence Scale (Wechsler, 1997) a test to assess working memory and attention and higher cognitive functioning such as processing speed and visuospatial skills

<sup>30</sup> Hinting Task(Corcoran, Mercer and Frith, 1995) a test of social cognition for people with schizophrenic – spectrum disorders

<sup>31</sup> Nurses' Observation Scale for Inpatient Evaluation (Honigfeld, Gillis and Klett, 1966) clinician rated indicator of acute psychosis and behaviour

Citation	Journal	Country	Type of study	Aim of study	Measures	Population	Time scale	Quality assessment
Peer and Spaulding (2007)	Schizophrenia Research	USA	Retrospective cohort study using archival clinical assessment data	To investigate psychosocial functioning recovery trajectories	COGLAB <sup>32</sup> Nurses' Observation Scale for Inpatient Evaluation Rey Auditory Verbal Learning Task <sup>33</sup>	N= 162	18 months	Good to Fair  Selection process not clear
Vandevooren et al (2007)	Psychiatric Rehabilitation Journal	Canada	A retrospective cohort, repeated measures design	To evaluate outcomes following rehabilitation in terms of community living and functioning	Number of hospitalisations community living and accommodation  Colorado Client Assessment Record <sup>34</sup>  Global Assessment of Functioning	N = 25	7 years (6 years prior to rehabilitation and 1 year post)	Poor  Limited detail due to it being a 'brief report'  Errors on reporting results %'s

<sup>32</sup> COGLAB (Spaulding, Garbin and Dras, 1989) a computerized neuro cognitive test of attention and executive functioning

<sup>33</sup> The Rey Auditory Verbal Learning Task (Schmidt, 1996)

<sup>34</sup> Colorado Client Assessment Record (Ellis, Wackwitz and Foster, 1991) A problem checklist of symptom severity and functioning

Citation	Journal	Country	Type of study	Aim of study	Measures	Population	Time scale	Quality assessment
Arfken et al (2002)	International Journal of Rehabilitation Research	USA	A current cohort, repeated measures design	To evaluate living situation, use of health care facilities and medication after discharge	Use of health care facilities Duration of Clozapine usage Living and working situation Becks Depression Inventory <sup>35</sup> Abnormal Involuntary Movement Scale <sup>36</sup> SF-36 <sup>37</sup> BPRS	N =77	Unclear – approximately 4 years	Fair Multiple changes to original design Attrition rate > 50%
Leff and Szmidla (2002)	Social Psychiatry and Psychiatric Epidemiology	UK	Controlled study. Current cohort compared to retrospective cohort	To evaluated a rehabilitation programme for difficult-to-place patients	Social Behaviour Scale <sup>38</sup> Behaviour and Everyday Living Skills Schedule <sup>39</sup> Special Problems Rating Scale	N= 22	1 year	Fair to poor Drug company provided medication. Author had responsibility for treatment strategy

<sup>35</sup> Becks Depression inventory (Beck *et al.*, 1961) A self-reported assessment to symptoms to establish level of depression

<sup>36</sup> Abnormal Involuntary Movement Scale (Lane *et al.*, 1985) A clinician rated measure of abnormal movement due to extrapyramidal symptoms (Tardive dyskinesia)

<sup>37</sup> SF-36 (Ware Jr and Sherbourne, 1992) A short and generic, self-reported measure of quality of life

<sup>38</sup> Social Behaviour Scale (Wykes and Sturt, 1986) a clinician rated scale measuring socially acceptable behaviour in terms of speech and mannerisms

<sup>39</sup> Behaviour and Everyday Living Skills Schedule (O'Driscoll and Leff, 1993b) developed as part of the TAPS study, a clinician rated measure of self-harming, destructive and inappropriate behaviours



Citation	Journal	Country	Type of study	Aim of study	Measures	Population	Time scale	Quality assessment
Svensson et al (2000)	Journal of Mental Health	Sweden	Controlled study. Current cohort of cognitive rehab matched to retrospective comparison group receiving conventional rehabilitation	To evaluate differences in terms of quality of life, functioning and symptoms between the two groups	Occupied bed days Living and working arrangements Medication Target Complaints <sup>40</sup> Hopkin's Symptom Check List -90 <sup>41</sup> Comprehensive Psychopathological Rating Scale <sup>42</sup> GAF Strauss-Carpenter Scale <sup>43</sup> Kajandi <sup>44</sup>	N= 21	2 years post treatment	Good  Rationale for use of tools not clear  25% drop out rate

<sup>40</sup> Target Complaints - Used as an individualized measure of outcome

<sup>41</sup> Hopkins Symptom Check List -90 (Derogatis and Cleary, 1977) a 90 item self-report inventory on psychological symptoms and distress

<sup>42</sup> Comprehensive Psychopathological Rating Scale (Åsberg *et al.*, 1978) A self-reported and clinician observed semi structured interview of clinical symptoms

<sup>43</sup> Strauss- Carpenter Scale (Strauss and Carpenter, 1972) a clinician rated assessment of functioning considering social contacts, symptoms, employment and use of services

<sup>44</sup> Kajandi (Kajandi, 1994) A structured interview targeting 17 dimensions of Quality of Life

Citation	Journal	Country	Type of study	Aim of study	Measures	Population	Time scale	Quality assessment
Bruseker and O'Halloran (1999)	Australian Journal of Mental Health Nursing	Australia	Repeated measures design of current cohort	To evaluate a new service following national reform using process and clinical measures	Client Satisfaction Survey <sup>45</sup> The information Questionnaire <sup>46</sup> Brief Psychiatric Rating Scale Scale for the Assessment of Negative Symptoms <sup>47</sup> Quality of Life Scale <sup>48</sup>	N= 76	2 years	Poor Little known about how sample was selected or those used as a comparison Interviews conducted by staff on the unit Attrition rate > 50% Measures not referenced

<sup>45</sup> Client Satisfaction Survey (no reference) The degree of client satisfaction with the service

<sup>46</sup> The Information Questionnaire (no reference ) Measures client comprehension of their schizophrenia

<sup>47</sup> Scale for the Assessment of Negative Symptoms (Andreasen, 1982) measures the severity of negative symptoms of schizophrenia, for example anhedonia and apathy

<sup>48</sup> Quality of Life Scale (Heinrichs et al 1984)

### Appendix 2.3: A brief critique of the measures identified in the literature review

Measure	Brief critique
Wechsler Adult Intelligence Scale (WAIS) (n=1) (Wechsler, 1997)	<b>The WAIS is a commonly used adult IQ test for measuring intelligence with an emphasis on working memory, attention and higher cognitive functioning such as processing speed and visuospatial skills</b>
Hinting Task (n=1) (Corcoran <i>et al.</i> , 1995)	A test of social cognition for people with schizophrenia, and those with spectrum disorders
Rey Auditory Verbal Learning Task (n=1) (Schmidt, 1996)	A test of verbal learning and memory through the use of timed recall of 30 words, not specifically designed for people with long term mental health needs.
COGLAB (n=1) (Spaulding <i>et al.</i> , 1989)	A computerized neruo-cognitive test of attention and executive functioning
Life skills profile (n=2) (Parker <i>et al.</i> , 1991)	A general measure of social functioning, but not specifically designed for people with long term mental health needs. Inter-rater reliability is low and disparities seem to be linked to how well the staff member completing the tool knows the patient (Trauer <i>et al.</i> , 1995)
Time use diary (n=1) (Jolley <i>et al.</i> , 2006)	Measures activity levels at four time periods across a day. While this is important to establish meaningful engagement in an activity, it is unclear how this observational tool captures this information
Global Assessment of Functioning (GAF)(n=3) (Patterson and Lee, 1995)	The GAF provides a numerical score between 100 – 1 (high to low functioning) of a person’s ability to address and cope with everyday life events. It is widely used within mental health services, and is reported to have good reliability (Schwartz, 2007; Jones <i>et al.</i> , 1995). However, the inter-rater reliability of the scale has been questioned due to its brief administration instructions and a lack of clarity on how to score it (Aas, 2011).
Health of the Nation Outcome Score (HoNOS) (n=1) (Gonda, Deane and Murugesan, 2012).	HoNOS is a DoH commissioned measure of clinical change, administered by clinicians, to evaluate the health and social functioning of people with a mental illness; it is to be completed after other assessments to give a full picture of the personal global health and social functioning. It has been used widely within all mental health services since the mid 1990’s and is now an integral part of payment by results (Lee <i>et al.</i> , 2013; Lee <i>et al.</i> , 2011). It measures 12 items, including behaviours and risk taking activities, but also considers a person’s relationships and their ability to engage in activities and occupations (Wing, Curtis and Beevor, 1996). The ubiquity if the use of the tool makes it a pragmatic measure for research and it has been found to have concurrent validity with other measures, for example BPRS and SBS (Pirkis <i>et al.</i> , 2005), which measure symptoms and behaviour, not a person’s ability to function in their own

	environment. However, despite the HoNOS seeming to be an effective measure of global functioning for rehabilitation clients, there are concerns regarding its internal reliability (Bebbington <i>et al.</i> , 1999), its limited sensitivity for those with serious, long-term problems and its content validity and subjectivity of the measure (Pirkis <i>et al.</i> , 2005), leading to its overall utility being questioned (Speak, Hay and Muncer, 2015).
Strauss- Carpenter Scale (S-CS) (n=1) (Strauss and Carpenter, 1972).	The S-CS is a scale used to predict the likelihood of psychosis amongst people deemed to be at high clinical risk by comparing social contact, symptoms and employment (Strauss and Carpenter, 1977; Strauss and Carpenter, 1972). The relevance of this tool is limited within the rehabilitation setting, when most service users will have a long history of a psychotic illness preceding their admission.
Brief Psychiatric Rating Scale (BPRS) (n=4) (Lukoff, Liberman and Nuechterlein, 1986)	The BPRS is a well-recognised and established tool that has been found to have good cross cultural inter-rater reliability and is frequently used as a benchmark measure, from which the reliability and validity of other measures are compared. However, it has been found to be less sensitive at picking up the negative symptoms of schizophrenia, such as avolition and a more sensitive tool is recommended (Bell <i>et al.</i> , 1992).
Kessler 10 (n=1) (Kessler <i>et al.</i> , 2002)	A non-specific, non-instructive self-rating scale of psychological distress. It asks general questions about how one has been feeling over the last 30 days, for example 'Did you feel tired out without good reason?' However, the sensitivity in relation to those with long term mental illness and with a collection of negative symptoms is questioned as it has been found to have a strong association with anxiety and affective disorders as opposed to more long term illness such as schizophrenia (Andrews and Slade, 2001).
Colorado Client Assessment Record (n=1) (Ellis <i>et al.</i> , 1991)	A multi-dimensional problem checklist of symptom severity and functioning. Originally designed to assess need in terms of establishing bed requirements and the cost effectiveness of mental health care across the state of Colorado. It correlates highly with the GAF and BPRS (Coffman, Bloom and Wallace, 2004) probably accounts for why, on inspection, the tool appears to be clinician rated measure of symptoms, behaviour and physical functioning and not a measure of the person's own perception of need as originally believed.
Comprehensive Psychopathological Rating Scale (CPRS) (n=1) (Åsberg <i>et al.</i> , 1978)	CPRS has now been superseded by the Montgomery-Åsberg Depression Rating Scale (MADRAS) (Montgomery and Åsberg, 1979). The CPRS is based on a structured interview, combining both self-report and observed items
Becks Depression Inventory (BDI) (n=1) (Beck <i>et al.</i> , 1961)	The BDI is used routinely in secondary mental health and primary care services having good internal consistency for psychiatric and non-psychiatric populations (Beck, Steer and Carbin, 1988). It is a self-rating measure of depression, with 21 questions, each with a 0-3 scale, offering a total of up to 63 points which are categorised into 6 levels of mood 1-10 – 'normal ups and down'

	to over 40 – extremely depressed.
Hopkin’s Symptom Check List -90 (n=1) (Derogatis and Cleary, 1977)	A 9-dimension, self-rated assessment of psychological symptoms and distress, with a high validity of depression (Derogatis and Savitz, 1999) with low sensitivity for people with psychosis
Scale for the Assessment of Negative symptoms (SANS) (n=1) (Andreasen, 1982)	The SANS was specifically designed to measure subdued and withdrawn behaviour traits frequently observed in people with long term schizophrenia. It is based on a semi structured interview evaluating across 5 areas (affect, alogia, avolition, anhedonia and attention). It has been tested to have good interrater reliability and internal validity (Andreasen, 1989).
The Abnormal Involuntary Movement Scale (AIMS) (n=1) (Lane <i>et al.</i> , 1985)	The AIMS is a measure of abnormal movement, due to extra pyramidal side effects, in particular tardive dyskinesia. While the rationale to use AIMS is not clear in the study, it is probably linked to the motivation in the study to initiate Clozaril (an anti-psychotic medication with a lower side effect profile that requires careful monitoring of the white blood cells via a National Registry).
Special Problems Rating Scale (SPRS) (n=3) (Trieman and Leff, 1996).	The SPRS was designed to focuses on challenging behaviours, for example, aggressiveness and sexually inappropriate behaviour that may make it difficult for a people to be discharged from hospital into the community (Trieman and Leff, 1996). While it is found to have high interrater reliability (Trieman and Leff, 2002), the potentially subjective nature of this tool allows for a judgmental interpretation of behaviour based on observation alone.
Clinicians rating Alcohol Use and Drug use Scales (n=2) (Drake, Mueser and McHugo, 1996)	Two separate rating scales, each of 5 questions each, used to determine a clinicians perception of the severity of a problem combining client’s self-report, records and other information gathered over a six month period.
Nurses Observation for Inpatient evaluation (n= 2) (Honigfeld, Gillis and Klett, 1966)	The NOSIE is a 30-item scale designed to give a behavioural and observational rating of psychiatric inpatients based on nurse observations of the previous 72 hours, with good reliability for people with long term schizophrenia (Lyll, Hawley and Scott, 2004)
Social Behaviour Scale (SBS) (n= 1) (Wykes and Sturt, 1986)	Both the SBS and the BELS were designed for the TAPS project (Leff <i>et al.</i> , 2000) focusing on ‘socially unacceptable’ institutional-type behaviour which was prevalent in the population of those residing in long stay psychiatric hospitals, making it difficult for staff to find them post institutional accommodation. While some patients still struggle to manage their behaviour, the prevalence of institutional – type behaviour, for example learned behaviour patterns that have proved beneficial over time, has reduced as the rehabilitation population has changed (Killaspy <i>et al.</i> , 2005),as a consequence the contemporary relevance of such measures is limited.
Behaviour and Everyday Living skills schedule (BELS) (n=1) (O’Driscoll and Leff, 1993b).	
SF-36 (n=1) (Ware Jr and Sherbourne, 1992),	The SF-36 is a short self-reported measure of general health and ability with good reliability and validity (Jenkinson, Wright and Coulter, 1994). It is a very generic measure of health status, including anxiety and depression, physical fitness and stamina, with arguably limited sensitivity

	for people with severe mental health needs.
Kajandi (n=1) (Kajandi, 1994)	The Kajandi is a quality of life tool based a semi- structured interview targeting 17 areas over three key life domains (external life conditions, interpersonal relationships and internal psychological state). It was specifically developed for people with psychiatric problems recognising the interplay of the environment in which they were living (Kajandi, 1994).
Quality of Life Scale (n=1) (Heinrichs, Hanlon and Carpenter Jr, 1984)	The QoL Scale is a 21-point scale designed to assess the negative symptoms of schizophrenia over the past 4 weeks. It is a semi structured interview, where clinical staff ask probing questions to elicit thoughts in relation to the questions. It is structured around 4 categories; intrapsychic foundations, interpersonal relationships, instrumental role and common objects and activities, giving a score that is reported to be more representative of the impact of schizophrenia on function than quality of life. The validity and reliability of this measure is rated as good however, the authors compared their results with a study that investigated small number of psychology students (Heinrichs, Hanlon and Carpenter Jr, 1984) so this statement may not be as sound as it first seems.
Camberwell Assessment of Needs Short Appraisal Scale (n=1) (Slade <i>et al.</i> , 1999)	The CANSAS, is adapted from the Camberwell Assessment of Needs (Phelan <i>et al.</i> , 1995) and covers 22 domains, including accommodation, food, self-care and symptoms. The perceived client need is derived from collating the perceptions of the client, carers and staff. It requires some staff training and found to have moderate inter-rater reliability, however it has limited sensitivity at an individual level (Slade <i>et al.</i> , 1999)

Appendix 3.1a  
08 October 2010

Mrs Rachel Dadswell

Dear Mrs Dadswell

**Full title of study:** Is there a place for inpatient mental health rehabilitation in modern day mental health services?  
**REC reference number:** 10/H0502/47

Thank you for your letter of 28<sup>th</sup> August 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 13 July 2010. Please note these documents are for information only and have not been reviewed by the committee.

**Documents received**

The documents received were as follows:


Document	Version	Date
REC application		28 August 2010
Covering Letter		28 August 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

10/H0502/47

Please quote this number on all correspondence

Yours sincerely



**William Goodyear**  
**Committee Co-ordinator**

E-mail: w.goodyear@nhs.net

**Appendix 3.1b**

27 January 2011

Mrs Rachel Dadswell



Dear Mrs Dadswell

**Study title:** Is there a place for inpatient mental health rehabilitation in modern day mental health services?  
**REC reference:** 10/H0502/47  
**Amendment number:**  
**Amendment date:** 06 January 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 18 January 2011.

**Ethical opinion**

The Committee reviewed the amendment and gave a favourable opinion without comments.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Questionnaire: LQoLP-EU		
Questionnaire: WHOQOL-BREF 26		
Notice of Substantial Amendment (non-CTIMPs)		06 January 2010
Covering Letter		17 December 2010

**Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

*The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England*



## Appendix 3.2 Letter of Invitation Version 1 (LoIV1)

Rehabilitation Services

### LETTER OF INVITATION

Dear

#### **Re: Inpatient mental health rehabilitation: is there a place for it today?**

During your stay [REDACTED], Rachel Dadswell, Consultant Occupational Therapist will be undertaking some research. This research will be investigating how a stay at Forest Lodge helps individuals to improve their quality of life and support them with developing the skills required to live a satisfying and meaningful life.

You are invited to be part of this research as an important feature of the research is understanding what it means to be in a residential unit from an individual perspective. Rachel is particularly interested in hearing your story as you move through [REDACTED], from admission to discharge and three months post discharge; what helped and hindered you.

Although you will not receive financial payment from taking part in the study, it is hoped that you will gain information about your recovery and be able to share your experience to help us to continually develop and improve what we do.

The study will involve you being asked to complete a short questionnaire in relation to quality of life. It will also involve you being observed by Rachel while you undertake two familiar and relevant activities of daily living (e.g. making tea and toast or making a bed). You will be observed, and asked to complete the questionnaire on three separate occasions. You may also be invited to attend an interview session at each of the three time points so that Rachel can gain a full picture of your experience to date.

If you are interested in being part of the study, a Declaration of Interest form is attached. Please read this carefully, and discuss with your key nurse if required, before signing it and returning it to your nurse. I will not be able to make contact with you until I receive written confirmation from you that you are willing to be in the study. Whether you choose to be part of the study or not, your care and treatment at Forest Lodge will not be affected.

If you have any concerns or require any further information, please do not hesitate to contact me (Rachel) [REDACTED]

Thank you for your time,

Yours sincerely,

Rachel Dadswell *Consultant Occupational Therapist (Msc, DIPCOT)*

Date

**DECLARATION OF INTEREST**

Dear

**Re: Inpatient mental health rehabilitation: is there a place for it today?**

Thank you for your interest in the above study. I am writing to ask you if you would give your written consent for me Rachel Dadswell, to meet with you at [REDACTED] to discuss the research, and what it would mean to you in more detail.

At this moment I only require your name and some way of contacting you to arrange an appointment. At this appointment I will be able to share with you the patient information sheet, answer any questions you may have and talk you through the research process.

By meeting with me you are not committing yourself to anything, but if you do wish to continue with the study I will require that you sign your written consent. Even, if you do this you are under no obligation to continue with the study, and may withdraw at any time without explanation. Your care at [REDACTED] will not, in anyway be influenced by whether you take part in the study or not.

**Declaration of Interest**

I,..... give my permission for Rachel Dadswell to contact me on..... to further discuss the following research project.

Inpatient mental health rehabilitation: is there a place for it today?

I understand I am no way committed to continuing with the study, but if I do go ahead I will be required to sign my written consent. I am free to withdraw from the study at anytime without explanation.

Signed ..... Date.....

## **TAKING PART IN RESEARCH**

### **Inpatient mental health rehabilitation: is there a place for it today?**

You are being invited to take part in a research study, and have already expressed an interest in knowing more about it. Here is some information to help you decide whether or not to take part. Please take your time to read the following information carefully and discuss it with friends, relatives and a healthcare professional, if you wish. Please ask if there is anything that you do not understand or if you would like more information.

You will not receive any financial benefit from taking part in this study. However, the information we obtain will help us better understand the process of inpatient rehabilitation, how it helps and what, from an individual point of view is most beneficial. It will also help us understand what we may need to do differently.

It is up to you to decide whether or not to take part, and even if you do decide to go ahead, you will be free to withdraw at *any* time and without giving a reason. This will not affect the standard of your care or how quickly you are treated. If you decide not to take part, nobody will mind.

All of the information gathered about you during the course of the research will be kept strictly confidential. If the final report is published it will not identify you.

Your psychiatrist, care co-ordinator, GP and any other professional regularly involved in your care (for example, your key nurse) will normally be informed that you are taking part. If this is a problem for you, please discuss this with Rachel Dadswell, who is leading on this piece of research.

### **Inpatient mental health rehabilitation: is there a place for it today?**

#### **Information for Participants.**

##### **1. The history of rehabilitation services**

Traditional rehabilitation services evolved from the National Closure Programme of large psychiatric institutions in the late 1970's early 1980's. Since then, the way we work with people who have a mental illness has changed and improved. We now know people can and do recovery and go on to live full and meaningful lives, even with symptoms. Today rehabilitation services work within this 'recovery model', to help people rebuild the skills and confidence to carry out the tasks they need to do, to live the life they wish.

## **2. What is the purpose of this study?**

While we recognise that inpatient rehabilitation is an effective treatment for some people; we do not fully understand what it is about the rehabilitation / recovery process that is helpful. We do not know for example, if a person's skill and ability to carry out the tasks they need and desire to do is affected by the rehabilitation / recovery process. Nor do we know if an individual's quality of life changes over the period of time they are in the inpatient unit.

This study aims to investigate how the current model of multi-professional, recovery oriented practice is effective in helping people gain the skills and confidence they need to live the life they choose, which has purpose, meaning and quality.

## **3. Why have I been chosen?**

You have been asked to take part because you have recently been admitted to an inpatient rehabilitation unit. In addition to this, your key nurse or psychiatrist has identified you as being someone who might be interested in participating. We will be asking approximately 20 people to take part in the study.

## **4. Who is organising the study?**

This study has been organised by Rachel Dadswell as part of her PhD study. This study will take approximately four years to complete, (although your involvement will not be this long).

## **5. What will happen to me if I take part?**

You will then be invited to meet with Rachel Dadswell, at Forest Lodge who will provide you with further information and answer any questions you may have. If you decide to go ahead, you will be asked to give your written consent to take part in the study.

Following discussions and your written consent you will be asked to do three things. The first is to complete a short questionnaire on quality of life issues. This will take about 15 – 30 minutes and consist of a multiple choice type questions. The second thing you will be asked to do is undertake two agreed activities of daily living which you are familiar with and have relevance to you and thirdly, you will be invited to take part in a semi –structured interview.

You will complete these agreed activities while Rachel observes you. The activities are likely to be something that you would need to, or choice to do routinely. Rachel will be able to talk you more about this when you meet with her. You will be asked to complete both these elements soon after admission, prior to discharge and three months after discharge.

In addition to this, some people will be asked if they would be willing to take part in an interview at each of the time frames (admission, prior to discharge and three months post discharge) It is anticipated each interview will last no longer than 30 minutes. The aim of the interview is to gain

an understanding from your perspective what was particularly helpful or otherwise about the whole rehabilitation process.

## **6. What are the possible risks of taking part?**

Some people find been observed or talking about themselves difficult or distressing. Rachel will be very sensitive towards this and will contact your key nurse or care co-ordinator if you feel that you require additional support. You may also request a break at any time, and if you wish to end the session at any point, nobody will mind.

## **7. What are the possible benefits of taking part?**

Although we believe inpatient rehabilitation is effective for some people, we hope that we will gain a deeper understanding about how it is helpful. The findings will also contribute to developing our services in the future so that we continue to improve what we do.

## **8. What if something goes wrong?**

It is highly unlikely that taking part in this study could harm you. However, there are no special compensation arrangements. If you are harmed due to someone's negligence then you may have grounds for legal action. Regardless of this, if you have any grounds to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you.

## **9. Confidentiality – Who will know that I am taking part in this study?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you, which leaves [REDACTED] will be anonymous, so you cannot be recognised from it.

## **10. Notification of professionals involved in your care**

If you agree to take part in the study, we will notify your Psychiatrist, Care co-ordinator, GP and any other professional regularly involved in your care (for example, your key nurse) by letter. If this is of concern to you however, please talk to Rachel about it.

## **11. Ethical Approval**

This study has been approved as ethical by the Local Medical Ethics Committee.

## **12. What will happen to the results of this study?**

The results of the study will be written up into a report that will be available to staff at the [REDACTED] and University College Cork. Your name will appear nowhere in the report and you will not be recognisable. If you want to receive a copy of the completed report, this can be arranged through Rachel. If the report is published in an academic or practice based journal, as before, your name will appear nowhere in the text and you will not be recognisable.

### **13. Further information**

Further information about this study can be obtained from Rachel Dadswell who will be carrying out the research. Rachel can be contacted at [REDACTED]

### **14. Contact for further information.**

If you wish to talk to an independent person about this study and its implications for you, you can contact [REDACTED], at the Research and Development Service, [REDACTED], telephone [REDACTED]. Additionally your key nurse would be happy to speak to you in more detail about the study.

## Appendix 3.5 Consent form Version 1 (CF V1)

Patient Identification Number for this trial:

### CONSENT FORM

**Title of Project: Inpatient mental health rehabilitation; is there a place for it today?**

Name of Researcher: Rachel Dadswell

Version: CF V1

Please initial each box

1.	I confirm that I have read and understand the participant information sheet dated June 2010 (PIS V1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected	
3.	I understand that data collected throughout this study may be looked at by Rachel Dadswell and her academic supervisors. I give permission for these individuals to have access to the data collected from this study, to store and to process it.	
4.	I agree that in order for me to participate in the study, Rachel may have access to my contact details, which will be stored securely on an NHS, password-protected computer or locked in an NHS filing cabinet.	
5.	I agree to my psychiatrist / care-coordinator / key nurse / GP being informed of my participation in the study.	
6.	I agree that data obtained from this trial can be used, in anonymous form, for publication.	

\_\_\_\_\_  
Participant name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 3.6 Interview schedule – phase one

Interview Schedule – Phase One  
Within first month of admission

### Preamble

Thank you for meeting with me today. As you know I am an occupational therapy researcher and I am interested to know more about people's experiences of mental illness, especially what happens when they are admitted to somewhere [REDACTED] and how useful they find the rehabilitation process here. There are no right or wrong answers.. I am just interested in **your** experience and your opinions of **your** recovery

Firstly can I confirm that you are still happy for me to talk to you generally and to ask you some questions about being at [REDACTED]

Can I also confirm that you are happy for me to audio-tape what you are saying?

I will be making a few notes, but these will be just to prompt me along the way. Once we have finished the interview, I will type up our conversation. Then I would like to send you a copy of the interview to make sure you are happy with it

Do you have any questions about the research or about the interview before we start?

Can I please confirm your

Name

DoB

DoA to [REDACTED]

- 1) **Can we start with you telling me what has been happening over the past few months / year and about why you have come to [REDACTED]**
  - a. I have noticed that you have mentioned
  - b. Can you tell me more about
  - c. What do you remember about
  - d. Can we go back to
  
- 2) **What were your thoughts and feelings on hearing that you were coming to [REDACTED]**
  - a. What happened then/next
  - b. Can you recall anything about
  - c. Can you give me an example of
  - d. Tell me more about
  
- 3) **What has it felt like being in [REDACTED] so far?**
  - a. Can we start with when you arrived
  - b. How did that feel
  - c. Can you give me an example of that
  - d. Tell me more about



- 4) **What can you tell me about your hopes for your time at [REDACTED]**
  - a. Can you tell me more about
  - b. Can you give me an example of what you hope to achieve
  - c. What would help with that
  - d. What is that like for you
  
- 5) **How was the experience of being interviewed?**
  
- 6) **Do you have any questions for me?**
  
  
- 7) **Is there anything else you would like to say about [REDACTED] that you haven't had the opportunity to mention yet?**

Thank you again for your time, I will get a copy of the interview to you shortly, please read and amend as necessary and return to me in the addressed envelope. If I don't receive it back, I will assume you are happy with it. I look forward to meeting with you again to .....

## Appendix 3.7 Interview schedule – phase two

### Interview schedule – Phase two

#### Within the month of discharge

#### Preamble

Thank you for meeting with me- today, it's good to see you again. As you may recall I am conducting some research at [REDACTED] and I am particularly interested to know more about people's experiences of mental illness, especially what happens when they are admitted to somewhere like Forest Lodge, and how useful they find the rehabilitation process. There are no right or wrong answers... I am just interested in **your** experiences and **your** opinions of what happened to you during your recovery process.

Firstly, can I confirm that you are still happy for me to talk to you today and that you are happy for me to audio-tape what you are saying? I will be making a few notes, but these will be just to prompt me along the way. Once we have finished the interview, I will type up our conversation. I would then like to send you a copy of the interview to make sure you are happy with it.

Do you have any questions about the research or about the interview before we start?

#### Although we have meet already could I ask you just to confirm

Your name

Your date of birth

Date of admission to [REDACTED]

- 1) **Can we start with you telling me what has been happening while you have been at [REDACTED]**
  - How did that make you feel?
  - Did you like/dislike that
  - I've noticed that you mentioned
  - Can you tell me more about
  - What do you remember about
  - Can we go back to
  
- 2) **Has anything particular stood out about your stay here? What have you liked or disliked while being in [REDACTED]**
  - How did that make you feel?
  - What happened then / next
  - Can you recall anything about
  - Can you give me an example of that
  - Tell me more about

**3) Can you tell me how you feel now that you are ready to leave [REDACTED]**

- Do you feel ready/not ready to leave?
- Can you tell me more about
- Can you give me an example
- Was there any impact of that

**4) What did you hope to achieve during your stay at [REDACTED]**

- How or why have they changed
- What has helped or hindered you to get where you are
- Are you able to say any more about that
- Can you give me an example
- What contributed to

**5) Do you think you have achieved these?**

- If not why not? If partially... what has not been done

**6) What are your thoughts about leaving [REDACTED]**

- Has being here helped/not helped your recovery...? In what way?
- Can you tell me more about your plans...
- What has happened to get you to this point
- Can you give me an example of ...
- Tell me more about ...

**7) How was the experience of being interviewed**

**8) Do you have any questions for me**

**9) Is there anything else you would like to say about [REDACTED] that you haven't had the opportunity to mention yet.....(make sure you leave plenty of TIME for this question...)**

Thank you again for your time, I will get a copy of the interview to you shortly, please read and amend as necessary and return to me in the addressed envelope. If I don't receive it back, I will assume you are happy with it. I look forward to meeting with you again to .....

## Appendix 3.8 Interview schedule – phase three

### Interview Schedule – Phase Three Three months post discharge

#### Preamble

Thank you for meeting with me today, as you know I am a research occupational therapist interested in knowing more about peoples experiences of mental illness, especially what happens when they are admitted to somewhere like [REDACTED], and how useful they find the rehabilitation process here. There are no right or wrong answers; I am just interested in **your** experiences and your opinions of **your** recovery

Firstly, can I confirm that you are still happy to talk to me about your experiences and for our conversation to be audio-recorded so that I can refer to it again at a later date?

I will be making a few notes, but these will just be to prompt me along the way. Once we have finished the interview, I will type up our conversation. I would like to send you a copy of the interview to make sure you are happy with it.

Do you have any questions about the research or the interview before we start?

1. Can we start with you letting me know how life is for you now you have left [REDACTED]
  - a. I notice you mention ...
  - b. Can you tell me more about ...
2. Has anything about the last three months particularly stood out for you?
  - a. What happened then / next...
  - b. Can you give me an example of...
  - c. Tell me more about ...
3. Can you recall what your hopes were while at [REDACTED] Have these hopes been achieved?
  - a. If not why do you think that might be...
  - b. Can you expand on that ...
  - c. Can you give me another example ...
4. [REDACTED] With hindsight, what is your understanding of the rehabilitation process at [REDACTED]
  - a. Do you have particular memories?
  - b. I notice you mention ...
5. Can you give me an example ...
6. Would you recommend rehabilitation to others?
  - a. I notice you mention ...
  - b. Can you tell me more about ...
7. How was the experience of being interviewed?
8. Do you have any questions for me
9. Is there anything else you would like to say about rehabilitation that you haven't had the opportunity to mention yet?

**Appendix 3.9:** Example from P1 of in text coding

In text codes	Codes	Themes
<p>P9 Well, you know, maybe a letter to say that I was here and whatever. Certification that he cooks his own meals, just to say – not sincerely, but how he finds it, in what areas ...does he actually go to bed on time, does he go out and about, does he socialise, socialises a lot with residents, often speaks to staff quite a lot and they help him out with free toilet paper, free sandwich spreads and sauces and coffee and tea– how I use the facilities that are available – does he use them, what has he made of them Have I completed my tasks? kept my goals?</p> <p>P17 I’ve been told I’ve got to be here between a year and eighteen months and then obviously I’ll probably ... if I can last the course, you know, I’ll get my own place, so ...</p>	<p>Evidence</p> <p>Do as required</p> <p>Makes the most of the opportunities</p> <p>Do as required</p> <p>Survive</p>	<p>Sense of being tested – something to pass</p>

## Appendix 7.1: The hierarchy of tasks for each of the three phases

The difficulty of the task is expressed in logits, the easiest tasks rated as 0.7 logits, average tasks rated at 0.0 logits and the hardest tasks being rated as -0.7. The task list is generated by Rasch analysis and organised in a hierarchy from 'very easy ADL tasks', 'much easier than average ADL tasks', 'easier than average ADL tasks', 'average ADL tasks', 'harder than average ADL tasks' and 'much harder than average ADL tasks'

At phase one (n=18), when given a choice of meaningful and familiar tasks to complete, 25 out of the 36 tasks chosen by the participants were rated as average or harder than average difficulty in the AMPS manual. Mopping a floor (either the kitchen or the bathroom), vacuuming a bedroom, sweeping the smoking area or making beans on toast were the most commonly chosen tasks to complete. The four much easier than average tasks were chosen by three different participants, based on what they felt was meaningful and achievable. (See Table 5.3)

**Table 1: Summary of hierarchy of tasks chosen by the participants at phase one** (Fisher & Jones 2012, *Process Task Hierarchy, AMPS manual, Volume 2*)

Logit	Task description	Task hierarchy
0.7	putting on socks and shoes	Much easier than average
0.6	<b>brushing teeth (x 2)</b>	
0.5	making a bed with sheets	
0.4	instant coffee	Easier than average
0.4	<b>making bed against a wall (x 2)</b>	
0.3	polishing shoes	
0.2	hand washing laundry	
0.1	pre sliced ham sandwich	Average
0.1	ironing – board already set up	
0.1	jam sandwich	
0.1	cleaning windows	
0.1	<b>sweeping outside (x2)</b>	
0.0	vacuuming, moving no furniture	
0.0	<b>vacuuming, moving light furniture (x2)</b>	
0.0	<b>mopping the floor (x3)</b>	
0.0	ironing a shirt setting up the board	
0.0	<b>changing sheets and duvet with bed against a wall (x2)</b>	
0.0	changing sheets and duvet on freestanding bed	
0.0	hand washing, drying and putting away pots	
0.0	heating a frozen meal	
-0.1	boiled eggs	
-0.2	sandwich with a hot drink	
-0.3	<b>beans on toast (x2)</b>	
-0.3	fresh fruit salad	
-0.3	fresh green salad	
-0.4	eggs on toast with hot drink	
-0.5	muffins	Much harder than average
-0.5	eggs on toast with added ingredient and hot drink	

### Choice of ADL tasks -Phase two

At phase two (n=10), the participants were again interviewed prior to the administration of the AMPS and asked which tasks they would like to do. When given a choice of meaningful and familiar tasks to complete, 13 out of the 20 tasks chosen by the participants were rated as average, or harder than average. Food preparation, vacuuming and making a bed were the most commonly chosen tasks to undertake at phase two.

**Table2: Summary of hierarchy of tasks chosen by the participants at phase two**

Logit	Task description	Task hierarchy	
0.6	Brushing teeth	Much easier than average	
0.5	making a bed with sheets		
0.4	making a bed against a wall	Easier than average	
0.2	hand washing dishes		
0.2	handwashing laundry		
0.1	<b>pre sliced ham sandwich (x2)</b>	average	
0.1	instant noodles		
0.1	cleaning windows		
0.0	ironing a shirt, setting up the board		
0.0	<b>vacuuming, moving no furniture (x2)</b>		
0.0	vacuuming, moving light furniture		
0.0	changing sheets ad duvet on bed against a wall		
-0.1	prepare tomato sauce for pasta		
-0.3	fresh fruit salad		Harder than average
-0.3	beans on toast		
-0.3	green salad		
-0.4	scrambled eggs on toast with a hot drink		
-0.5	fried eggs on toast, with hot drink	Much harder than average	

### Choice of ADL tasks- Phase 3

At phase three (n=5), seven out of the 10 tasks chosen by the participants were rated as average or harder than average in the AMPS manual, with sweeping, vacuuming and mopping the floor as the most commonly chosen tasks.

**Table 3: Summary of tasks chosen by the participants at phase three**

Logit	Task description	Task hierarchy
0.4	making a bed against a wall	Easier than average
0.2	<b>sweeping the floor (x2)</b>	
0.1	cleaning windows	Average
0.0	ironing a shirt, setting up the board	
0.0	<b>mopping the floor (x2)</b>	
0.0	vacuuming, moving no furniture	
0.0	changing sheets and duvet on bed against the wall	
-0.2	toast and a pot of tea for one	

