

**Understanding the facilitators and barriers to participation in  
people with acquired cognitive impairment**

**Jacob Waite**

**D.Clin.Psy. thesis (Volume 1), 2017**

**University College London**

**UCL Doctorate in Clinical Psychology**

**Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: . 

Name: Jacob Waite

Date: 16/07/2017

## Overview

The International Classification of Functioning, Disability and Health (ICF) model of disability holds that both personal and environmental factors predict participation. However, little is known about these predictors for people with dementia. Similarly, 'partnership between patients and clinicians in research' is a stated aim of UK government policy but little is known about what facilitates this in the dementia population, particularly with respect to peer research. This thesis sought to throw light on both areas.

Part 1 comprises a systematic review of research about factors associated with social participation by adults with acquired cognitive impairment. Results showed that, in some studies, psychological factors (e.g. self-efficacy) social factors (e.g. caregiver functioning or social support), and societal factors (e.g. the built environment), and transport were associated with social participation.

Part 2 comprises an interview-based, qualitative, empirical study of different perspectives regarding the facilitators and barriers to people with dementia (PWD) doing peer research. Findings highlighted multiple factors that facilitated or hindered this activity: assumptions and language, adapting activity to the needs and abilities of PWD, perceptions of danger and opportunities for building trust, and motivations.

Part 3 comprises a critical appraisal of issues encountered in the course of carrying out this research. Topics discussed include: personhood versus citizenship, insider research, creating the topic guide and defining peer research.

## Table of Contents

Overview	3
Acknowledgements	6
Part 1: Literature Review	
Title	7
Abstract	8
Introduction	9-10
Methods	11-12
Results	12-36
Discussion	36-42
References	42-54
Part 2: Empirical Paper	
Title	55
Abstract	56
Introduction	57-60
Methods	61-66
Results	66-84
Discussion	84-94
References	94-99
Part 3: Critical Appraisal	
Title	100
Introduction	101
Conclusions	109-110
References	110
Appendices	111-122

## List of Tables and Figures

Figure 1:1 PRISMA flow chart	13
Table 1:1 Quality assessment of studies using QualSyst (Kmet et al., 2004)	16
Table 1:2 Description of measures of CI/SP used in included studies	21
Table 1:3a Sample characteristics & main findings for longitudinal analyses	23-25
Table 1:3b Sample characteristics & main findings for cross-sectional analyses	26-33
Table 2:1 Participant characteristics	67
Table 2.2 Themes and subthemes	68

## **Acknowledgments**

First and foremost I would like to acknowledge the sustaining love, support and patience of Kat and Jonnie, my wife and son. Thank you for not making me feel worse than I did already about not being around as much as a husband or a daddy should be over the last 3 years!

I would also like to thank my participants for inviting me into their homes, and giving such thoughtful, engaged and engaging interviews. And I would like to thank the Alzheimer's Society and Scottish Dementia Working Group for putting me in touch with several potential participants.

Finally, but very importantly, I want to thank my research supervisors: Dr Georgina Charlesworth for her availability, responsiveness and clear-thinking throughout the project, especially the trials and tribulations of the literature review, and Professor Fiona Poland for generously sharing her expertise and passion for qualitative research. I would also like to thank the members of the PRIDE team for their support, especially Dr Linda Birt, who was always super quick in responding to e-mails when I was in the recruitment stage!

## **Part 1: Literature Review**

**A systematic review of modifiable factors associated with  
social participation by adults  
with acquired cognitive impairment**

## **Abstract**

### **Aims**

To identify and examine the published quantitative research evidence relating to factors associated with social participation by adults with acquired cognitive impairment. This was done in the context of PRIDE, an ESRC-funded programme of research, whose aim is to identify ways in which people with dementia can keep control of their lives.

### **Methods**

A systematic search of PsycInfo, Medline and Web Of Science databases identified studies meeting inclusion criteria.

### **Results**

Twenty three studies were identified that met inclusion criteria but none related to individuals with dementia. Together they showed that, in individuals with acquired cognitive impairment, positive psychology constructs (e.g. self-efficacy), social, family and caregiver factors, as well as more distal environmental factors, were often significantly associated with social participation. Driving status was consistently found to be associated with the outcome variable. Studies were of variable quality, and used different tools to measure social participation, making comparisons difficult.

### **Conclusions**

The literature in this area is limited but existing findings provide some support for the view that multiple modifiable factors, besides functional impairment and depression, contribute to social participation in this population.



## Introduction

Since its inclusion in the 2001 International Classification of Functioning, Disability and Health (ICF) model of disability, 'participation' has been used by health and social care policy makers and professionals to designate a desirable outcome for individuals with disability, including those with acquired cognitive impairment.

'Community integration', 'participation' and 'social participation' are terms often used interchangeably (Dijkers, 2010) to describe functioning, not – to use the terms of the ICF model – at the level of the body, or at the level of the individual but at the level of the person as a member of society. While many competing definitions exist (Dijkers, 2010; Levasseur, Richard, Gauvin, & Raymond, 2010; Piskur et al. 2014), community integration/social participation (henceforth CI/SP) is generally conceptualised as comprising multiple domains (McColl et al., 1998). An early colloquial definition described community integration as 'having something to do; somewhere to live and someone to love' (Jacobs, 1993, cited in McColl et al., 1998).

By 'adults with acquired cognitive impairment', this review refers to people with dementia and acquired brain injury (mainly traumatic and stroke). CI/SP has been shown to be lower in these populations than in non-cognitively impaired populations (Reyes, & Ramirez, 2009; Sorenson, Waldorff, Waldemar, 2008; Tate, Broe, Cameron, Hodgkinson, & Soo, 2005). The ICF model of disability holds that CI/SP is influenced by both personal and environmental factors, suggesting that research seeking to understand low CI/SP in disabled groups should investigate these areas. The majority of research attempting to do this has focussed on non-modifiable demographic factors (e.g. gender, age), severity of symptoms, and depression (Sorenson et al., 2008; Tate et al. 2005; Willemse-van Son, Ribbers, Verhagen, & Stam, 2007). The result of this research is that we can say with some confidence that the more severe the symptoms, or functional impairments, resulting from

dementia and acquired brain injury, the lower will be the person's CI/SP. Older age, depression and female gender in these populations have also been found consistently to be associated with lower CI/SP (Fleming, Tooth, Hassel, & Chan, 1999). Much less is known about modifiable personal and environmental factors that might explain why one person with severe symptoms has better CI/SP outcome than another with similarly severe symptoms.

This review is aligned to a large, ESRC-funded programme called PRIDE (PRomoting Independence in Dementia). The core aim of the PRIDE programme is to identify ways people with dementia can keep control of their lives, stay healthy, contribute to society and feel valued. It is often observed that many people with dementia withdraw socially, while others continue to be socially engaged and meaningfully occupied in their communities. To support the aims of the PRIDE programme, it was decided to conduct a review looking at the factors associated with this continued engagement. Given this emphasis, for the purpose of this review, CI/SP is defined as an outcome that includes at least two domains: productivity (i.e. activity like work or voluntary activity that goes beyond basic activities of daily living) and social integration (i.e. quality and/or extent of relationships with others). When an initial scoping search showed that the dementia-related literature on predictors of CI/SP was extremely small, it was decided to broaden inclusion criteria to include other populations with acquired cognitive impairment. Thus, the review was carried out to answer the question 'What can the current literature tell us about modifiable factors (other than symptom severity and depression) associated with CI/SP in those with acquired cognitive impairment?'

## **Methods**

### **Search Strategy**

A systematic search was carried out using PsycInfo, Medline and Web of Science databases. Keywords and free text, identified in a scoping search as relevant to the outcome (e.g. 'community integration'), study design (e.g. 'correlation') and populations of interest (e.g. 'dementia', 'stroke' and 'TBI'), were combined, as illustrated in Appendix 1:1.

### **Inclusion and Exclusion Criteria**

Studies were included if they used a correlational or quasi-experimental design quantitatively to measure the relationship of modifiable factors to CI/SP in community dwelling adults with acquired cognitive impairments. Studies were therefore excluded which did not focus exclusively on adults with acquired cognitive impairments. Intervention studies were excluded. Studies were excluded if they used a measure of CI/SP, which did not include items tapping both productivity and social integration. In order to maximise opportunities for meaningful comparison, studies were also excluded if they used an idiosyncratic measure, created for that study and not made available for future research. In addition, studies were excluded that focussed exclusively on non-modifiable factors (e.g. demographics), and/or symptom (or injury) severity, and/or mood. The scoping search had shown that many relevant studies found that symptom severity (or severity of functional impairment), depression and CI/SP were strongly associated. The finding that people who have worse symptoms and who are more depressed are less likely to participate fully in their communities is both intuitive and well-evidenced (Abdallah et al., 2009; Fleming et al. 1999; Sorenson et al., 2008; Tate et al. 2005; Willemse-van Son et al. 2007). The decision to exclude studies with these factors as their exclusive focus was both a practical and a strategic decision, made to keep studies

to a manageable number and also help focus the review on findings more likely to influence clinical practice. A final additional exclusion criterion was a sample size of fewer than 50 participants.

### **Quality Assessment**

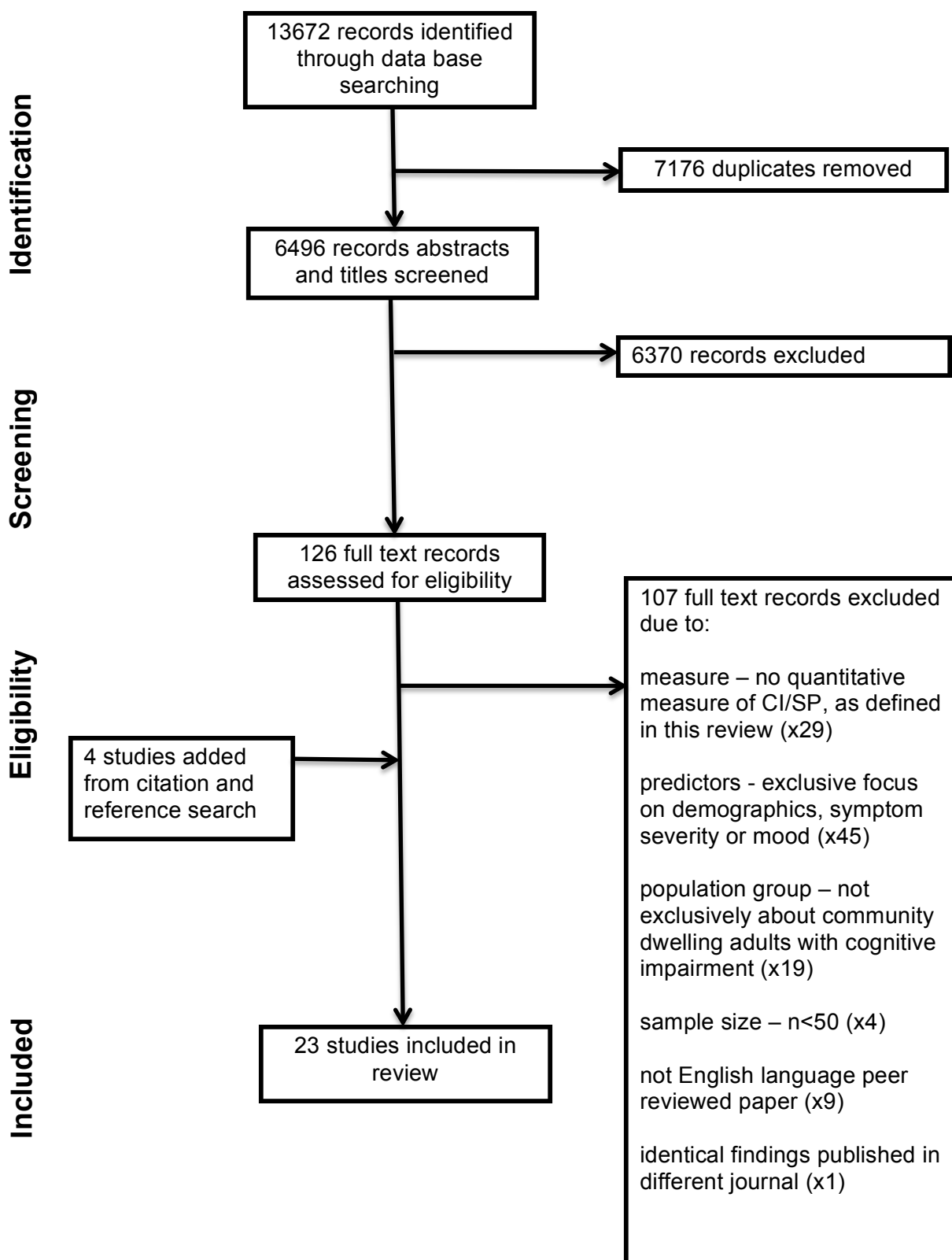
To provide a standard measure of quality for included studies, a generic quality assessment checklist was used (Kmet, Lee, & Cook, 2004). Given the heterogeneous nature of the studies selected, a generic checklist was judged more appropriate than a topic specific tool, which would fit some studies but not others. The QualSyst provides standard quality assessment criteria for primary research papers from a variety of fields, using quantitative methods. Of the tool's fourteen items, three (numbers five to seven) were omitted because they were relevant only to intervention studies, which were not included in this review. Each study was then scored by the researcher on the remaining 11 items, depending on the degree to which the specific criteria were judged to have been met ('yes' = 2, 'partial' = 1, 'no' = 0). A summary score of between 0 and 1 was then calculated by summing the total score and dividing this by the total possible score. A \* was given to studies which reported the different dimensions of the CI/SP construct separately, as a topic-specific indicator of quality. For the QualSyst scoring checklist, please refer to Appendix 1:2.

## **Results**

### **Identification of Studies**

A total of 13672 studies were found using the search strategy specified: PsycInfo = 2624, Medline = 4248, Web of Science = 6800. After duplicates were removed, there were 6496 papers for screening. Examination of titles and abstracts led to the exclusion of 6370 papers. Exclusion on the basis of title alone was mainly due to a study not investigating the outcome and population group of interest (e.g.

Figure 1:1 PRISMA flow chart



studies about children or people with intellectual disabilities), or using a qualitative methodology). Additional common reasons for exclusion on the basis of abstracts were a clear exclusive focus on demographics, depression (or negative affect), or symptom or injury severity as predictors of interest, and study design (e.g. non-correlational intervention studies). A total of 126 papers remained. The full texts of these papers were then assessed for relevance, leading to 107 further papers being excluded. The main additional reason for exclusion at this stage was measure (i.e. no quantitative measure of CI/SP as defined in this review). A reference and citation search of the remaining 19 papers was carried out, identifying four further studies for inclusion. Twenty three papers remained which met inclusion criteria.

### **Study Sample Characteristics**

Of the 23 included studies, seven were longitudinal (Table 1:3a), with two from the USA, three from Canada, one from Australia and one from the Netherlands. The period between baseline and follow-up ranged from a mean of five months (Fleming et al., 2014) to 18 months (Egan et al., 2014). There were 16 cross-sectional studies (Table 1:3b) with eight from USA, three from the Netherlands and, two from Australia and one each from Canada, Australia and Hong Kong. One study (Fleming et al., 2014) included both longitudinal and cross-sectional analyses and appears in both Tables 1:3a and 1:3b. Settings were primarily rehabilitation hospitals, but also included general hospitals, post-acute rehabilitation programmes, neurosurgery units and university campuses.

Eleven studies involved individuals with traumatic brain injury (TBI). Eleven studies recruited individuals who had experienced stroke. One study (Brands et al., 2014) included people with any diagnosed, non-progressive, acquired brain injury aetiology (including 66% stroke and 10% TBI). None of the included studies

involved individuals with dementia. Most TBI studies did not report causes of TBI but, in those three that did, two reported a range of causes with 'car accident' and 'domestic accident' or 'fall' the most common (Dumont et al., 2004; Fleming et al., 2014), while the other focussed exclusively on a population of army veterans with TBIs caused by 'bomb blasts' (Meyers et al., 2016). With the exception of the army veteran study all TBI studies did specify that they were conducted in mixed populations, with a range of occupations and causes of TBI. Six stroke studies reported location of stroke (i.e. right or left hemisphere, or bilateral), right-sided strokes were, in all but one case, the most common, accounting for between 32.2% and 55.7% of participants, while bilateral strokes were always the least common, accounting for between 0% and 14.4%. Only two stroke studies reported type of stroke (i.e. haemorrhagic or ischemic), one reporting a 50/50 split (Oluwatitfunmi et al., 2016) and the other 91.9% ischemic (Gum et al, 2006). As with the TBI studies, most stroke studies were conducted in mixed populations; the one exception was a study that focussed exclusively on a stroke population with aphasia (Dalemans et al., 2010).

There were differences in the age profile for the TBI and stroke patient groups with the mean age of TBI participants ranging from 32 to 44 years, whereas the mean age of participants in the 11 stroke studies was between 55.4 (Asakawa et al, 2009) and 72.5 (Gum et. al., 2006).

Where details of gender split were given, participants were predominantly male in all 11 TBI studies and three of the 11 stroke studies (Beckley et al., 2007; Griffen et al., 2009; Gum et al., 2006).

Ethnicity was only reported in US-based studies and one Australian study (Whiteneck et al., 2004). The populations were predominantly white with the

exception of three TBI studies (Hanks et al., 2014; Rapport et al., 2006; Rapport et al., 2008) and one stroke study (Beckley et al., 2007), in which the samples were predominantly African American.

The majority of both TBI and stroke studies reported either years of education or highest educational attainment. Most samples had a mean of between 11 and 13 years in education, and the majority of participants had high school as their highest educational attainment. In contrast, primary school or less was the most common educational category (74.5%) for Chau and colleagues study in Hong Kong (2009).

There was considerable variation both within and between studies for injury or stroke severity (mild concussion to severe coma, time since injury/illness onset (months to 9 years)), and degree of residual impairment in functioning (mild to severe).

### **Quality Assessment**

The quality of included studies, as measured by the QualSyst tool (see Table 1:1) was variable, ranging from 0.64 (Rochette et al., 2007) to 1 (Fleming et al., 2014). The overall mean was 0.85 (sd 0.09).

Sample size ranged from 51 to 472. A further 11 had an insufficient sample size given the number of variables of interest, according to the  $N \geq 50 + (8 \times \text{number of variables})$  rule of thumb for calculating sample size required to detect a medium size effect (Tabachnick & Fidell, 2007). Ten of these studies were given a 'partial' score on this item. The remaining study (Van Baalen et al. 2007) was given '0' because the type of analysis used considerably reduced the study's power.



**Table 1:1 Quality Assessment of Studies using QualSyst (Kmet et al., 2004)**

<b>Author (Date)</b>	<b>Objectives</b>	<b>Design</b>	<b>Recruitment</b>	<b>Sample characteristics</b>	<b>Measurement</b>	<b>Sample size</b>	<b>Analysis</b>	<b>Estimate of variance</b>	<b>Controlling for confounds</b>	<b>Reporting of results</b>	<b>Conclusions supported</b>	<b>Total</b>	<b>Score</b>
Asakawa (2009)	1	2	1	2	1	1	2	1	2	2	1	16	0.73
Beckley (2007)	1	2	2	2	1	1	2	2	1	2	1	18	0.77
Brands (2014)	2	2	2	1	2	2	2	2	1	2	2	20	0.91
Chau (2009)	2	2	1	2	2	2	2	0	2	2	2	18	0.82
Corrigan (2012)	2	2	2	2	2	2	2	0	2	2	2	20*	0.91*
Dalemans (2010)	1	2	2	2	1	2	2	2	2	1	2	19	0.86
Desrosiers (2002)	2	2	2	2	2	1	2	1	2	2	2	2	0.91
Dumont (2004)	2	2	2	1	2	1	2	0	0	2	2	16	0.73
Egan (2014)	2	2	2	2	2	1	2	2	2	2	2	21	0.95
Fleming (2014)	2	2	2	2	2	2	2	2	2	2	2	22*	1*
Griffen (2009)	2	2	2	2	2	2	2	0	2	2	2	20*	0.91*
Gum (2006)	2	2	2	2	2	2	2	0	2	2	2	20	0.91
Hanks (2014)	2	2	2	2	2	1	1	0	1	2	2	16	0.73
Meyers (2016)	2	2	2	1	2	1	2	2	1	2	2	19*	0.86*
Oluwatifunmi (2016)	2	2	1	2	2	1	2	1	2	2	2	19	0.86
Rapport (2006)	2	2	1	2	2	1	2	0	2	2	2	18	0.82*
Rapport (2008)	2	2	1	2	2	2	2	2	2	2	2	21*	0.95*
Rochette (2007)	1	2	1	2	2	1	1	1	1	1	1	14	0.64
Sady (2010)	2	2	2	2	2	2	2	0	2	2	2	20*	0.91*
Sander (2012)	2	2	2	1	2	2	2	0	1	2	2	18	0.82*
Tielemans (2015)	1	2	2	2	2	2	2	1	2	2	2	20	0.91
Van Baalen (2007)	2	2	2	2	1	0	0	1	2	2	2	16	0.73
Whiteneck (2004)	2	2	2	2	2	1	1	1	2	2	2	19	0.86*

\* indicates that study reported dimensions of productivity and social integration separately.

The research question was clearly described in all but five studies, all of which failed clearly to specify the variables of interest: one (Dalemans et al., 2010) referred to 'several factors related to social participation' without saying what they were, while

the other four papers failed to define participation. All papers clearly described study design.

Most papers clearly described the method of recruitment, including efforts made to minimise bias. Some studies were scored 'partial' on this item because their account omitted information; for example, Rapport and colleagues (2006 & 2008) recruited participants from a database but did not specify whether there were systematic differences between those who declined to participate and those who agreed.

Most studies used only validated measures and gave references for validation and reliability studies. Studies were given a 'partial' score if they included idiosyncratic measures based on qualitative research, or any unvalidated measures; for example, one study (Beckley, 2012) used an unvalidated measure of activities of daily living. ,

Most studies were judged to have analysed data appropriately. Where '1' scores were given on this item it was due to the absence of a clear rationale for the type of analysis used; one study (Van Baalen et al., 2007) was given a '0' score because of a decision to dichotomise continuous predictor and outcome variables and perform logistic regression analyses. This results in a considerable loss of information and, concomitantly, power, which, given the small sample size of this study, was judged inappropriate.

The most common reason for a study receiving a '0' score was a failure to report an estimate of variance for the main results. This was true of nine studies, several of which otherwise scored highly. It may be that, for this sample, this item was not a reliable indicator of quality and simply reflected different journals' requirements for reporting statistics.

In terms of controlling for confounding variables, studies were given '1' scores if they controlled for some but failed to control for either severity of impairment or depression, given that the scoping research had identified these as the factors most consistently associated with CI/SP (Brand et. al, 2014; Hanks et al., 2014; Meyers et al., 2016; Sander et al., 2012). One study did not control for any confounding variables, including severity, in its analyses, despite reporting data on these variables in descriptive statistics (Dumont et al., 2004).

Results were generally reported in sufficient detail but there was sometimes a lack of clarity which resulted in a '1' score. Conclusions were judged to follow from findings in all but one paper, whose abstract claimed that social support quality and quantity accounted for 31% and 35% of the variance in the outcome variable respectively, whereas in fact these were the percentages of variance accounted for by the entire regression model which included these variables amongst others (Beckley, 2007).

### **Measures of CI/SP**

As is shown in Table 1:2 across the 23 studies, 13 different scales were used to measure the outcome of interest. As well as providing an overall measure of CI/SP, most instruments also included subscales, which provided scores for subdomains of the outcome variable. In addition to social integration and productivity, other domains typically reported were mobility, physical independence, and orientation - all derived from the WHO model of disablement (Walker, 2003). The number of items varied considerably with just six in the London Handicap Scale to 68 in the Impact Profile 68; the mean was 28. With the exception of the CHART, responses consisted of endorsing a point on a Likert scale, most commonly a five point scale was used. In terms of psychometric properties, all measures were

reported as having adequate or good internal reliability (mostly good, where good is a co-efficient of 0.8 or greater); test-retest reliability was also reported for the majority of instruments, and was mostly good.

Although most instruments had subscales, these were not always reported in the studies included in this review. Only eight studies separately reported the domains of social integration and productivity particularly focussed on in this review. The 15 remaining studies reported overall CI/SP without separating dimensions. Some of these remaining studies used measures that were not designed to measure CI/SP but were chosen by their authors as providing a meaningful approximation of this construct. The Frenchay Activities Index is used by Brands and colleagues (2014) and Asakawa (2009) to measure social participation; this scale, originally designed (Holbrook & Skilbeck, 1983) to measure 'lifestyle' in survivors of stroke but adapted (Post & De Witte, 2003) for use in the brain injured population, includes items like 'social occasions' and 'actively pursuing hobbies' which can be seen to tap the constructs of social integration and productivity but also includes items like 'preparing meals' or 'washing up', which belong to an activities of daily living domain that sometimes features in measures of CI/SP and sometimes does not. Other studies used measures that were designed to measure social participation but included many items that did not tap the constructs of productivity and social integration; for example, the short version of the Life Habits (Life- H) questionnaire (Fougeyrollas et al., 1998) used in three studies (Desrosiers et al., 2002; Dumont et al., 2004; Rochette et al, 2007) is a measure of CI/SP which, in addition to items tapping productivity and social integration also includes items on nutrition, fitness, housing and personal care. The domains of interest (productivity and social integration) inevitably make a smaller contribution to the overall CI/SP score produced by such measures.

**Table 1:2 Description of measures of CI/SP used In included studies**

<b>Instrument</b>	<b>Author</b>	<b>Population</b>	<b>No. items (point scale)</b>	<b>No. subscales</b>	<b>Admin</b>	<b>Validation Studies</b>
CHART: Craig Handicap Assessment & Reporting Technique	Whiteneck (1992)	People with disability	32	6	Interview	Segal et al., 1995; Whiteneck et al., 1992
CHART (s): Craig Handicap Assessment & Reporting Technique – Short Form	Walker (2003)	People with disability	19	6	Interview	Walker et al., 2003
CIM: Community Integration Measure	McColl (2001)	TBI	10 (5)	NA	Self-report	McColl et al., 2001
CIQ: Community Integration Questionnaire	Willer (1994)	TBI	15: 12 (3), 3 (6)	3	Self-report	Willer et al. 1994
FAI: Frenchay Activities Index (Modified)	Holbrook (1983)	Stroke patients	15 (4)	3	Self-report	Post & De Witte 2003.
LIFE- H Assessment of Life Habits, Short Form	Fougeyrollas (1998)	People with disability	58 (5)	12	Self-report	Dijkers et al., 2000; Dumont et al., 2003; Fougeyrollas et al., 1999
LHS: London Handicap Scale	Harwood (1994)	Gen population	6 (6)	6	Self-report	Harwood et al., 1994; Lo et al. , 2001
RNLI: Reintegration to Normal Living Index	Wood-Dauphinee (1988)	Rehab population	11 (5)	NA	Self-report	Wood-Dauphinee et al., 1988; Stark et al. 2005
PART-O: Participation Assessment Recombined Tools-Objective	Bogner, (2011)	TBI	17 (6)	3	Self-report	Whiteneck et al., 2011
SIP 68: Impact Profile 68	Nanda (2003)	Gen population	68 (2)	2	Self-report	Nanda et al., 2003; Van Baalen et al., 2007
SIS: Stroke Impact-Scale.	Duncan (1999)	Stroke	64 (5)	9	Self-report	Duncan et al., 2003
SPRS: Sydney Psychosocial Reintegration Scale (SPRS)	Tate (1999)	TBI	12 (7)	3	Self-report	Tate et al., 1999
SPRS (V2): Sydney Psychosocial Reintegration Scale Version 2	Tate (2011)	Neurological Conditions	12 (5)	3	Self-report	Tate et al., 2011
USER Participation: Utrecht Scale for Evaluation of Rehabilitation Participation	Post (2012)	People with physical disability	31 (3)	3	Self-report	Post et al., 2012; Van der Zee et al., 2011.

## **Main Findings**

Findings relating to psychological, social and environmental factors are summarised in Tables 1:2a and 1:2b.

**Psychological constructs.** Two of the seven longitudinal studies studied the relationship between individual psychological factors at baseline and CI/SP at follow-up: Brands and colleagues (2014) found a small but significant relationship between baseline self-efficacy score and CI/SP, as measured by the Frenchay Activities Index, at one-year. Similarly, there was a small but significant relationship between baseline task-orientated coping (problem-solving) and one year CI/SP, but no significant relationship between other psychological variables at baseline (emotion-oriented and avoidant coping) and CI/SP after one year; Rochette and colleagues (2007) found that, in a stroke population, appraisal (e.g. whether the stroke was seen as a threat or a challenge) significantly predicted CI/SP as measured by the LIFE-H. However, in neither study did analyses control for injury or stroke severity, functional impairment or depression.

Six cross-sectional studies examined the relationship between CI/SP and 'positive psychology' constructs including self-efficacy (Asakawa et al., 2009; Dumont et al., 2004; Tielemans et al., 2015), hope (Gum et al., 2006; Hanks et al., 2014), 'positivism' (Dalemans et al., 2010), positive affectivity (Hanks et al., 2014), proactive-coping (Tielemans et al., 2015), self-esteem (Chau et al., 2009) and wellbeing (Egan, 2014). Significant direct or indirect relationships were found between CI/SP and most positive psychology constructs. The only exceptions to this were results from two stroke papers, one of which found no relationship between self-efficacy, proactive coping and CI/SP (Tielemans et al., 2015) and another which found no relationship with a 'positivism' construct (Dalemans et al., 2010). All but one of the stroke studies adjusted for functional impairment (Rochette et al., 2007)

**Table 1:3a: Sample characteristics & main findings for longitudinal analyses**

Lead Author (Year) Country Setting	Demographics	Injury/ impairment characteristics	Analysis	Outcome Measure (s) & Key Variables	Findings
<b>Acquired brain injury</b>					
Brand (2014) Netherlands General & rehab hospitals	N=148 (64.2% male) Mean age 56 yrs (sd 12.3) Mean yrs education 11.4 (sd 2.5)	66% stroke, 10% TBI; Time since stroke/injury 15.1 months (sd 9.6)	Hierarchical regression Baseline: 2-4weeks post hospital discharge Follow-up: One year ( $\pm$ 4 weeks)	FAI Self-efficacy (TBI-SE), Coping style (CISS: emotion oriented, avoidant, task-oriented), age, gender, time since injury, education level	Baseline self-efficacy predicted 3% of FAI score at 1-year follow-up ( $\beta=0.19$ ; $p<0.01$ ; 95% CI [0.017 - 0.099]). Baseline task-oriented coping predicted 2% of FAI score at 1 year follow-up ( $\beta=0.14$ ; $p<0.03$ ; 95% CI [0.011 - 0.18]).
<b>Stroke</b>					
Desrosiers (2002) Canada University stroke rehab unit.	N=102 (52.3% male) Education: 1-8 years 61 (46.2) 9-13 years 52 (39.4)	Functional Impairment (at discharge): SMAF 44.1 (12.2) Cognitive Impairment: 3MS 86.3 (sd 9.9)	Bivariate correlations Multiple Regression (backward method) Baseline: At discharge Follow-up: 6 months	LIFE-H Physical impairment, incontinence, cognitive impairment (3MS), time between stroke and rehab, motivation, negative affect, age, length of stay in rehab, perceived social support, education	In bivariate correlations, perceived social support sig associated with LIFE-H score: $r=0.28$ ; $p=0.01$ This relationship was no longer significant when social support was entered into multiple regression model ( $p=0.76$ ).

Egan (2014) Canada Acute care hospital or rehab centre.	<b>N=67</b> (58.2% male) Mean age 64.8 (sd 13.3)	Functional Impairment: FIM 112.4 (sd 14)	Multilevel modelling Baseline: 6 months post hospital discharge Follow up: 9, 12, 18 & 24 months post stroke.	RNLI Emotional wellbeing (GWS), physical wellbeing, functional impairment (FIM), income, time since stroke, gender, age	Baseline wellbeing was sig associated with later RNLI score ( $\beta = 0.14$ ; $SE=0.06$ ; $t= 2.24$ ; $p<0.05$ ).
Rochette (2007) Canada Hospital.	<b>N=88</b> (58% male) Mean age 71.8 (sd 10.8)	Cognitive Impairment: CNS 7.8 (sd 2.3)	Multiple Regression Baseline: 2 weeks post stroke Follow-up: 3 and 6 months	LIFE-H Stress appraisal (SAM: threat, challenge, centrality, stressfulness), coping (RWCC: rationalise, hope, escape, openness towards others, give control to others).	Stress appraisal (threat, challenge, centrality and stressfulness) explained 25% of variance in LIFE-H score ( $p <0.01$ ).
<b>Traumatic Brain Injury</b>					
Fleming (2014) Australia Rehab Unit	<b>N=135</b> (78.5% male) Mean age 35.6 yrs (sd 12.7) 75.2% full-time employment at time of injury	Mean PTA 29.1 days (sd 29.3)(WMS) Functional Impairment: Mean MPAL-4 40 (32-47)	Multiple regression Baseline: 1 month post-discharge Follow-up: 3 months & 6 months post-discharge	SPRS (productivity, social integration, total) Length of hospital stay; disability severity (MPAL-4); environmental barriers (CHIEF: physical, services, social support, policy, workplace)	Baseline CHIEF total score and CHIEF total score at 3 months both predicted 3% of total SPRS score at 6 months ( $\beta=-0.18$ , $p=0.01$ ; & $\beta=-0.2$ , $p=0.002$ respectively).



Sady (2010)	<b>N=141</b> (73.5% male, 73% white) Mild/mod: Mean age 44.1 yrs (sd19.1) Severe: Mean age 29.4 yrs (sd13.6) Education: 60% high- school Caregivers: 53 partners, 68 parents, 15 other	n=47 mild/moderate GCS (mean 12.1 sd 2.17)  n=89 severe GCS (mean 4.9 sd 1.74)	Multiple regression  Baseline: 1.25 months (sd 0.86) post- injury Follow-up: 13.38 months (sd 2.54)	CHART (productivity, social integration) CIQ (productivity, social integration)  Family functioning, (FAD), severity of symptoms, perceived social support (MSPSS), caregiver distress (BSI-GSI)	Family functioning, caregiver distress and perceived social support did not contribute sig to CHART productivity score variance.  For participants with severe injuries, greater perceived social support sig associated with higher CIQ productivity score ( $\beta =0.29$ ; $p<0.01$ ) and higher CIQ ( $\beta=0.28$ ; $p=0.01$ ) and CHART social integration score ( $\beta=0.41$ ; $p<0.001$ ).  Lower caregiver distress sig associated with higher CHART social integration score ( $\beta=-0.27$ ; $p=0.031$ ) in people with mild/moderate injuries.
Sander (2012)	<b>N=136</b> (73% male, 69% white) Mean age 32.4 yrs (sd 14.4) Mean yrs education 13.3 (sd 2.3)  Caregivers: 56% parents 30% partners 14% others	Limited severity data available (n=87) n=37 mild/moderate GCS, n=50 severe GCS  Time since injury 9.7 months (sd 29.1)	Multiple regression  Baseline: within two weeks of admission. Follow-up: approximately one month of discharge.	CHART (productivity, social integration) CIQ (productivity, social integration, total)  Family functioning (FAD), caregiver distress (BSI-GSI), years education, age, ethnicity, time (between injury and post-acute admission)	Lower caregiver distress at baseline sig associated with higher CHART productivity score at follow-up ( $B=-0.60$ , $\beta=-0.18$ , $p<0.05$ ). This was qualified by a sig interaction between caregiver distress and time since injury ( $B=0.08$ , $\beta=0.20$ , $p<0.05$ ).  Caregiver distress at baseline was sig associated with both CHART productivity and social integration scores at follow-up ( $B=-0.87$ , $\beta=-0.17$ , $p<0.05$ ; $B=-$ $0.32$ , $\beta=-0.17$ , $p<0.05$ ) when time since injury at baseline was <6 months, but not where it was >6 months.  Neither family functioning nor caregiver distress predicted either CIQ productivity or social integration scores..

**Table 1:3b: Sample characteristics & main findings for cross-sectional analyses**

<b>Traumatic Brain Injury</b>						
Corrigan (2012)	<b>N=472</b> (72% male; 74% White)	Mean PTA 25.9 days (sd 24.5)	Hierarchical regression	PART-O (productivity, social integration, total)	Neighbourhood characteristics explained less than 5% of PART-O overall score.	
United States	Mean age 33.1 yrs (sd 14.9)	Functional Impairment: Mean FIM 31.8 (sd 3.5)		<b>Individual characteristics:</b> Gender, age, education, pre-injury hours employed per week, no benefits, no arrests since discharge, transportation (drives), functional independence (FIM cognitive), life satisfaction	Individual variables explained 48% of variance in PART-O overall score, 48% of variance in PART-O productivity & 17% of variance in PART-O social integration score.	
12 TBI Centres	Mean yrs education 12.6 yrs (sd 2.3)	Mean FIM motor 69.1 (sd 16.3)		<b>Neighbourhood characteristics:</b> % population 0-19, median age, unemployment rate, % population married	Individual variables + neighbourhood variables explained 49% of variance in PART-O overall score.	
		Time since onset 1 year (39%) 2 years (35%) 5 years (26%)			Transportation (drives) explained most variance in overall PART-O score (25%) ( $\beta=0.54$ , $p<0.001$ ) and in PART-O productivity score (26%) ( $\beta=0.537$ , $p<0.001$ ).	
Dumont (2004)	<b>N=53</b> (70% male)	Mean time since injury 47 months (sd 20.4)	Univariate & multiple regression models	LIFE-H Short	Not receiving benefits explained most variance in PART-O social integration (6%) ( $\beta=0.36$ , $p<0.001$ ).	
Canada	Mean age 37 yrs (sd 8.7)			Perceived self-efficacy (SES), personal characteristics (PER): will, self-acceptance, anxiety, autonomy, dynamism, relationships with others and emotional stability	In univariate analyses, dynamism explained 38% of the variance in LIFE-H Short overall score, self-efficacy 34%, will 32%. Dynamism and self-efficacy were highly correlated ( $r=0.83$ ).	
Rehab Centre					A multiple regression model including dynamism, self-efficacy and will explained 51% of the variance.	

Fleming (2014) as for longitudinal analysis	as for longitudinal analysis	as for longitudinal analysis	Regression analysis with 6 month (cross- sectional) data	as for longitudinal analysis
Hanks (2014) United States Rehab Hospital	<b>N=65</b> (85% male, 55% African American) Mean age 38.5 yrs (sd 12.9) Mean yrs education 12.2 (sd 2.3)	Moderate mean GCS 8.1 (sd 4.3) PTC 24.9 days (sd 21.7) Mean time since injury 916.9 days (sd 664.7) Functional Impairment: Mean DRS 1,7 (sd 1.6)	Bivariate & partial correlations	CIM Disability, physical health, virtues and VIA-IS (measure of character strengths: wisdom, perspective, courage, perseverance, zest, humanity, justice, temperance, transcendence, hope, humour, spirituality, appreciation of beauty), PANAS
Meyers (2016) United States University Campuses	<b>N=60</b> (100% male, 60% white) Mean age 32.9 yrs (sd 9) Means yrs education 14.9 (sd 2)	Mean 'blasts' * exposed to 2.65 (sd 3.3) Mean time since most recent blast 40.68 months (sd 18.79) Cognitive Impairment: Mean VCAT 17.92 (sd 4.08)	Non- parametric bivariate correlations	SPRS-2 (productivity, social integration) Masculine gender role adherence, cognitive flexibility, IQ, depressive symptomatology, subjective wellbeing, marital status

Total CHIEF score explained 21% of the variance in SPRS productivity score ( $p < 0.001$ ). Of CHIEF subscales, only physical barriers made significant contribution to SPRS productivity score, explaining 8% of the variance ( $\beta = -0.36$ ,  $p < 0.01$ ). Physical barriers and social support both explained 4% of SPRS social integration score ( $\beta = -0.27$ ,  $p = 0.04$ ; &  $\beta = -0.29$ ,  $p = 0.01$  respectively).

In bivariate correlations, hope was significantly positively correlated with CIM score ( $r = 0.41$ ,  $p < 0.01$ ), as were all other character strengths measured by the VIA-IS. In partial correlations, controlling for age and negative affectivity, hope remained as strongly associated with CIM score ( $r = 0.41$ ,  $p < 0.01$ ), but the correlation was weaker when age and positive affectivity were controlled for ( $r = 0.24$ ,  $p < 0.01$ ).

Positive affectivity was significantly correlated ( $r = 0.37$ ,  $p < 0.01$ ) with CIM score.

In bivariate correlations, masculine gender role adherence was negatively significantly associated with the SPRS social integration score ( $r = -0.46$ ,  $p < 0.01$ ). After controlling for marital status, association no longer held.

Rapport (2006) United States Rehab Hospitals	<b>N=51</b> (88% male, 75% African American) Mean age 39.1 yrs (sd13.3) Mean yrs education 11.9 (sd 2.1)	Moderate mean GCS 8.8 (sd 4.4) Mean time since injury 4.3 yrs (sd 3.5)	Bivariate correlations & multiple regression ANCOVA	CHART Short (productivity) CIM Barriers to driving (BDQ total and BDQ social barriers subscale), driving status, social support (SPS), negative affectivity (PANAS – negative affectivity scale only), use of alternative transport	In bivariate correlations, driving status was sig associated with CHART productivity score ( $r=-0.55$ ) and with CIM ( $r=-0.20$ ).  BDQ social barriers were sig related to CHART productivity ( $r=-0.46$ ), as was social support ( $r=0.21$ ). Social support was sig related to CIM( $r=0.47$ ) as were BDQ social barriers ( $r=0.41$ ).  Multiple regressions models with CIM and CHART productivity as outcome variables were both sig, explaining 41% of the variance ( $F=6.32$ (5,45), $p<0.01$ ) and 25%, ( $F=2.98$ (5,45), $p=0.02$ ) respectively, with unique contributions from social support and BDQ total. Social support accounted for 15% CIM variance and 1% CHART productivity variance. BDQ accounted for 14% CIM and 10% CHART productivity variance.
Rapport (2008) United States Rehab Hospitals	<b>N=261</b> (82% male, 75% African American) Mean age 44 yrs (sd 13.6) Mean yrs education 11.9years (sd 2.1)	Moderate mean GCS 9.2 (sd 4.2) Mean time since injury 5.2 years (sd 4.8)	MANCOVA & Post-hoc ANCOVA	CHART Short (productivity, social integration, total) CIM Barriers to driving (BDQ), social support (SPS), negative affectivity (PANAS – negative affectivity scale only), use of alternative transport, self-rated driving ability, injury severity.	Sig differences between drivers and non-drivers on CHART and CIM, controlling for social support and injury severity ( $F(8, 416)=7.05$ , $p<0.001$ , partial $\eta^2=0.11$ ).  Non-drivers sig lower CHART productivity ( $F(2, 221)=17.07$ , $p=0.001$ ). Non-drivers who sought to resume driving had lower social integration than non-drivers and drivers ( $F(1,222)=12.2$ , $p<0.001$ ) whose scores were equivalent. Use of alternative transport was related to CHART social integration ( $r=0.13$ , $p=0.02$ ), but not productivity.  SPS Social support related to CIM ( $r=-0.58$ ) and to CHART productivity ( $r=0.30$ ) and social integration ( $r=0.27$ ).

Van Balen (2007)	N= 51(68.6% male) Mean age 32.3 yrs (sd 12) Education: 78% less than degree Caregivers: 45% children or parents 55% partners	71% severe GCS	Logistic regression	SIP-68 (dichotomised into restriction in participation present or absent) <b>Patient variables:</b> physical ability, cognitive status, gender, age, TBI severity, education <b>Caregiver variables:</b> kinship, gender, age, coping styles (UCL)	Carer passive coping (i.e. isolating self from others, worrying about past) was sig associated with participation restriction in patient (OR 1.3; 95% CI (1.0-1.7))
Netherlands Neurosurgery Units					
Whiteneck (2004)	N=73 (75% male, 86% white)	n=37 severe GCS, n=29 moderate GCS, n=34 mild GCS	Non-parametric bivariate correlations	CHART (social integration, productivity)	CHIEF social support barriers were sig negatively associated with CHART social integration and productivity (r=-0.26, p<0.05 and r=-0.30, p<0.05 respectively). There was no relationship between other CHIEF barriers and CHART social integration.
Australia Rehab Hospital	16-30yrs 60% 31-45yrs 26% 46-60yrs 14 % 92% working or full time education at time of injury	Time since injury=12months Functional Impairment: Mean FILM cognitive 27.9 (sd 4.3) Mean FILM physical 83.5 (sd 11)		CHIEF environmental barriers (social support, physical, service, policy, workplace & school); functional independence (self-care, locomotion, mobility, sphincter control, communication and social cognition)	CHART productivity was sig related to physical (r=-0.29, p<0.05), service (r=-0.35, p<0.05), policy (r=-0.23, p<0.05), & work and school (r=-0.33, p<0.05) barriers.
<b>Stroke</b> Asakawa (2009)	N=85 (79% male)	Physical impairment: Mean SIAS 49.1 (sd 13.8)	Multiple regression	FAI	Self-efficacy was not directly sig associated with FAI score but did sig moderate relationship between FAI score and both physical impairment ( $\beta=0.28$ , p<0.01) and mobility ( $\beta=0.27$ ).
Japan Hospital rehab ward.	Mean age 55.4 (sd 13.6) Education: 38% high school	Functional impairment: Mean BI 91.3 (sd 12.5)		Physical impairment, age, gender, education, depression, apathy (AS), self-efficacy (GSES), mobility	Apathy also moderated relationship between FAI score and both physical impairment ( $\beta=0.31$ , p<0.01) and mobility ( $\beta=0.30$ ).

Beckley (2007) United States Rehab hospital	<b>N=95</b> (51% female, 52% black) Mean age 68.46 (sd 12.16)	Functional impairment 114.63/126 (sd 18.75)	Ordinary least squares analysis	RNLI Age, gender, income, functional impairment, race, quality of social support (SSIPAD), quantity of social support (SSIPAD)	Quantity of social support explained 7% of overall RNL score (SE 0.06; p<0.01). Quality of social support explained 5% of overall RNL score (SE -0.08; p<.05).
Chau (2009) Hong Kong Rehab hospitals	<b>N=188</b> (62% male) Mean age 71.7 yrs (10.2) Education: 74.5% primary school or less	Functional Impairment: Mean BI 85.9 For 16% BI = <60, indicating marked dependency Mean time post stroke 12 months approx.	Multiple regression	LHS State self-esteem, depressive symptoms (GDS), social support satisfaction, age, functional ability (BI), gender, living, arrangement	Social support was not sig associated with variance in LHS score ( $\beta=0.02$ , p=0.74). Self-esteem explained 2% variance in LHS score, controlling for depression and functional ability ( $\beta=0.19$ , p=0.01).
Dalemans (2010) Holland Rehab centres & hospitals	<b>N=150</b> (59% male) Mean age 64.2 yrs (sd 11) Education: 37% high school	9% severe, 30% moderate, 50% mild, 21% minimal (FAST) Mean time post-stroke 90.6 months (sd 80.9)	Bivariate correlations Multiple regression	CIQ Demographics, illness severity & duration, premorbid & current function, personal factors (including positivism, motivation, determination), 'environmental' factors (social support, aphasia 'friendliness')	'Environmental' factors and 'positivism' unrelated to CIQ.

Griffen (2009) United States Rehab hospital	<b>N= 90</b> (53% female) Mean age 57.1 yrs (sd 11.5) Mean years education 14.1 (sd 2.4)	Stroke severity measured and controlled for but not directly reported. Mean time post-stroke 48.4 months (sd 63.8)	MANCOVA	CHART Short (productivity, total) CIM SIS-2 Driving status, barriers to driving (BDQ), social support, gender, stroke severity	Sig main effect of driving status ( $F(5,76)=8.01$ , $p<0.001$ , partial $\eta^2=0.34$ ) on CI/SP. Use of alternative transport was unrelated to CI/SP. The main effect of social support was not sig.  Sig difference between drivers and non-drivers in CHART productivity, after controlling for stroke severity ( $\eta^2=0.09$ , $p<0.01$ ).  Sig driving status x social support interaction ( $F(5, 76)=3.04$ , $p=0.02$ , partial $\eta^2=0.17$ ) – drivers with high social support had higher CI/SP than non-drivers with high social support.
Gum (2006) United States Health Facilities	<b>N=110</b> (59% female) Mean age 72.50years (sd 9.75) 59.5% high school	7% severe, 46% moderate, 47% minor (OPS) Time post-stroke 3-4 months	Bivariate correlations & multiple regression	SIS-2 Participation Degree of disability (SIS-2 Physical, Communication, Memory), mini-mental state exam, depressive symptoms, hope	Sig correlation between hope and SIS-2 ( $r=0.24$ , $p<0.05$ ). Hope non sig in regression model. Sig hope x degree of disability interaction (e.g. in low hope condition, SIS Physical subscale predicted SIS Participation subscale score ( $\beta=0.42$ , $p<0.001$ ) but in high hope the subscale was more strongly predictive ( $\beta=0.78$ , $p<0.001$ )).
Oluwatifunmi (2016) Nigeria Hospital physiotherapy department	<b>N=96</b> Mean age 56.6 yrs (sd 12) Education: 53.1% tertiary education	Functional Impairment (mRS): moderately severe 25% moderate 25% slight 15.6% not sig 30.2% none 4.2% Mean time post-stroke 19 months (sd 24.6).	Multiple regression	LHS Age, gender, marital status, education, living arrangement, functional impairment (mRS), social support (MSPSS), employment status, type of stroke	Social support was not sig related to LHS score.

Tielemans (2015)	<b>N=112</b> (52.7% male) Mean age 57.1 (sd 8.9) Education: 36% university or higher	Functional Impairment: BI <18 17.9% Cognitive impairment: MoCA <26 58.9%	Multiple regression	USER-Participation (restriction subscale)  Proactive coping (UPCC), self-efficacy (GSES), functional impairment, cognitive impairment, age, number of strokes.	Neither proactive coping nor self-efficacy was significantly associated with USER-Participation score.
Rehab centres and hospital outpatient settings					
Netherlands		Time after stroke 18.9 months (sd 28.5)			

\* 'blasts' here means the number bomb blasts to which participants had been exposed. The study was conducted in a war veteran population.

†GCS 13-15 = mild, 9-12 = moderate to severe; 0-8 = severe.

3MS = Modified Mini-Mental State examination (Teng & Chui, 1987).

AS = Apathy Scale (Starkstein, Fedoroff, Price, 1998).

BI = Modified Barthel Index (Granger, Dewis, Peters, Sherwood & Barrett, 1979).

BDQ = Barriers to Driving Questionnaire (Rappoport, Hanks, Coleman, & Koviak, 2004), which includes a 'social barriers' subscale, featuring items like 'spouse or caregiver does not want me to drive'.

BSI-GSI = Brief Symptom Inventory-Global Severity Index (Derogatis, L.R., 1993).

CBS = Current Behaviour Scale (CBS) (Elsass & Kinsella, 1989).

CHIEF = Craig Hospital Inventory of Environmental Factors (Harrison-Felix, 2001).

CISS = Coping Inventory for stressful situations (De Ridder & Van Heck, 2004).

CNS = Canadian Neurological Scale (Cote, Battista, Wolfson, Boucher, Adam, Hachinski, 1989).

DRS = Disability Rating Scale (Rappoport, Hall, Hopkins, Belleza, Cope, 1982).

FAD = General Functioning Scale (Epstein, Baldwin, Bishop, 1983).

FAI = Frenchay Activities Index (Post & De Witte, 2003).

FAST (Frenchay Aphasia Screening Test (Enderby & Crow, 1996).

FIM = Functional Independence Measure (Turner-Stokes, Nyein, Turner-Stokes, Gatehouse, 1999).

GCS = Glasgow Coma Scale (Williams, Levin, Eisenberg, 1990).

GDS = Geriatric Depression Scale (Yesavage, 1988).

GSES = General Self-Efficacy Scale (Scholz, Dona, Schwarzer, 2002).

GWS = General Wellbeing Schedule (McDowell, Newell, 1987).



MoCA = The Montreal Cognitive Assessment (Nasraddine et al., 2005).  
 MPAI-4 = Mayo-Portland Adaptability Inventory (Malec, Lezak, 2003).  
 mRS= Modified Rankin Scale (Banks, Marotta, 2007)  
 MSPSS = Multidimensional Scale of Perceived Support (Zimet, Dahlem, Zimet, & Farley, 1988).  
 OPS = Orpington Prognostic Scale (Kaira & Crome, 1993).  
 PER = Test de Personalite (Pepin, Rheauime, Loranger, 1999).  
 PANAS = Positive and Negatives Affect Schedule (Watson, Clark & Tellegen, 1988).  
 PSI = The Problem Solving Inventory (PSI) (Heppner & Peterson, 1982).  
 PTA = Post Traumatic Amnesia  
 RWCQ = Revised Ways of Coping Questionnaire (Folkman & Lazarus, 1988).  
 SAM = Stress Appraisal Measure (Peacock & Wong, 1990).  
 SES = Self-Efficacy Scale (Bandura, 2001).  
 SIAS = Stroke Impairment Assessment Set (Tsuji, Liu, Sonoda, 2000)  
 SIS Stroke Impact Scale – v2 (Duncan et al., 1999).  
 SMAF = Functional Autonomy Measurement System (Hebert, Carrier, Bilodeau, 1988).  
 SPS = Social Provision Scale (Cutrona, Russell, 1987) includes items such as “There are people I can depend on to help me when I really need it”.  
 SSES = State Self-esteem Scale (Heatheron & Polivy, 1991).  
 SSI PAD = Social Support Inventory for People with Acquired Disabilities (McColl & Friedland, 1989)  
 TBI-SE = TBI Self-Efficacy Questionnaire (Cicerone & Azulay, 2007).  
 UCL = Utrecht Coping List (Schreurs, Willige, Tellegen, Broschot, 1988).  
 UPCC =Utrecht Proactive Coping Competence Scale (Tielemans, Visser-Meily, Schepers, Post, van Heugten, 2014).  
 VIA-IS = Values in Action Inventory of Strengths (Peterson & Seligman, 2004).  
 WCST = Wisconsin Card Sorting Test (Heaton, Chelune, Talley, Kay, & Curtis, 1993).  
 WMS = West Mead (Marrosszky, Ryan, Shores, Batchelor, Marosszky, 1998  
 VCAT = Verbal Concept Attainment Test (Bornstein, 1982).

2007), three also adjusting for depression (Asakawa et al., 2009; Chau et al., 2009; Gum et al., 2006). Among the TBI studies only Hanks and colleagues (2014) adjusted for either variable.

One further paper is considered under the 'psychological constructs' theme, a study examining 'masculine gender role adherence' (Meyers et al., 2016), a construct that includes the sense of 'achieving goals at all costs'. Adherence to masculine gender roles was negatively associated with social integration but only in men without partners.

**Social, family & caregiver factors.** Twelve studies examined the relationship between social factors and CI/SP. Of those 12 studies, three (Sander et al., 2012; Sady et al., 2010; Van Balen et al., 2007), examined caregiver distress or coping and family functioning, while ten investigated the relationship between perceived social support and CI/SP. (Beckley et al, 2007; Chau et al., 2009; Dalemans et al., 2010; Desrosiers et al., 2002; Fleming et al, 2014; Griffen et al., 2009; Oluwatifunmi et al., 2016; Rapport et al. 2006; Rapport et al. 2008; Whiteneck et al., 2004)

Of the two longitudinal studies examining the influence of social, family and caregiver factors on CI/SP, neither found any relationship between family functioning and CI/SP (Sady et al., 2010 & Sander et al., 2012). However, both studies found significant associations between caregiver distress and CI/SP domains. For example, lower carer distress was associated with higher social integration in patients with mild injuries (Sady et al., 2010) and those within six months of injury (Sander et al., 2012). In addition, higher perceived social support at baseline was associated with higher productivity and better social integration at follow-up for those with severe injuries (Sady et al., 2010). There were also

significant associations between higher perceived social support and better social integration in those with severe injuries (Sady et al., 2010). However, there were differences between findings depending on whether CI/SP was measured using the CHART or CIQ, and neither study controlled for depression or functional impairment.

In their cross-sectional study, Van Baalen and colleagues (2007) found that passive coping style in caregivers was significantly associated with lower overall CI/SP, as measured by the SIP-68, in a population with traumatic brain injury. However, the study did not control for depression.

In the three cross-sectional TBI studies using CHART (Whiteneck et al., 2004) and CHART short form (Rapport et al., 2006; Rapport et al., 2008) to measure CI/SP, higher social support was associated with higher productivity. The study by Rapport and colleagues (2006) also reported a stronger relationship between the more specific 'social barriers to driving subscale' of the BDQ and CHART measured productivity. Fleming and colleagues' TBI study (2014) did not find a significant relationship between social support and productivity, as measured by the SPRS, but did find a relationship between social support and social integration. In stroke studies, a direct relationship between social support and overall CI/SP was reported in only two papers (Beckley, 2007; Desrosiers, 2002) and, of those, the relationship only held in one, after controlling for confounds (Beckley, 2007). However, Griffen and colleagues (2009) found an interaction between social support and driving status, such that drivers with higher social support had higher overall CI/SP.

**Societal and environmental factors.** Three cross-sectional (Corrigan et al., 2012; Fleming et al., 2014; Whiteneck et al., 2004) studies considered the impact of wider societal variables on CI/SP in individuals with traumatic brain injury. These

societal, or 'distal environmental' factors, included physical barriers (i.e. impact of problems caused by building design, availability of technology, the natural environment & noise), services barriers (i.e. availability of transport, information, education and training) and policy barriers (i.e. service availability and government policy) as measured by the CHIEF.

Both Fleming and colleagues (2014) and Whiteneck and colleagues (2004) found significant relationships between physical barriers and SPRS-measured productivity. In addition, Fleming and colleagues (2014) found a relationship between physical barriers and social integration, and Whiteneck and colleagues (2004) found higher Service Barriers (including transport availability), Policy Barriers and Work & School Barriers were significantly associated with lower productivity. Both studies controlled for functional impairment but not depression.

**Driving status.** Three TBI studies (Corrigan et al., 2012; Rapport et al., 2006; Rapport et al., 2008) and one stroke study (Griffen et al., 2009) examined the relationship between driving status and CI/SP. All found a significant relationship between driving status and CI/SP particularly in the productivity domain. All four of these studies adjusted for injury or symptom severity in their main analysis, two also adjusted for depression (Rapport et al., 2006; Rapport et al., 2008).

## **Discussion**

A systematic search resulted in 23 empirical papers for inclusion in this review of factors associated with community integration and social participation (CI/SP) in populations with acquired cognitive impairments. 11 papers examined CI/SP in the traumatic brain injury population, 11 in the stroke population, and one included people with acquired brain injury of mixed aetiology (66% stroke, 10% TBI).. The original purpose of this review was to identify factors that might predict CI/SP in the

dementia population by searching for predictors in populations with acquired cognitive impairment. No studies in the dementia population met inclusion criteria. The search only produced one study (Sorenson, Waldorff & Waldemar, 2008), which investigated CI/SP in individuals with dementia. The study was excluded because it focussed exclusively on demographics and symptom severity as predictors.

Studies in TBI and stroke populations, examining the relationships between positive psychology constructs (self-efficacy, hope, positive affectivity, pro-active coping, wellbeing and self-esteem) and CI/SP mostly found a significant, positive relationship. The only exceptions were two stroke studies. Studies looking at the influence of social, family and caregiver factors showed more mixed results. In TBI studies, social support was consistently found to relate to overall CI/SP and/or productivity and social integration but the majority of stroke studies did not find significant associations. There may be measurement issues involved here. The instruments used in the stroke studies that did not find an association were different from those used in TBI and stroke studies that did; they therefore measure slightly different constructs and it may be this that underlies these apparent differences. Equally, there may be an actual difference between these populations with respect to the association between the outcome variable and social support. It may be that due to a range of factors, some of them age-related (e.g. being retired), levels of social support are more homogenous among the stroke population, with the result that this variable is less useful in explaining differences in CI/SP.

Two TBI studies found that physical barriers (e.g. building design) were related to productivity. Finally, the most unequivocal finding pertained to driving status: three TBI studies and one stroke study all found a significant relationship with overall CI/SP, especially in the productivity domain.

These findings offer some support for the ICF model of disability that holds that not just biological but also both environmental and personal (including psychological) factors influence the extent to which acquired cognitive impairment, or any other disability, impacts on CI/SP.

The finding that factors like self-efficacy may to some extent influence CI/SP in the stroke and TBI populations may suggest that the same is true of individuals with dementia. Quality of life is a psychosocial outcome that shares some characteristics with CI/SP, and there is some evidence that greater self-efficacy in individuals with dementia is associated with superior quality of life (Dawson, Powers, Krestar, Yarry, & Judge, 2012). Likewise, social support has been found to predict superior quality of life for individuals with dementia (Lima, Gago, Garrett, & Pereira, 2016). Finally, while there are no studies using quantitative measures of CI/SP to investigate the impact of driving cessation in individuals with dementia, driving cessation has been shown negatively to affect one of its subdomains, namely productivity, in older adults generally (Curl, Stowe, Cooney, & Proulx, 2013).

### **Limitations**

The review sought to compare findings from studies across different acquired cognitive impairment populations (TBI, stroke, dementia) because the scoping search revealed the literature on factors associated with CI/SP in dementia to be extremely limited. For the same reason, inclusion criteria did not specify which measures of CI/SP were acceptable. The result is an extremely heterogeneous sample of studies of variable quality, making comparisons and generalisations difficult.

The vast majority of studies were correlational, meaning that the direction of relationships cannot be inferred (e.g. lower CI/SP may lead to lower self-efficacy rather than vice versa). The studies that found the strongest relationships between predictor and outcome variables were cross-sectional. The scoping search indicated that functional impairment (or symptom severity) and depression were consistently associated with CI/SP, suggesting that studies investigating its relationship to other variables should control for these factors. Among the seven longitudinal studies included in this review, only three controlled for functional impairment, or symptom severity, and one controlled for depression. Where functional impairment, or depression, were controlled for a range of measures were used across different studies. While some studies used the same measures of CI/SP, 13 different scales were used across the 23 studies, and where two scales were used within the same study, different results were often obtained for each scale. This would suggest that, in other studies too, whether significant associations were found depended partly on which outcome measure was used.

The review process itself had limitations. The search was confined to studies that used quantitative measures of overall CI/SP. This meant that studies that examined associations with just one domain of CI/SP (e.g. studies looking at predictors of productivity) were excluded. A broader search, which had also considered predictors of outcomes like volunteering, might have produced different results. With this exception, the search strategy was comprehensive, as is evidenced by the small number of studies added at the citation and reference search stage. This comprehensiveness gives confidence that all published studies in the populations of interest were included in the review. This does not mean that there are not studies with negative findings that have remained unpublished due to publication bias. All studies included in the review reported at least some positive

findings, even if these findings were not those focused on in this review; this may indicate a distorted picture.

Although the QualSyst tool provides a useful heuristic for judging quality, the significance of the scores thus generated should not be exaggerated. In the validation study carried out by its authors (Kmet et al. 2004), the QualSyst tool showed by item inter-rater agreement of between 73% to 100%, but only 11 studies were rated. This small sample size prevented the estimation of statistical measures of agreement. In addition, as the authors acknowledge, the checklist is subjective, based, as it is, on their assumptions about the key components of a study, defined in terms of internal validity. In the absence of a standard operational definition of internal validity and a 'gold standard' measure to compare the QualSyst tool with, it is impossible to be sure that the tool measures what it sets out to measure. Additionally, the quality of studies was rated by the author alone, not double-rated, which may reduce confidence in these quality ratings' reliability.

### **Research Implications**

Future research should consider and address the methodological and conceptual limitations of currently published findings. In order to increase the possibility of comparisons between studies, it would be helpful if a gold-standard measure of CI/SP could be agreed and routinely used. In order to increase the precision of the findings of such studies, it would be helpful if the subdomains of CI/SP could be routinely reported and included in analyses. Studies should be longitudinal, and should control for functional impairment and depression, to ensure the most conclusive findings.

The findings have several implications for dementia research. It is interesting to ask what lies behind the lack of research examining the outcome of CI/SP in the



dementia population. Thirty years ago the idea of someone with dementia being a research participant was considered controversial but this is no longer the case. However, it could be that the influential concept of personhood has, despite its positive impact on dementia care practice, had the unwanted side-effect of causing people with dementia to be seen as people but not citizens, with the more active role in society that this implies (Bartlett & O'Connor, 2007). Were this the case, it is easy to see why the community integration or social participation of people with dementia might be less likely to be considered by researchers as a promising area for research. With this in mind, it is perhaps telling that the only study identified that did look at social participation in the dementia population, used an outcome measure that did not include items relevant to the productivity domain. Similarly, although a small number of studies examine the impact of self-efficacy on other psychosocial and functional outcomes of people with dementia (Dawson et al., 2012; Sabol et al., 2011), the majority of dementia studies investigating this topic focus on the self-efficacy of carers. It is as if there is a general bias away from considering self-efficacy, with its associations of being an active participant in life rather than a passive recipient of care, as a relevant topic for people with dementia. Carrying out research on CI/SP in the dementia population could help underpin efforts to reconceptualise and support the dementia population as active citizens. In addition, the very clear finding that driver status is consistently associated with CI/SP in the TBI and stroke populations, adds weight to the campaign to promote a dementia friendly public transport system in London currently being run by the Alzheimer's Society.

### **Clinical Implications**

The review findings also suggest that professionals working with those with acquired cognitive impairments should consider factors other than functional impairments and depression when assessing the reasons for a person's disengagement from active

involvement in the community. Lower self-efficacy, inadequate social support, family and caregiver coping and distress, and limited access to transport, have all been shown sometimes to have an impact, and are all modifiable factors and, therefore, amenable to intervention.

## **Conclusions**

This review brought together for the first time the literature on modifiable factors associated with community integration and social participation in people with acquired cognitive impairment. There were no eligible studies for predictors of community integration or social participation for people with dementia.

Psychological factors, such as self-efficacy, social factors, such as family and caregiver functioning or social support, and societal factors, such as the built environment, have, especially in TBI studies, been shown to be significantly associated with higher CI/SP. Driving status was consistently associated with CI/SP in both stroke and TBI populations. Given the variable quality and methodological differences of included studies results should be interpreted with caution.

## **References**

- Abdallah, C., Cohen, C.I., Sanchez-Almira, M., Reyes, P., & Ramirez, P. (2009). Community integration and associated factors among older adults with schizophrenia, *Psychiatric Services*, 60, 1642-8.
- Andresen, E. M., Malmgren, J. A., Carter, W. B., & Patrick, D. L. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *American Journal of Preventive Medicine*, 10, 77–84.
- Asakawa, Y., Usuda, S., Misukami, M., Imura, S. (2009). Moderator and Mediator Effects of Personal Factors in Patients with *Stroke*, 21. 55-63.

- Bandura, A. (2001). *Guide for constructing self-efficacy scales*. Stanford University.
- Banks, J.L., & Marotta, C.A. (2007). Outcomes validity and reliability of the modified Rankin scale: implications for stroke clinical trials. A literature review and synthesis. *Stroke*, 38, 1091-1096.
- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research, *Journal of Aging Studies*, 21, 107–118.
- Beckley, M.N. (2007). The influence of the quality and quantity of social support in the promotion of community participation following stroke. *Australian Occupational Therapy Journal*, 54, 215-220.
- Bogner, J.A., Whiteneck, G.G, Corrigan, J.D, Lai, J, Dijkers, M.P., & Heineman, A.W. (2011). Comparison of Scoring Methods for the Participation Assessment with Recombined Tools-Objective. *Archive of Physical Medicine Rehabilitation*, 92, 552-559.
- Bornstein, R.A. (1982). A factor analytic study of the construct attainment test. *Journal of Clinical Neuropsychology*, 4, 43-50.
- Brands, I., Köhler, S., Stapert, S., Wade, D., & van Heugten, C. (2014). Influence of self-efficacy and coping on quality of life and social participation after acquired brain injury: a 1-year follow-up study. *Archives of Physical Medicine and Rehabilitation*, 95, 2327-2334.
- Chau, J. P., Thompson, D. R., Twinn, S., Chang, A. M., & Woo, J. (2009). Determinants of participation restriction among community dwelling stroke survivors: a path analysis. *BMC Neurology*, 9, 49-68.
- Cicerone, K.D., & Azulay, J. (2007). Perceived self-efficacy and life satisfaction after traumatic brain injury. *Journal of Head Trauma Rehabilitation*; 22, 257-66.
- Corrigan, J. D., Bogner, J., Pretz, C., Mellick, D., Kreider, S., Whiteneck, G. G., &

- Heinemann, A. W. (2012). Use of neighborhood characteristics to improve prediction of psychosocial outcomes: a traumatic brain injury model systems investigation. *Archives of Physical Medicine and Rehabilitation*, 93, 1350-1358.
- Cote, R., Battista, R.N., Wolfson, C., Boucher, J., Adam, J., & Hachinski, V. (1989). The Canadian Neurological Scale: Validation and reliability assessment, *Neurology*, 39, 638-643.
- Curl, A.L., Stowe, J.D., Cooney, T.M., & Proulx, C.M. (2013). Giving up the keys: how driving cessation affects engagement in later life. *The Gerontologist*, 54, 423-433.
- Cutrona, C.E., & Russell, D. (1987). The provisions of social relationships and adaptation stress. In: Jones, W.H., Periman, D. (Eds.), *Advances in personal relationships, Vol 1* (37-67). Greenwich, CT: JAI Press.
- Dalemans, R.J.P., de Witte, L., Wade, D., & van den Heuvel, W. (2010). Social participation through the eyes of people with aphasia. *International Journal of Language & Communication Disorders*, 45, 537-550.
- Dalemans, R. J., De Witte, L. P., Beurskens, A. J., Van Den Heuvel, W. J., & Wade, D. T. (2010). An investigation into the social participation of stroke survivors with aphasia. *Disability and Rehabilitation*, 32, 1678-1685.
- Dawson, N.T, Powers, S.M., Krestar, M., Yarry, S.J., & Judge, K.S. (2012). Predictors of self-reported psychosocial outcomes in individuals with dementia. *The Gerontologist*, 53, 748-759.
- De Ridder, D.T., & Van Heck, G.L. (2004). *Coping inventory for stressful situations*. CISS Handleiding. Lisse: Swets Test Publishers.
- Derogatis, L.R. (1993). *The brief symptom inventory*. Minneapolis: National Computer Systems.

- Desrosiers, J., Noreau, L., Rochette, A., Bravo, G., & Boutin, C. (2002). Predictors of handicap situations following post-stroke rehabilitation. *Disability and Rehabilitation*, 15, 774-785.
- Dijkers, M., Whiteneck, G., El-Jaroudi, R. (2000). Tools of disability outcomes research. Measures of social outcomes in disability research. *Archive of Physical Medical Rehabilitation*, 81, 63–80.
- Dijkers, M.P. (2010). Issues in the conceptualisation and measurement of participation: an overview. *Archive of Physical Medical Rehabilitation*, 91, 5-16.
- Dumont, C., Bertrand, R., Fougeryrollas, P., Gervais, M. (2003). Rasch modeling and the measurement of social participation. *Journal Applied Measurement*, 4, 309–325.
- Dumont, C., Gervais, M., Fougeryrollas, P., & Bertrand, R. (2004). Toward an explanatory model of social participation for adults with traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 19, 431-444.
- Duncan, P. W., Wallace, D., Lai, S. M., Johnson, D., Embretson, S., & Laster, L. J. (1999). The stroke impact scale version 2.0: evaluation of reliability, validity, and sensitivity to change. *Stroke*, 30, 2131–2140.
- Duncan, P.W., Bode, R.K., Lai, S.M., Perera, S. (2003). Rasch analysis of a new stroke-specific outcome scale: the stroke impact scale. *Archive of Physical Medicine Rehabilitation*, 84, 950-963
- Egan, M., Davis, C.G., Dubouloz, C-J., Kessler, D., Kubina, L-A. (2014). Participation and wellbeing-poststroke: evidence of reciprocal effects. *Archives of Physical Medicine and Rehabilitation*, 95, 262-268.
- Elsass, L., & Kinsella, G. (1989). Proceedings of 14<sup>th</sup> Annual Brain Impairment Conference, *Development of a scale for measuring behaviour change following closed head injury*. Melbourne, Australia.

- Enderby, P., & Crow, E. (1996). Frenchay aphasia screening test: validity and comparability. *Disability Rehabilitation*, 18, 238 -240.
- Epstein, N.B., Baldwin, L.M., & Bishop, D.S. (1983). The McMaster family assessment device. *Journal of Marital Family Therapy*, 9,171-180.
- Fleming, J., Tooth, L., Hassell, M., & Chan, W. (1999). Prediction of community integration and vocational outcome 2-5 years after traumatic brain injury rehabilitation in Australia, *Brain Injury*, 13, 417-31.
- Fleming, J., Nalder, E., Alves-Stein, S., & Cornwell, P. (2014). The effect of environmental barriers on community integration for individuals with moderate to severe traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 29, 125-135.
- Folkman, S., & Lazarus, R.S. (1988). *Manual for the ways of coping questionnaire*. Washington, DC: Consulting Psychologists Press.
- Fougeyrollas, P., Noreau, L., Berger, H., Cloutier, R., Dion, S., & St-Michel, G. (1998). Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. *The International Journal of Rehabilitation Research*, 21, 127-141.
- Friedland, J., & McColl, M. (1992). Social support, and psychosocial dysfunction after stroke: buffering effects in a community sample. *Archives of Physical Medicine and Rehabilitation*, 73, 573-581.
- Geffen, L., Hinton-Bayre, A. D., Geffen, S., & Geffen, G. (1998). Head injuries in sport. In E. Sherry & S. Wilson (Eds.), *The Oxford handbook of sports medicine*. New York: Oxford University Press.
- Goodman, S.H., Sewell, D.R., Cooley, E.L. (1993). Assessing levels of adaptive functioning: the role functioning scale. *Community Mental Health Journal*, 29, 119-130.

- Granger, C.V., Dewis, L.S., Peters, N.C, Sherwood, C.C., & Barrett, J.E. (1979). Stroke rehabilitation: analysis of repeated Barthel index measures. *Archive of Physical Medicine Rehabilitation*, 60, 14-17.
- Griffen, J. A., Rapport, L. J., Coleman Bryer, R., & Scott, C. A. (2009). Driving status and community integration after stroke. *Topics in Stroke Rehabilitation*, 16, 212-221.
- Gum, A., Snyder, C. R., & Duncan, P. W. (2006). Hopeful thinking, participation, and depressive symptoms three months after stroke. *Psychology and Health*, 21, 319-334.
- Hanks, R. A., Rapport, L. J., Waldron-Perrine, B., & Millis, S. R. (2014). Role of character strengths in outcome after mild complicated to severe traumatic brain injury: a positive psychology study. *Archives of Physical Medicine and Rehabilitation*, 95, 2096-2102.
- Harrison-Felix, C. (2001). The Craig hospital inventory of environmental factors. *The center for outcome measurement in brain injury*. Retrieved from <http://www.tbims.org/combi/chief>.
- Harwood, R.H., Rogers, A., Dickinson, E., & Ebrahim, S. (1994). Measuring handicap: the London handicap scale, a new outcome measure for chronic disease. *Quality in Health Care*, 3,11-16.
- Heaton, R., Chelune, G., Talley, J., Kay, G., Curtiss, G. (1993). *Wisconsin card sorting test manual revised and expanded*. Odessa, Florida: Psychological assessment resources.
- Heatheron, T.F., & Polivy, J. (1991). Development and validation of a scale for measuring state self-esteem. *Journal of Personal Social Psychology*, 60, 895-910
- Heppner, P. P., & Petersen, C. H. (1982). The development and implications of a personal problem-solving inventory. *Journal of Counseling Psychology*, 29,

66–75.

- Hebert, R., Carrier, R., & Bilodeau, A. (1988). The functional autonomy measurement system: description and validation of an instrument for the measurement of handicaps. *Age Ageing*, 17, 293-302.
- Holbrook, M., & Skilbeck, C.E. (1983). An activities index for use with patients with stroke. *Age and Ageing*, 12, 166-170.
- Kalra, L., & Crome, P. (1993). The role of prognostic scores in targeting stroke rehabilitation in the elderly. *Journal of the American Geriatrics Society*, 41, 396-400.
- Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*. Edmonton, Canada: Alberta Heritage Foundation for Medical Research.
- Levasseur, M., Richard, L., Gauvin, L., & Raymond, E. (2010). Inventory and analysis of definitions of social participation found in the literature: proposed taxonomy of social activities. *Social Science & Medicine*, 71, 2141-2149.
- Lima, S., Gago, M., Garrett, C., & Pereira, M.G. (2016). Predictors and moderators of quality of life in Alzheimer's disease patients. *Journal of Alzheimer's Disease*, 54, 1113-1121.
- Lo, R., Harwood, R., Woo, J., & Yeung, F. (2001). Cross-cultural validation of the London handicap scale in Hong Kong Chinese. *Clinical Rehabilitation*, 15, 177-186.
- Malec, J., Lezak, M.D. (2003). *Manual for the Mayo Portland adaptability inventory (MPAI-4)*. Portland, Oregon: Oregon Health and Sciences University.
- Marrosszeky, N., Ryan, L., Shores, E., Batchelor, J., & Marrosszeky, J. (1998). *The PTA protocol: guidelines for using the Westmead post-traumatic amnesia (PTA) Scale*. Sydney, New South Wales: Wild & Woolley.
- McColl, M.A, Carlson, P., Johnston, J., Minnes, P., Shue, K., Davis, D., & Karlovits, T. (1998). The definition of community integration: perspectives of people



- with brain injuries. *Brain Injury*, 12,15–30.
- McColl, M.A., Davies, D., Carlson, P., Johnston, & J, Minnes, P. (2001). The Community integration measure: development and preliminary validation, *Archives of Physical Medicine and Rehabilitation*, 82, 429-434.
- McDowell, I., & Newell, C. (1987). *Measuring Health: A guide to rating scales and questionnaires*. New York: Oxford University Press.
- Meyers, N. M., Chapman, J. C., Gunthert, K. C., & Weissbrod, C. S. (2016). The effect of masculinity on community reintegration following TBI in military veterans. *Military Psychology*, 28,14-24.
- Mellick, D. (2000). The Craig handicap assessment and reporting technique - short form. *The Center for Outcome Measurement in Brain Injury*. Retrieved from: <http://www.tbims.org/combi/chartsf>
- Nanda, U., McLendon, P.M., Andresen, E.M., & Armbrecht, E. (2003). The SIP68: An abbreviated sickness impact profile for disability outcomes research. *Quality of Life Research*, 12, 583-595.
- Nasreddine, Z.S, Phillips, N.A., Bedirian, V. (2005). The Montreal Cognitive Assessment, MoCA: a brief screening. *Journal of American Geriatric Society*, 53, 695-699.
- Oluwatitofunmi Vincent-On, G., Ihaza, L.O., Ali, M.U., Masta, M.A., Majidadi, R., Modu, A., & Umeonwuka, C. (2016). Impact of social support on participation after stroke in Nigeria. *Topics in Stroke Rehabilitation*, 23. 305-310.
- Peacock, E.J., & Wong, P.T.P. (1990). The Stress Appraisal Measure: A multidimensional approach to cognitive appraisal. *Stress Medicine*, 6, 227-36.
- Pepin, M., Rheume, D., & Loranger, M. (1999). *Le test de personnalité PER: guide d'utilisation*. Quebec, Canada: Le Réseau Psychotech Inc.
- Peterson, C., Seligman, & M.E. (2004). *Character strengths and virtues: a handbook and classification*. New York: Oxford University Press.

- Piskur, B., Daniels, R., Jongmans, M.J., Ketelaar, M., Smeets, R., Norton, M., & Beurskens, A. J. (2014). Participation and social participation: are they distinct concepts? *Clinical Rehabilitation*, 28, 211-220.
- Post, M.W.M, & de Witte, L.P. (2003). Good inter-rated reliability of the Frenchay activities index in stroke patients. *Clinical Rehabilitation*, 17, 548-552.
- Post, M.W., van der Zee, C. H., J., Scharfrat, C.G., Visser-Meily, J.M., & van Berlekom, S.B. (2012). Validity of the Utrecht scale for evaluation of rehabilitation participation, *Disability Rehabilitation*, 34, 478-85.
- Rappaport, M., Hall, K.M., Hopkins, K., Belleza, T., Cope, D.N. (1982). Disability Rating-Scale for severe head trauma-coma to community. *Archive of Physical Medicine Rehabilitation*, 89, 904-911.
- Rapport, L.J., Hanks, R.A., & Coleman, R.D. (2004). The proceedings of the meeting of the International Neuropsychological Society, *Barriers to driving after traumatic brain injury*. Brisbane, Australia.
- Rapport, L. J., Hanks, R. A., & Bryer, R. C. (2006). Barriers to driving and community integration after traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 21, 34-44.
- Rapport, L. J., Bryer, R. C., & Hanks, R. A. (2008). Driving and community integration after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 89,922-930.
- Rochette, A., Bravo, G., St-Cyr/Tribble, D., Bourget, A. (2007). Adaptation process, participation and depression over six months in first-stroke individuals and spouses, *Clinical Rehabilitation*, 21, 554-562.
- Sabol, V.K., Resnick, B., Galik, E., Gruber-Baldini, A.L, Morton, P., Hicks, G.E. (2011). Exploring the factors that influence functional performance among nursing home residents, *Journal of Aging and Health*, 23, 112-134.
- Sady, M. D., Sander, A. M., Clark, A. N., Sherer, M., Nakase-Richardson, R., & Malec, J. F. (2010). Relationship of preinjury caregiver and family functioning

- to community integration in adults with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 91,1542-1550.
- Sander, A. M., Maestas, K. L., Sherer, M., Malec, J. F., & Nakase-Richardson, R. (2012). Relationship of caregiver and family functioning to participation outcomes after postacute rehabilitation for traumatic brain injury: a multicenter investigation. *Archives of Physical Medicine and Rehabilitation*, 93, 842-848.
- Scholz, U., Dona, B.G., Sud, S., & Schwarzer, R. (2002). Is general self-efficacy a universal construct? *European Journal of Psychological Assessment*, 18, 242-251.
- Schreurs, P.J.G, Willige, van de G, Tellegen, B, & Brosschot, J.F. (1988). *Handleiding Utrechtse Coping Lijst: UCL*. Lisse: Swets en Zeitlinger.
- Segal, M.E. & Schall, R.R. (1995). Assessing handicap of stroke survivors: a validation study of the Craig handicap assessment and reporting technique. *American Journal of Physical Medicine and Rehabilitation*, 74, 276-286
- Snyder, C.R., Harris, C., Anderson, J.R., Holleran, S.A., Irving, L.M., & Sigmon, S.T.(1991). The will and the ways: development and validation of an individual-differences measure of hope. *Journal of Personality and Social Psychology*, 60, 570–585.
- Sørensen, L. V., Waldorff, F. B., & Waldemar, G. (2008). Social participation in home-living patients with mild Alzheimer's disease. *Archives of Gerontology and Geriatrics*, 47,291-301.
- Stark, S.L., Edwards, D.F., Hollingsworth, H., & Gray, D.B. (2005). Validation of the reintegration to Normal Living Index in a population of community dwelling people with mobility limitations. *Archive Physical Medicine Rehabilitation*, 86, 344-345.
- Starkstein, S.E., Fedoroff, J.P., & Price, T.R. (1993). Apathy following cerebrovascular lesions. *Stroke*, 24, 1625-1630.

- Tabachnick, B. G., Fidell, L. S. (2007). Multiple regression. In Tabachnick, B. G., Fidell, L. S. (Eds.), *Using multivariate statistics* (117-194). Boston, MA: Pearson Education
- Tate, R.L., Hodgkinson, A., Veerabangsa, A., & Maggiotto, S. (1999). Measuring psychosocial recovery after traumatic brain injury: psychometric properties of a new scale, *Journal of Head Trauma Rehabilitation*, 14, 543-557.
- Tate, R. L., Broe, G., Cameron, I.D., Hodgkinson, A.E., & Soo, C.A. (2005). Pre-Injury, injury and early post-injury predictors of long-term functional and psychosocial recovery after severe traumatic brain injury, *Brain Impairment*, 6, 75-89.
- Tate, R.L., Simpson, G.K., Soo, C.A., Lane-Brown, A.T. (2011). Participation after acquired brain injury: clinical and psychometric considerations of the Sydney psychosocial reintegration scale (SPRS). *Journal of Rehabilitation Medicine*, 43, 609-618.
- Teng, E.L., & Chui, H.C. (1987). The modified mini-mental state (3MS) examination. *Journal of Clinical Psychiatry*, 48, 314-318.
- Tielemans, N.S., Schepers, V.P., Visser-Meiler, J.M., Post, M.W., van Heugten, C.M. (2015). Associations of proactive coping and self-efficacy with psychosocial outcomes in individuals after stroke, 96, *Archives of Physical Medicine Rehabilitation*, 1484-1491.
- Tielemans, N.S., Visser-Meily, J.M., & Schepers, V.P., Post, M.W., van Heugten, C.M. (2014). Proactive coping poststroke: psychometric properties of the Utrecht proactive coping competence scale. *Archives of Physical Medicine Rehabilitation*, 95, 670-675.
- Tsuji, T., Liu, M., & Sonoda, S. (2000). The stroke impairment assessment set: its internal consistency and predictive validity. *Archives of Physical Medicine Rehabilitation*, 81, 863-868.

- Turner-Stokes, L., Nyein, K., Turner-Stokes, T., Gatehouse, C. (1999). The UK FIM + FAM: development and evaluation. Functional assessment measure, *Clinical Rehabilitation*, 13, 277-87
- Van Baalen, B., Ribbers, G. M., Medema-Meulepas, D., Pas, M. S., Odding, E., & Stam, H. J. (2007). Being restricted in participation after a traumatic brain injury is negatively associated by passive coping style of the caregiver. *Brain Injury*, 21, 925-931.
- Van Baalen, B., & Odding, E. (2007). Reliability and sensitivity to change of measurement instruments used in a traumatic brain injury population. *Clinical Rehabilitation*, 20, 696-700.
- Van der Zee, C.H., Kap, A., Rambaran Mishre, R., Schouten, E.J., & Post, M.W. (2011). Responsiveness of four participation measures to changes during and after outpatient rehabilitation. *Journal of Rehabilitation Medicine*, 43, 1003-1009.
- Walker, N., Mellick, D, Brooks, C.A, & Whiteneck, G.G. (2003). Measuring participation across impairment groups using the Craig handicap assessment reporting technique. *American Journal of Physical Medicine Rehabilitation*, 82, 936-941.
- Watson, D., Clark, L.A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *Journal of Personal and Social Psychology*, 54, 1063-70.
- Whiteneck, G.G., Brooks, C.A., Charlifue, S., Gerhart, K.A., & Mellick, D., Overhoiser, D., & Richardson, G.N. (1992). *Craig handicap assessment and reporting technique*. Englewood: Craig Hospital.
- Whiteneck, G. G., Gerhart, K. A., & Cusick, C. P. (2004). Identifying environmental factors that influence the outcomes of people with traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 19, 191-204.

- Whiteneck, G.G., Dijkers, M.P., Heinemann, A.W., Bogner, J.A., Bushnik, T., Cicerone, K.D., Corrigan, J.D., Hart, T., Malec, J.F., Millis, S.R. (2011). Development of the participation assessment with recombined tools—objective for use after traumatic brain injury. *Archive of Physical Medicine Rehabilitation*, 92, 542-551
- Williams, D.H., Levin, H.S., Eisenberg, H.M (1990). Mild head injury classification. *Neurosurgery*, 27, 422-8.
- Willemsse-van Son A., Ribbers, G.M., Verhagen, A.P., Stam, H.J. (2007). Prognostic factors of long-term functioning and productivity after traumatic brain injury: a systematic review of prospective cohort studies. *Clinical Rehabilitation*, 21,1024-37.
- Willer, B., Ottenbacher, K.J., Coad, M.L. (1994). The Community integration questionnaire – a comparative examination. *American Journal of Physical Medicine and Rehabilitation*, 73,103-111.
- Wood-Dauphinee, S.L., Opzoomer, M.A, Williams, J.I, Marchand, B., & Spitzer, W.O. (1988). Assessment of global function: the Reintegration to Normal Living Index, *Archive Physical Medicine Rehabilitation*, 68, 583-590.
- World Health Organisation. (2001). *International classification of functioning, disability and health: ICF short version*. Geneva, Switzerland: World Health Organization.
- Yesavage, J.A. (1988). Geriatric depression scale. *Psychopharmacology Bulletin*, 24, 709-711.
- Zimet, G.D., Dahlem, N.W., Zimet, S.G, Farley, G.K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52, 30-41.

## **Part 2: Empirical Paper**

**Facilitators and barriers to people with dementia  
doing peer research: a qualitative study.**

## **Abstract**

### **Aims**

Peer researchers are individuals with the condition under study, who carry out research alongside an academic researcher. Very few people with dementia have assumed this role. This qualitative study sought to discover the perspectives of different UK-based stakeholders as to the barriers and facilitators.

### **Participants**

6 researchers, 9 gatekeepers (carers, ethics committee members and dementia charity employees) and 5 people with dementia participated in the study.

### **Methods**

Interviews were guided by the use of a topic-guide, based on the COM-B (Michie et al., 2011), a psychological model for studying facilitators and barriers of particular behaviours.

### **Analysis**

A thematic analysis (Braun & Clarke, 2006) was carried out.

### **Results**

Analysis identified four overarching themes: assumptions about research and dementia, and different forms of language; practicalities (e.g. transport and accessibility of communication); perceptions of danger, protectiveness and opportunities for building trust; and motivations.

### **Conclusions**

Data collected from this sample suggests that whether people with dementia do peer research depends on multiple factors rather than being a matter of ability alone.



## **Introduction**

In recent years, public and patient involvement has become a core feature of policy for health research in the United Kingdom. The 2010 government white paper 'Equity and Excellence, Liberating the NHS' explicitly advocated the 'partnership between patients and clinicians in research'. This partnership is presented as a logical extension of the principle of 'nothing about me without me', that holds that decisions about patient groups should not be made without the involvement of the patients themselves. Applicants to funding bodies like the National Institute for Health Research must now outline how the public has been involved in the design and planning of their project and what further plans they have for involvement, and the same is true for applications to the Health Research Authority for ethical approval of research projects (Caress et al., 2012). Typically, however, such involvement is limited to researchers consulting service user groups about the design, planning, and findings of research (Mockford, Stanszewska, Griffiths, & Herron-Marx, 2012) – service users are not involved in the collection and analysis of data.

### **What is Peer Research?**

'Peer-researcher' and 'co-researcher' are terms used interchangeably to describe a person, with the condition under study, who works alongside an academic researcher to carry out data collection and / or analysis. Peer research, therefore, differs from other forms of public and patient involvement in inviting individuals not merely to comment and make suggestions about research design and planning but also to be actively involved at all stages of empirical research (Di Lorito et al.; Frankham, 2009; Staley, 2009; Turner & Beresford, 2005). It is suggested that, by virtue of being 'experts by experience', peer researchers enhance the research process by, for example, identifying issues that may be overlooked by 'professional researchers' (Caress et al., 2012) and, where interviews are being carried out,

putting interviewees more at ease, thereby enabling them to talk more openly, thanks to the knowledge that they are with someone who shares their experiences (Beresford & Croft, 2001; Hanley, 1999; Tanner, 2012).

### **Who does Peer Research?**

This activity is most commonly conducted with marginalised groups not usually seen as active in research. Peer research, involving data collection and / or analysis, has been carried out more frequently with young people than with any other population group (Bradbury-Jones & Taylor, 2015; Fleming, 2012; Powell, 2011). It has also been carried out with vulnerable adult populations, especially those with intellectual disability (March, Steingold, Justice, & Mitchell, 1997; Miller, Cook, & Alexander, 2006; O'Brien, McConkey, & Garcia-Iriarte, 2014; Stevenson, 2014; Walmsley, 2004), but also those with mental health difficulties (Candace, 2007; Miller et al., 2006; Rose, 2003; Shields, Wainwright, & Grant, 2007), and the elderly (Clough, Green, Hawkes, Raymond, & Bright, 2006; Littlechild, Tanner, & Hall, 2015; Miller et al., 2006). Accounts of attempts to involve people with dementia as co-researchers are rarer. Furthermore, with the exception of one recent study, which describes a one-off session to involve individuals with dementia in the analysis of data (Stevenson & Taylor, 2017), such accounts as there are describe recruitment to the role of peer researcher in this population group as problematic, reporting either very low numbers as having been recruited or no people with dementia having been recruited as co-researchers at all (Mockford et al., 2016; Tanner, 2012).

### **Facilitators and Barriers**

The COM-B (Michie, van Stralen, & West, 2011) is a psychological model which has been used to study barriers and facilitators of health behaviours qualitatively (Moore et al., 2014 ; Newlands et al., 2016; Russell et al., 2016). This model accounts for whether or not a particular target behaviour occurs, in this case whether or not a

PWD becomes a peer researcher, with reference to 3 factors: **C**apability, both physical and psychological (e.g. being able to engage in the thought processes necessary for the target behaviour, having capacity etc...); **O**ppportunity (i.e. both that provided by the physical environment (e.g. being provided with transport) and by the cultural environment that determines how we think about things (e.g. not invited to participate because of assumptions about their abilities), and **M**otivation, including intentional processes (e.g. 'I want to make a difference') and automatic processes (i.e. impulses and emotions arising from associated learning or innate dispositions). In describing how co-research was carried out with people with dementia, the current literature offers anecdotal evidence as to what may facilitate co-research in this population once people have volunteered, which can be described using the COM-B framework. Tanner (2012) describes the importance of adapting the research activity (opportunity) to fit the abilities (capability) of individual co-researchers with dementia (e.g. by providing some kind of aide-memoire for interviewees to refer to during interviews), and of taking time to reconnect with co-researchers prior to and after each interview to ensure their continued understanding and engagement with the purpose of the research. In another paper, documenting different aspects of the same study, Littlechild and colleagues (2015) identify 'wanting to make a difference' as an important motivation that prompts older co-researchers both with and without dementia to get involved. In addition, some qualitative studies have examined facilitators and barriers to people with intellectual disability being involved in research; these studies have found that negative previous experiences of research (capabilities), lack of transport and inaccessible research materials (opportunities) were identified as barriers, while researchers with a more 'personal approach' (e.g. meeting potential participants prior to recruitment) were identified as facilitators (Crook et al., 2015; Nicholson et al., 2013).

There is currently no research that asks what lies behind the low numbers of people with dementia volunteering for the role, or why so few attempts to recruit to this role have been made, although a recent review paper speculates that global assumptions on the part of researchers about the cognitive abilities of people with dementia may partly be to blame (Di Lorito et al., 2017). Nor is there any attempt, reported in the literature, to explore qualitatively the perspectives of stakeholders involved in the dementia peer research as to what factors help and what get in the way of a person with dementia (PWD) becoming a peer researcher.

### **Study Context**

In 2013, the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR), announced that they were awarding £20 million to 6 dementia research projects; one of these was Promoting Independence In Dementia (PRIDE). One element of PRIDE is an interview and observational study with up to 120 people across the spectrum of cognitive ability from no subjective cognitive impairment to having had a diagnosis of dementia for up to 2 years. As part of this project, it was planned that up to eight people with early stage dementia, would be recruited and trained to work as peer researchers alongside university researchers, carrying out interviews and in some cases undertaking analysis. This presented an opportunity qualitatively to gain a better understanding of the factors that lead to someone with dementia becoming a peer researcher. I decided to use the COM-B to inform an interview based-study.

### **Study Aim**

The aim of this study was to explore the perspectives of those directly involved, or with relevant experience, as to what facilitates and what poses barriers to people with dementia becoming peer researchers.

## **Methods**

### **Approach**

I was interested in different aspects of these perspectives. Firstly, I hoped participants' accounts could tell me about something 'out there' – the experience of peer research – that I could not observe directly. I was also interested in how different accounts of the facilitators and barriers to this activity might highlight different aspects of this experience. Relatedly, I was interested in the beliefs, assumptions, and forms of language, underpinning different accounts that might, in themselves, hinder the activity (e.g. the belief that someone with dementia is incapable of research). These interests led me to adopt a 'subtle realist' (Ritchie, Lewis, McNaughton-Nicholls, & Ormston, 2014; Hammersley, 1992) approach. This approach shares with naïve realism the idea that research investigates a reality that exists independently of any claims we make about it but breaks with it in denying that we have direct access to this reality. Instead, this approach holds that we have multiple accounts, all of which are themselves shaped by various contexts, assumptions and beliefs. In assessing these accounts, following Hammersley (1992), I do not assume that a participant's understanding of the phenomenon must be valid simply because they 'were there' (it is important to consider how each account is informed not only by the phenomena it describes but also by its originator's various contexts) but I do consider the fact that they were there (or that they have some other relevant knowledge and experience) as an important type of evidence for the validity of their account.

### **Inclusion Criterion**

Initially, the key criterion for inclusion was having direct or indirect experience of a research project, which attempted either successfully or unsuccessfully to involve people with dementia as peer researchers. As recruitment progressed, I relaxed this criterion for people with dementia, to include people with experience of research and service-user involvement relating to people with dementia. In addition,

participants needed to be able to speak English well enough to take part in an interview and to have capacity to give informed consent.

### **Sampling Strategy and Settings**

Based on discussions with the PRIDE team, I decided to recruit from three groups: researchers with experience of recruiting (or attempting to recruit) and working with people with dementia as peer researchers; gatekeepers with experience of this type of research, and people with dementia. (A gatekeeper was defined as someone who stood between the researcher and the PWD in some way: carers and professionals working with people with dementia, as well as ethics committee members). I recruited researchers currently involved in the recruitment of peer researchers in the PRIDE team, and UK based-researchers who had published accounts of successful or unsuccessful attempts at recruiting people with dementia as peer researchers, or who were currently engaged in this kind of work. I recruited participants with dementia from voluntary sector organisations in the UK, and from among peer researchers recruited to the PRIDE study. I recruited gatekeepers via snowballing (i.e. following-up references made in my interviews). Numbers of people with relevant experience was low, so this was largely a convenience sample. However, where I did make selections, following relevant guidance (Ritchie et al., 2014), I did this to maximise the breadth of the sample (e.g. in the gatekeepers group, I ensured that I interviewed both carers with current and past carer responsibilities). To enable comparisons within and between groups, I aimed to recruit a minimum of 5 individuals to each group.

### **Ethical Approval**

Ethical Approval for the recruitment of healthy volunteers (i.e. the researcher and gatekeeper groups) was obtained from UCL Clinical, Educational and Health Psychology Research Department's Ethics Chair (Ref: CEHP\_2015\_529); approval

for the recruitment of people with dementia was obtained from the University College London Research Ethics Committee (Ref: 8635/011; Appendix 2:1).

### **Service User Involvement**

I carried out two service-user involvement exercises: the first with a patient and public involvement forum established by the PRIDE team, and the second with an Alzheimer's society service-user review panel. At the first meeting, which I conducted before starting data-collection, I invited the members of the forum to comment on consent forms, information sheets and a draft of the topic guide; the members (two former carers) gave feedback, mainly concerned with matters of clarity. At the second meeting, conducted prior to starting interviews with participants with dementia, I consulted 3 service-users with dementia about how to conduct interviews. They said that I should adopt a personal approach, as opposed to being too 'clinical' (i.e. that I should take time getting to know the person, as well as avoiding jargon), offer breaks and be aware of my body language because many people with dementia are sensitive to this. Their feedback informed how I carried out the interviews.

### **Procedure**

I began recruitment by approaching researchers who had already published accounts of working with people with dementia as peer researchers, and approaching members of the PRIDE team who were currently involved in recruiting people with dementia as peer researchers. I did this by sending e-mails to these individuals (whose contact details were either in the public domain, or available to me by virtue of being members of PRIDE) describing my study, providing an information sheet and inviting them to participate. All gatekeepers and one person with dementia were then recruited via snowballing; that is, I asked my researcher interviewees to identify 'gatekeepers' and people with dementia from their

experience of peer research. In most cases, I then asked them to pass information sheets on to these potential participants. When it concerned ethics committee members, (i.e. when the researcher could identify which ethics committee had approved their research involving peer researchers with dementia), researchers did not have contact details and so were unable pass on information sheets on my behalf. In these cases, I contacted the committee administrator by e-mail, providing an information sheet, and asking them to share it with individuals who had been on the panel for the specific study I knew they had discussed.

For people with dementia who had not been peer researchers per se but who had similar experience of research and service-user involvement, I contacted third sector organisations (e.g. the Alzheimer's Society and the Scottish Dementia Working Group), known to encourage involvement in research and provided them with the information sheet (Appendix 2:3). Interviews were carried out wherever was convenient for the participant (e.g. home or workplace) and lasted around an hour. Prior to each interview, I obtained informed consent (see Appendices 2:4 and 2:5 for consent forms for healthy volunteers and PWD respectively). The procedure for informed consent did not differ fundamentally for healthy volunteers and PWD; however, I tended to spend a little longer ensuring that PWD had understood the purpose of the research, what participation involved and their right to withdraw at any time. Once interviews were completed, I debriefed participants, and also offered to share my findings with them.

### **Interview**

I developed an initial topic guide (Appendix 2:6) in consultation with service-users and members of the PRIDE team, and following relevant guidance (Ritchie et al., 2014). The core section of the interview comprised the three domains of the COM-B model, and questions designed to elicit participants' views about the capabilities,



opportunities and motivations that might enable or prevent a PWD doing peer research. After four interviews, I made some revisions to the guide, following discussion with my supervisor (Appendix 2:7), so that it could be applied more flexibly not only to those with direct experience of peer research but also to participants who had tried and failed to recruit people with dementia as peer researchers, and those I was asking to think hypothetically.

## **Analysis**

I collected 19 one-to-one interviews, all approximately an hour in duration. Subtle realism encourages us to use accounts both as evidence about the phenomena they describe and as social constructions, reflecting beliefs and assumptions. Thematic analysis is not tied to any particular approach, and can be used to develop both semantic and latent themes, as defined by Braun and Clarke (2006) – a semantic theme being one identified within the surface level of the data, while latent themes consist of underlying ideas and assumptions that inform the semantic content. For these reasons, I decided that thematic analysis was well suited to my data. At the outset of this study, I had envisaged using the COM-B to inform analysis as well as data collection, coding data within the broad categories of capabilities, opportunities and motivations. However, as data collection progressed, I began to identify themes that did not fit neatly into these categories. For this reason I decided to conduct an inductive rather than a theoretical analysis.

**Phase 1: Familiarisation.** I transcribed all 19 interviews verbatim, ensuring that any punctuation clarified the meaning of the original utterance (Braun & Clarke, 2006). I then familiarised myself with all 19 transcripts, recording initial thoughts about what was of interest in the data.

**Phase 2: Initial coding.** I went through each transcript, identifying extracts of relevance to the research question, and coding these. At this stage, I shared a

selection of transcripts (one from each participant group) with my external supervisor, and we discussed initial codes.

**Phase 3 & 4: Searching for and reviewing themes.** I grouped initial codes into participant groups (i.e. researchers, gatekeepers and people with dementia), looking first for themes within each group then looking across the whole data set. (If I had found very different themes in the different groups, there might have been an argument for carrying out separate analyses for each group. In the event, however, despite differences between and within groups in terms of how individuals positioned themselves in relation to different themes, I identified superordinate themes that ran through the entire dataset). Once I had a map of themes, I proceeded to refining themes. While the four main themes were identified relatively early in this phase, the refinement of subthemes took longer, with several thematic clusters collapsing into each other once the full data set was taken into consideration. At this stage I discussed a list of themes and supporting extracts with my external supervisor.

**Phase 5: Naming and defining themes.** The process of naming and defining themes took place alongside the writing up of results. During this stage I attempted to apply terms that would bring sharper definition to the differences of perspective comprised within each theme.

## **Results**

### **Participants**

Nineteen individuals were recruited to the study: six academic researchers, eight gatekeepers, and five individuals with dementia. Participants were predominantly white and female. Further characteristics are provided in Table 2:1.

**Table 2:1 Participant characteristics**

Participant No.	Age	Gender	Ethnicity	Group	Key Relevant Experience *
1	60	F	White	R	Attempted to recruit peer researchers to do interviews
2	30	M	White	GK-DC	Supported attempt to recruit peer researchers
3	59	F	White	R	Carried out peer research involving analysis
4	53	F	White	R	Attempted to recruit peer researchers to do interviews
5	56	F	White	R	Carried out peer research involving interviews and analysis
6	57	F	White	GK-DC	Supported attempt to recruit peer researchers
7	-	F	Non-White	R	Part of team, attempting to recruit interviewing peer researchers
8	56	F	White	GK-EC	Member of ethics committee which considered peer research proposal
9	39	F	White	R	Carried out peer research involving analysis
10	71	F	White	GK-FC	Recruited as carer peer researcher
11	-	M	Non-White	GK-FC	Carer peer researcher
12	74	M	White	GK EC	Member of ethics committee which considered peer research proposal
13	72	F	White	GK-CC	Carer peer researcher
14	56	M	White	PWD	Recruited as peer researcher
15	59	F	White	GK-CC	Carer to PWD recruited as peer researcher
16	62	M	White	PWD	Experience of service user involvement and research as participant
17	73	F	White	PWD	Experience as interviewer of people with dementia for service evaluation
18	58	F	White	PWD	As above.
19	-	M	White	PWD	As above.

Key: R= Researcher; GK-DC = gatekeeper-dementia charity employee; GK-EC = gatekeeper- ethics committee member; GK-FC = gatekeeper-former carer; GK-CC = gatekeeper-current carer; PWD = PWD

\* indicates how participant met inclusion criteria. Where individual is described as having been recruited or attempting recruitment this indicates their experience of peer research does not go beyond this. 'Carer peer researchers', here, are carers of PWD who interview other carers.

## Themes

Analysis produced 4 super-ordinate themes, each with a number of subthemes

(Table 2:2).

**Table 2:2 Themes and subthemes**

Theme	Subtheme
<b>1. 'getting your head round it'</b>	<ul style="list-style-type: none"> <li>1. 'Fixed ideas' about dementia and research</li> <li>2. Language of stages</li> <li>3. Noticing individual differences</li> </ul>
<b>2. practicalities</b>	<ul style="list-style-type: none"> <li>1. 'A good fit'</li> <li>2. Accessibility</li> <li>3. Resources</li> </ul>
<b>3. 'this safe feeling'</b>	<ul style="list-style-type: none"> <li>1. Fears of research and dementia</li> <li>2. Comfort with self and others</li> <li>3. Familiarity</li> </ul>
<b>4. motivations</b>	<ul style="list-style-type: none"> <li>1. Making a difference</li> <li>2. 'Keeping doing'</li> </ul>

**Theme 1: 'getting your head round it'.** This theme refers to talk about (and expressing) thoughts that hinder or facilitate the view that peer research with people with dementia is feasible. When comparing interviews, it was noticeable that some participants were more doubtful than others about this. Some participants described how such doubts in others (and sometimes themselves) posed a barrier to recruiting PWD as peer researchers. It was also noticeable that within interviews, certain assumptions, or forms of language, were more likely than others to facilitate the view that this was something feasible.

**Subtheme 1: 'fixed ideas' about research and dementia.** Participants suggested that fixed ideas about what research and dementia were led people to dismiss the idea out of hand. One participant described the incredulity of an ethics committee member:

*"the world has gone mad. People with dementia, interviewing people with dementia. The world has gone mad" [ ] they just couldn't get their heads around it.*

5 (637-642) RESEARCHER

She attributed this to a stereotyped view of the abilities of people with dementia:

*I think they just thought 'what is the point?' That they won't be able to understand what is going on, they won't be able to follow the conversation. [ ]*

5 (667-673) RESEARCHER

Another researcher described how she had initially been reluctant to recruit people with dementia as peer researchers because of (now altered) assumptions.

*I: I had this sort of fixed idea of what dementia was [ ]. I thought people wouldn't be able to be involved in my research, that they wouldn't even consider it.*

1 (84-90) RESEARCHER

Similarly, gatekeepers suggested that fixed ideas about what research was put people off:

*The barriers are there before you've even got to [explain the process], in terms of the word 'research' and the thought 'academic', and the thought 'complicated'.*

673-679 (6) GATEKEEPER, Dementia charity employee

*'Analysis' – no! Because that conjures up poring over and getting involved in detail. It would put me off for him.*

413-423 (15) GATEKEEPER, Carer

While, in the preceding examples, assumptions were labelled as such, sometimes they were not. Here, it was possible to observe how categorical ideas about research and dementia made it harder for the speaker to entertain the idea. For some gatekeepers, assumptions about the technical expertise required by research, compounded the difficulties they envisaged:

*If you had dementia, would you remember enough of what was said to be able to lead **seamlessly** (my emphasis) into the next question?*

350-365 (10) GATEKEEPER, Former carer

The speaker, here, was herself preparing to be a co-researcher, and her idea of research, as something technical requiring 'seamless' transitions from question to question, was developing in this context. Present at both a semantic and latent level, this theme suggests that categorical definitions of dementia and research are barriers to this activity; their effect is to make their combination in the term 'peer-researcher with dementia' seem oxymoronic.

**Subtheme 2: the language of stages.** Contrasting with ideas that made it difficult for people to 'get their head around it', were ideas that made it easier. Among gatekeepers (x5), the idea of dementia as a series of stages rather than a homogenous category seemed to make it easier to countenance the idea of a peer researcher; for example, a carer, who herself had been a co-researcher several years previously, expressed scepticism about the idea of people with dementia *in general* doing research:

*I don't want to discredit any research but it's research isn't it? [ ] I don't know how they'd do it [ ] to me the inability to process could be a big stumbling block.*

360-364 (13) GATEKEEPER, Carer

But when she recalled that there had been a co-researcher with dementia in the project she had been involved in, she explained this exception with reference to the 'early stage':

*- it must have been early stage and she was probably alright. As I say she would sometimes forget at workshops but she would get through and it was fine.*

551-554 (13) GATEKEEPER, Carer

There is a sense here that the 'early stage' is not *real* dementia; while it makes it possible to think about someone with dementia doing research, this language of stages inevitably draws attention to the imminence of progression into a late stage, in which the person is imagined once again as completely incapable ('losing it altogether' (285) in the words of participant 12). As a result, talk of doing research during the early stage is often accompanied by concern about deterioration:

*Who judges where the threshold is, the line in the sand is crossed, you know?*

288-290 (12) GATEKEEPER, Ethics Committee Member

The language of stages seems to make it easier to envisage someone with 'early' stage dementia participating in research, at the same time as raising the spectre of the 'late' stage in which, implicitly, nothing is possible.

**Subtheme 3: noticing individual differences.** Also facilitative of the idea of dementia peer research, was talk about individual differences among people with dementia. While participants with dementia did sometimes (x1) use the language of stages they also (x2) stressed the diversity that exists within the diagnosis when considering the feasibility of peer research:

*Dementia is a thing of humans and humans are individuals and we are all different.*

127-129 (17) PWD

Researchers (x5) attributed stereotyped ideas about the capabilities of people with dementia to a limited exposure to individuals with dementia. Complementarily, gatekeepers (x5) endorsing the idea of peer research, often either drew on their own experience of individuals with dementia, or pointed to culturally available images of people with dementia who were self-evidently able; for example, one ethics committee member, after describing a colleague dismissing the idea of a PWD being involved in research, commented:

*I mean (laughs) it was quite strange because at the same time you could turn on Radio 4 and hear [ ] Terry Pratchett articulating quite clearly what it was like to live with dementia.*

105-107 (8) GATEKEEPER, Ethics Committee Member

Similarly, the talk of all six researchers reflected how peer research was made easier to consider by an immediate research context in which the individual service user perspective – not just that of the expert researcher - was seen to possess intrinsic validity. Somewhat similar to the talk around the importance of exposure to individuals with dementia in challenging assumptions, all three researchers who had undertaken co-research, also reflected on the necessity of ‘learning’ from experience, and letting go of assumptions:

*I learnt that if, really, you're serious about involving service users, you've got to be prepared to go where it takes you rather than staying on your fixed track.*

87-89 (5) RESEARCHER

This subtheme suggests that seeing people with dementia as individuals rather than members of a category and the valuing of experience over handed-down assumptions about what dementia and research are or should be, are facilitative of ‘getting one’s head around’ peer research.



**Theme 2: practicalities.** This theme refers to talk about practical barriers and facilitators to people with dementia doing peer research: whether the research task fit the peer researcher's skills and abilities, whether the PWD could access research (e.g. being contacted in the first place, acquiring information about the research, getting to wherever the research was happening), and whether all those involved had sufficient time and resources.

**Subtheme 1: 'good fit'.** This subtheme refers to talk about whether a person was able to do what the researcher required, or whether the research could be tailored to the person's abilities. The label 'good fit' is used to avoid suggesting either that barriers resided in the person or in the research task - depending on participant-perspective different aspects were emphasised. In people with dementia (x4), the emphasis tended to be more on the task as a barrier; for instance, imagining how analysis might work, one participant said:

*I could sit and discuss what people had said with you, maybe helping you to understand but if you gave me rows of figures to analyse or the text, forget it!*

672-685 (16) PWD

Similarly describing the interview task another participant remembered:

*I asked the questions and [a supporter] scribed for me but I couldn't have done both, no way.*

620-625 (19) PWD

The three academic researchers, who had done peer research, laid more emphasis on tailoring the research activity to fit the abilities of the PWD. So, for instance, in a project involving both carers and people with dementia as peer researchers, one researcher described how the analysis was done with both groups separately:

*...we thought [that otherwise] they won't have the space in the same way because other people will talk and things will move along too quickly.*

455-461 (5) RESEARCHER

Similarly two researchers talked about using 'excerpts' instead of entire transcripts to make the task less demanding. Among researchers who had not carried out peer research but who had tried or were trying to recruit, the emphasis was more on finding people who fit the research, and the needs and abilities of the PWD were more likely to be perceived as potential barriers; for example, in a project where despite attempting to recruit people with dementia, only carers had been involved, the researcher wondered whether they would have been able to cope with the analysis of full-transcripts, as the carers had:

*...there were a lot of people talking. A lot of issues were getting raised, a lot of stuff was getting written on flip charts [ ] I'm just wondering how they would cope.*

458-460 (1) RESEARCHER

There is perhaps a link here with theme 1 in that a research activity that is less tailored to the known difficulties of many people with dementia may reflect an unwillingness on the part of the researcher to let go of a particular idea of what research is. Overall, this sub-theme demonstrates how, depending on perspective, participants see the nature of the research task or the symptoms of dementia as posing more of a barrier.

**Subtheme 2: accessibility.** Even when the research task matches the skills and abilities of the PWD, the research may remain inaccessible to them, either because information about it never reached them in a format they could access or because they are unable to travel independently to wherever the research is happening. Difficulties with processing are common in dementia, meaning that when initial information about a project is in writing, the PWD is dependent on others, often carers, to pass information on:

*...[he] would not get involved in things at all if I did not put things under his nose.*

487-494 (15) GATEKEEPER, carer

*I wouldn't go looking for the research because I didn't know it was out there but [my wife] knows .. you know she can use a computer better than I can.*

551-556 (14) PWD

Participants from all three groups suggested, partly for these reasons, a face-to-face approach to recruitment was often preferable.

*He was saying about the method of recruitment [...] he doesn't like doing stuff over the phone because he finds that hard to follow a conversation, and he struggles with the written word now.*

449-473 (6) GATEKEEPER, Dementia charity employee

Travel was referred to as an issue by most participants. Again, most PWD are unable to drive, so are dependent on others for transport.

*Somebody asks me would I like to do something, the first things I think is 'How am I going to get there!'*

582-584 (18) PWD

This subtheme suggests that accessibility, particularly in terms of communication and transport, is an important factor in enabling or preventing participation.

**Subtheme 3: time & other resources.** Doing peer research takes time (the commitment required in research described here varied from one afternoon to two years), and making it accessible often requires someone, be it a carer, a researcher or other supporter, to use time and resources. Competing priorities can make this difficult. Participants from all three participant groups reflected that the PWD likely to be interested in peer research were also likely be busy:

*I get the invites, I look at them, and I decide yes or no. In most cases, I'm already booked for something else.*

413-418 (19) PWD

The sense of having limited time to play with is often particularly acute for people with dementia which, participants from all three groups reflected, might lead to a reluctance to commit to long-term projects:

*...research takes a long time, doesn't it? And I think sometimes we need to do it quicker because we don't know how much time we've got and you have to be aware of that.*

268-271 (18) PWD

Both researchers and carers described how limited time and resources, and competing priorities made it difficult for them to do what was needed in order to make the research task accessible.

*If the interviews were all over the place and [my husband] needed to get there himself [ ] then I have to get involved and ferry him all over the place. That gets difficult.*

135-138 (15) GATEKEEPER, Carer

*Now, I could if I had the time to go into every single dementia café in the county [to recruit PWD face-to-face] but that was not my sole role.*

578-588 (4) RESEARCHER

A lack of relevant knowledge was also identified by researchers (x3) and one gatekeeper as a barrier to this activity:

*One of the challenges we found was that there wasn't really guidance in how to do [peer research with PWD].*

88-92 (9) RESEARCHER

*Do the researchers really understand what life is like for the individual and trying to go with the grain and therefore making it as easy as possible for them to get involved?*

484-486 (15) GATEKEEPER, Carer

To overcome the practical barriers identified in the first two subthemes requires resources, the talk in this sub-theme suggests these resources are often limited and that this can pose a barrier to PWD doing research.

**Theme 3: 'this safe feeling'**. This theme refers to talk about building trust and a sense of safety in order to overcome perceptions of danger. Participants across all three groups spoke to these themes.

**Subtheme 1: fears of research and dementia.** Four of the five participants with dementia shared negative perceptions of research, based, in two cases, on experiences of not receiving feedback after participating in research:

*...you never heard another word. It could be that my input was absolutely rubbish. I would still like to know because I thought 'well, I won't do that again'.*

441-445 (19) PWD

Two talked about experiences of getting it 'wrong' in front of 'experts':

*...you've managed to get the confidence up to get involved with something like this [ ] and you are surrounded by all these experts who all know best anyway, and then they disagree totally with what you've said [ ].  
Would you want to do it again?*

235-243 (16) PWD

Both of these examples might be described as fears of invalidation, of being made to feel valueless. Two spoke about fears around the unpredictable emotionality of interviewees with dementia, as well as the emotional impact of interviews on themselves:

*We were all a wee bit wary of visiting the care home, thinking are we going to upset these people, you know? And we knew it could possibly upset us*

409-413 (18) PWD

Among the gatekeeper group, the most frequently mentioned danger was that of emotional harm. This was most strongly articulated by two individuals (one a former a carer, the other a carer of a person with advanced dementia) who wondered whether this danger was so great that people with dementia should not do peer research at all:

*I really do think that there's a chance for someone doing the interviewing to be messed up where perhaps they were doing not too badly.*

770-775 (10) GATEKEEPER, Former Carer

Complementary to these concerns, was a desire to protect the person with dementia from perceived dangers. This desire was expressed most strongly by gatekeepers, former carers in particular:

*If they were vulnerable, I think you would probably protect them rather than send them out there.*

699-700 (10) GATEKEEPER, Former Carer

From the perspective of researchers trying to recruit, and sometimes the PWD, this protectiveness was sometimes a barrier:

*[Carers would say] 'it will be upsetting for her, it will be too much. I'd rather you didn't carry on talking to her'*

234-235 (5) RESEARCHER

*If [my wife] thought that something might upset me, she would put her foot down. And she's got a very big foot!*

484-485 (19) PWD

Taken together this talk suggests that the idea of a PWD doing peer research, particularly if it involved doing interviews, was sometimes perceived, by gatekeepers especially, as threatening, and that this perception might sometimes people to rule it out.

**Subtheme 2: comfort with self and others.** Against this talk, many participants from all groups reflected that it was facilitative of peer research if the PWD was at ease both with themselves and their diagnosis, and with the academic researcher with whom they worked. Gatekeepers (x3) and people with dementia (x3) made a comparison between PWD who are so distressed by their diagnosis that they prefer to isolate themselves and those who have come to terms with their diagnosis. Four participants (x2 gatekeepers, x2 PWD), suggested the need for a kind of resilience for people with dementia to be able to interview others with the same condition and not be negatively affected by it:

*...that's a very important thing, that you're able to look at people a lot worse than yourself and be able to go home and cope with it.*

560-566 (19) PWD

*You've got to be comfortable in your own skin to be able to go and talk to somebody else and if you're not comfortable with it I think that would be very difficult.*

325-333 (10) GATEKEEPER, Former carer

Similarly participants from all three groups, but especially those with dementia, spoke about the importance of trust between co-researcher and academic, particularly in relation to the interview situation:

*I always had this safe feeling with her that if I got stuck I could just turn and ask her. Feeling safe is so important.*

657-661 (19) PWD

Those researchers and PWD, who had engaged in peer research, tended to describe the relationship in this way - the researcher is described as an enabling, supportive presence. There is a tension between these accounts and those of others who have not engaged directly in peer research that imagine the researcher keeping the PWD safe in a different way, not so much supporting, as monitoring:

*Whoever was supervising you would have to be watching you very closely because you, as a PWD, won't realise that you are deteriorating*

389-394 (10) GATEKEEPER, Carer

One PWD imagined the presence of the researcher not as reassuring but restrictive.

*We should be left alone, not being controlled, there is a lot too much control, I feel, but that is my opinion.*

112-119 (17) PWD

These last excerpts perhaps highlight tensions within the researcher's role – trying both to protect and empower. Overall, this subtheme identifies the perception, expressed mainly by gatekeepers and PWD, that to carry out this role, a person with dementia would need to be 'comfortable' with themselves and others.

**Subtheme 3: familiarity.** All three participant groups identified factors that help create the feeling of safety and security necessary for those with dementia to be able to engage in research. These factors are collectively labelled familiarity. Doing the research activity somewhere familiar to the PWD is something that researchers (x3) who engaged in peer-research involving analysis said was helpful in making the activity feel comfortable. Already knowing the person was identified as important by PWD (x2), who had carried out interviews in a care home. Developing a relationship by creating opportunities for relaxed, unpressured talk – often over 'cups of tea' - between researcher and co-researcher was frequently described (x3 researchers and x4 PWD) as helpful in developing a feeling of familiarity and trust:

*You have to find a way of spending time, non-productive time with the person, maybe a cup of coffee, a chat, where there's no pressure on anything that is going on, to allow a relationship to initiate.*

503-516 (16) PWD

The speaker's plea here for a corporatist research environment to loosen up to accommodate relationship-building is echoed by a researcher remembering her



decision not to prioritise efficiency to the detriment of relationships, when she decided to drive her researchers to and from interviews:

*I could have easily thought 'Oh let's buy taxis to save me, you know, driving around but actually that whole bit of picking them up and having a chat and driving them home and having a chat, all of that I think was quite important*

437-440 (5) RESEARCHER

Overall, the talk within this subtheme, suggested a degree of consensus across the different groups around the view that people with dementia are more likely to feel comfortable in familiar surroundings with familiar people.

**Theme 4: motivations.** This theme refers to talk about reasons why participants from different groups might, or might not, actively want a person with dementia to do peer research.

**Subtheme 1: Making a difference.** Across all three participants groups, people spoke about individuals with dementia participating in peer research (or research generally) out of desire to make a difference. This making a difference was often expressed as wanting to help people with dementia in the future:

*He has a very firm view that he wants to do everything he can to improve the situation for the generations to follow.*

100-108 (15) GATEKEEPER, Carer

Another aspect of making a difference was less about helping others and more about the experience of making a difference, the experience of one's words and actions having a tangible effect. PWD (x2), who carried out interviews as a part of an evaluation of care homes, spoke about different ways in which their words had an effect, one remembering how her opinion was decisive in determining whether they should inform staff of their diagnosis:

*...and I said 'Yes we do,' that's it! 'Because you have no idea what I would like if I was in a care home.' So that's what we did (proudly).*

75-80 (18) PWD

Similarly, the other remembered how he pointed out some uneven carpet as a potential hazard:

*...so I said 'That lady won't see that!' to the manager. 'And it needs to be flattened,' so before we left it was flattened.*

668-670 (19) PWD

The detail with which participants with dementia described discrete instances of this experience, contrasted with the more generalised way they talked about tokenism, by implication the more common experience:

*We weren't given the opportunity to speak, we weren't included in anything, we were just there, so they could say they 'had' you.*

595-608 (14) PWD

Participants from all three groups refer to the dangers of tokenism. While the emphasis for the PWD is on the experience of invalidation, the researchers' focus is on resisting the urge to recruit people just to fulfil the research brief:

*We wouldn't have wanted someone with dementia just sitting there just for the sake of saying oh we've got someone with dementia involved*

289-293 (5) RESEARCHER

In terms of what enables 'making a difference' there are some tensions within the data. Two of the researchers talk in terms of participants contributing as much or as little as they want, to accommodate those whose ability to be involved is limited:

*You know it's as much time as you feel you can give. We're also interested in your views on our analysis. So it's as much time as you can give.*

647-648 (4) RESEARCHER

Arguably, though, by locating this limitation-in-ability-to-be-involved inside the PWD, these researchers are avoiding the question of whether they might not create, for

example, a shorter project which would enable the person to participate more fully. One participant with dementia saw this kind of attempt at inclusion, as more tokenism:

*If your involvement is that haphazard, are you actually involved in it? Or are you just going along and saying 'Oh, we've got so and so and they've been diagnosed with...as part of our team.'*

586-590 (16) PWD

There are further tensions regarding the differences *researchers* hope to make through peer research. While most researchers saw peer research as potentially empowering PWD, there was more ambivalence as to whether it would make a positive difference to research data. Those who had carried out peer research (x3) saw a value in the additional perspective brought by the PWD, others (x2) were more ambivalent:

*What were we doing it for? Were we expecting it to make a difference to the data?*

672-674 (4) RESEARCHER

This subtheme identifies several kinds of making a difference: the PWD wanting to help others, described similarly by participants from different groups, seeing the impact of your actions, which is much more specific to participants with dementia. The flipside of the latter was the PWD's experience of tokenism. Finally, there were the motivations of researchers, some of whom wanted to make a difference to peer researchers by empowering them, and to research data by adding a new perspective, while others were more ambivalent.

**Subtheme 2: 'Keeping doing'.** This subtheme refers less to having an effect on others or the immediate environment, and more to remaining engaged in life, sometimes with an idea of holding dementia at bay, sometimes of maintaining one's pre-diagnosis identity:

*It just fed into her own personal outlook and past history of being someone who was very inquisitive.*

545-552 (3) RESEARCHER

*...something that takes him out of the home and engaging with other people [ ] it gives him something else to think about.*

112-116 (15) GATEKEEPER

*It makes me use my brain. Doing different things keeps you doing, you know?*

497-500 (17) PWD

In the main, participants saw this 'keeping doing' as a positive reason for engaging in peer research. However, there was one exception; one participant within the gatekeeper group described how for some people, who are retired, and who see a positive value in no longer being at work, the thought of being a researcher is quite unattractive:

*As far as they're concerned, they've done their job, this is a job, being in research is a bit like a job, and if you're old and you've retired, I don't want to go and sit and talk to an academic, I really don't.*

106-111 (6) GATEKEEPER, Dementia charity employee

So, with one exception, in this subtheme peer research was seen as a means of the PWD staying engaged with life, or maintaining valued aspects of their identity.

## **Discussion**

Using qualitative interviews, this study sought to elicit the perspectives of the members of different groups regarding factors that facilitate or inhibit people with dementia in doing peer research. The three groups interviewed were people with dementia, academic researchers and gatekeepers (a group comprising individuals working in the third sector, carers and ethics committee members). A thematic analysis embedded within a subtle realist approach, identified four overarching

themes: 'getting one's head round it', practicalities, 'this feelings of safety' and motivations. These themes are now discussed in relation to the existing literature.

### **Getting your head round it**

The 'fixed idea' of people with dementia subtheme repeats an already familiar pattern in dementia research (Di Lorito et al., 2017). Until the 1990s, the perspectives and subjective experiences of older people with dementia were largely absent from research thanks to a biomedical view of dementia that viewed people with dementia as incapable of verbally communicating their thoughts and feelings (Hubbard, Downs, & Tester, 2003). While it is no longer considered inappropriate for them to be research participants, the data collected for this study demonstrates that some are still influenced by an idea of people with dementia as lacking the cognitive ability to be involved in complex activities like doing research (Dewing, 2002; Downs, 1997; Moore & Hollet, 2003). More specifically, though, this theme suggests that it is the combination of assumptions about what dementia is *and* what research is that, for many of those in the study sample, made it particularly difficult to imagine this activity. The latter insight is new in the literature.

A corollary of this subtheme is the way in which different conceptions of dementia and research are linked with greater openness to the idea of peer research with people with dementia. This has not been shown before in relation to this topic. However, there is a parallel between the effect of the language of stages (at once facilitative of the idea that a PWD is still capable of doing things like research, but also accentuating, by contrast, the awfulness of 'the end stage') and what has been referred to elsewhere as the 'social imaginary' of the fourth age (Gilleard & Higgs, 2013); this refers to how the creation of the category of the third age (i.e. an old age during which the person continues to engage in life and is therefore not *really* old) has the paradoxical effect of heightening the perceived awfulness of the new fourth

age category. We do not know the consequences of the social imaginary of end stage dementia for those in the early stages. However, the way in which, in this sample, people with dementia were sometimes more inclined to use a time-neutral language of individual differences than the language of stages, is suggestive. Perhaps, it is often more comfortable for the PWD to say that whether one is able to do research depends on the unique characteristics of that individual than that it depends on their 'stage' of dementia. As well as avoiding the association of their self with the social imaginary of dementia, this language has the added advantage of allowing an identity separate from the diagnosis.

### **Practicalities**

The 'good fit', accessibility, and time and other resources subthemes add to similar previous findings in related fields. Qualitative studies have investigated the levers and barriers to participation in research (as interviewees not interviewers) of people with intellectual disability; for example, Crook and colleagues (2015) and Nicholson and colleagues (2013) both found that clinicians emphasised the person-with-intellectual-disability's abilities as barriers. They also found that, for this group, a clinician's belief that a person would not understand often meant they did not support them in participating in research. Those with intellectual disabilities laid more emphasis on the research as a barrier (Crook et al., 2015). These contrasting perspectives resemble the contrast found here between researchers who have not carried out peer research, and tend to emphasise the abilities of the PWD as a barrier, and PWD who emphasise the research task as a barrier instead. The additional perspective of researchers who have carried out peer research with people with dementia, with their tendency to emphasise the importance of tailoring research to suit the abilities of the PWD, echoes the reflections of Tanner (2012) on her experience of peer research with this group.

Both transport, the inaccessibility of recruitment information and a preference for a more personal approach to recruitment where participants had met the researcher prior to being recruited, are barriers and facilitators that also appear in studies about individuals with learning disabilities (Crook et al., 2015; Nicholson et al., 2013).

Although transport has not been identified before as a barrier in the context of dementia peer research, this finding is unsurprising given how well-evidenced it is that dependency on others for transport is a barrier to social participation by people with acquired cognitive impairments (Corrigan et al., 2012; Griffen et al., 2009; Rapport et al., 2006; Rapport et al., 2008). In addition, lack of time and resources has appeared in previous qualitative studies looking at caregiver-related factors preventing PWD from being involved in research as participants (Connell, Shaw, Holmes, & Foster, 2001), as well as at clinician-related factors preventing the participation in research of people with intellectual difficulties (Crook et al., 2015).

### **'This safe feeling'**

The fear expressed, both by gatekeepers and PWD, that the peer researcher's exposure to someone with worse dementia than themselves could have a negative emotional impact on them could be seen as a nuanced instance of 'dementia worry', the fear of developing dementia in healthy adults (Kessler, Bowen, Baer, Froelich, & Wahl, 2012); there is evidence that this worry drives some to minimize contact with people with dementia in order to keep fears at bay (Cohen, Werner, & Azaiza, 2009). It is interesting and maybe counter-intuitive to find 'dementia worry' among people with dementia but seen within the context of ideas discussed earlier about the social-imaginary of advanced-dementia it perhaps should not be surprising at all. If the idea of 'living well with dementia', with its emphasis on holding dementia at bay by continuing to engage in social activities, makes the 'end' stage appear more terrible by contrast, then one would expect to find some ambivalence about a research activity that potentially involves direct contact with advanced dementia.

Similar negative perceptions of research and researchers, expressed by several participants (gatekeepers and PWD) in this study have been identified in comparable contexts. The view that previous experiences of researchers failing to share findings might put people off participating in future research was found among gatekeepers in a qualitative study about people with intellectual disability (Nicholson et al., 2013). The perception of research as somewhat frightening to people with dementia, expressed in this study both by people with dementia and people caring for them, is also found in a qualitative study of factors preventing people with intellectual disability from being involved as research participants, where several interviewees described research as 'scary' (Crook et al., 2015). These fears are perhaps fuelled by assumptions identified in the 'getting your head around it' theme. If many people see research as something that, by its very definition, people with dementia, and by extension other cognitive impairments, cannot do, it is unsurprising if some of those who are labelled in this way are a bit apprehensive when someone invites them to do it.

The need for PWD to be at ease with themselves and their diagnosis in order to do peer research does not find a parallel in qualitative studies looking at the barriers to people with intellectual disability being research participants (Crook et al., 2015; Nicholson et al., 2013). This apparent difference between how people talk about people with dementia and people with intellectual disability perhaps owes something to different identity processes involved in acquired as opposed to developmental cognitive impairments, but perhaps also to the particular way in which we define dementia within our culture, as something unimaginably awful, which must therefore require enormous strength of character to come to terms with.



The familiarity subtheme also bears out what Bartlett (2015) has written about the importance of place in instilling feelings of safety in people with dementia invited to collaborate in research. The same paper also describes the importance of having opportunities for building relationships between researcher and collaborators with dementia, in a way which is reminiscent of the talk identified in this study around needing opportunities for relaxed, unpressured social contact between researcher and peer-researcher. Lack of time for people to talk and make relationships, is also identified as a barrier to PWD becoming involved in research by the Care Improvement Partnership (cited by Bartlett, 2015). Similarly in a qualitative study about involving people with intellectual disability in research, gatekeepers said it was helpful for potential participants to meet and become comfortable with the researcher prior to being recruited (Nicholson et al., 2013).

### **Motivations**

The 'making a difference' subtheme is more nuanced, and dementia-specific than what currently exists in the literature. Littlechild and colleagues (2015), identify 'making a difference' by improving services as having been the key motivation for their co-researchers but make no distinction between co-researchers who were carers and those with dementia. Similarly 'wanting to help others' has also been shown to be a motivation for the carers of people with dementia to encourage the person they care for to get involved in research (Connell et al., 2001). The more latent aspect of this theme, that is the way some participants described fondly *the experience* of their actions making an immediate difference, has not previously been identified in this context.

The 'keeping doing' subtheme fits with the dementia literature around 'valued identities'. Previous qualitative studies have documented strategies that people with dementia use to maintain a sense of continuity with their pre-diagnosis selves

(Macrae, 2010; Page & Keady, 2010; Wolverson, Clarke, & Moniz-Cook, 2010).

Doing research, or being a peer researcher fits into this wider agenda. Although within this particular sample, all five participants with dementia saw this continuity as something desirable, this may only be representative of the subset of the dementia population that they represent. As suggested by one gatekeeper, for many, the prospect of being a researcher may represent a quite undesirable continuity - that of continuing to work. Ideas like 'living well with dementia', 'successful ageing' and the notion of the third age, have been seen by some as creating new forms of ageism directed against the less vigorous and healthy (Holstein, 2010 cited by Gilleard & Higgs, 2013).

### **Limitations**

Perhaps the most obvious limitation of this study is that there was often some ambiguity as to whether participants were talking specifically about involvement in peer research, or research in general. This was especially true in interviews with individuals who did not have direct experience of peer research. This might have been at least partially avoided, if I had done more with my prompts and questions to encourage participants to identify which of the factors they referred to had particular importance for peer research with people with dementia.

The sample is also limited in several ways: the vast majority of participants were white and female and, although several had taken on very similar roles, only one participant with dementia had actually been recruited as a peer researcher. It is likely that different themes would have emerged from a more diverse sample. More specifically, all participants in the dementia group had a history of participation in service-user involvement, meaning that the voice of those who would never consider becoming a peer researcher, or were prevented from taking up this role in some way, was only represented in the words of others. This perhaps has the

result of skewing results so that some barriers to this activity were somewhat understated.

### **The COM-B Model**

The original intention had been to use COM-B model as a framework for coding different factors perceived as inhibiting or facilitating peer research in this population. I abandoned this in favour of a more bottom-up approach to analysis because in practice following the model meant separating themes that intuitively belonged together, in a way that obscured what participants had said. For example, the 'good fit' subtheme identified different perspectives as to whether abilities or the nature of research were barriers to involvement; within the COM-B model abilities would be categorised as 'capabilities' and the nature of research as 'opportunities'. Similarly, the 'this safe feeling' theme comprised talk about feelings (fear, comfort), and conditions that gave rise to those feelings (having time to get to know the researcher), which the COM-B model would conceive separately as motivations (i.e. emotions arising from associative learning) and opportunities. The 'motivations' theme did fit comfortably with the other aspect of motivation identified by the COM-B, namely intentional processes, and reflected the influence of the model in the topic guide.

### **Research implications**

If the purpose of this research is to inform the practice of future researchers, the theme of 'getting one's head around it' is helpful in several ways. First these results suggested that it may be helpful for researchers, as well as examining their own assumptions, to have an awareness of the different understandings of research and dementia that different individuals may bring to the idea of peer research. It may also be helpful to think about language that may be more or less facilitative of the idea of peer research in this population. This could help inform the language of

information sheets by, for example, referring to individual differences among people with dementia as a means of reassuring those who tend to understand dementia in a categorical way as well as avoiding the possibly unwanted associations of the language of stages for potential peer researchers with dementia.

The 'practicalities' theme draws attention to the need for researchers, who are seeking to recruit people with dementia to this role, to consider ways in which the research can be tailored to facilitate their participation. Relatedly, it is important for those applying for funding (and funders) to be aware of the resources that this type of research requires if it is to be properly supported and not merely tokenistic. All three of the researchers involved in projects that had not (yet) managed to recruit people with dementia to the role mentioned limited resources as a barrier to successful recruitment.

The 'feeling of safety' theme suggested that researchers should consider, and seek to foster, the feelings of safety of those they recruit to the peer research role. They should have an awareness of previous experiences and fears of research they may have, and consider different ways (e.g. using familiar spaces, and creating opportunities for unhurried getting-to-know-you talk) of building trust with them both post and prior to recruitment. It has been pointed out, in relation to recruiting individuals with intellectual disability to research, that ethical procedures, which often prevent a direct approach to participants to reduce the risk of coercion, may inadvertently deny them the right to be included as participants in research (Lennox, Rey-Conde, Bain, Purdie, & Boyle, 2005). Researchers recruiting people with dementia to peer research roles need to consider making a case for a more direct approach, given the barriers that more conventional approaches pose.

The theme of motivations may suggest helpful ways for researcher to 'sell' the role to people with dementia and their carers (e.g 'this is a way of making a difference to others'). It also suggests the importance of taking seriously the promise of service-user involvement to empower service users by creating opportunities for peer researchers to influence how the research they do is carried out. It may be helpful too for researchers to be alert to ways in which the research activity could build on existing skills of the peer researcher, in a way that is consistent with the 'keeping doing' agenda that drove many in this sample to do other service-user involvement activities.

### **Service implications**

Those seeking to involve people with dementia in the evaluation and running of services might take similar lessons from these findings. Specifically, the importance of having the power to make a difference suggests that being involved in the shaping of services is potentially particularly rewarding for this group. In addition, the pleasure participants took in seeing the immediate effects of their involvement in service evaluation and the displeasure caused by a lack of feedback, suggests the importance of services regularly informing the service users with dementia who do get involved about the impact of their contributions.

### **Conclusions**

As recently as 30 years ago, people with dementia were commonly seen as incapable of being research participants. The findings of this interview-based qualitative study indicated that such assumptions may still continue to pose a barrier to their being enabled to take part in research, only now extending to the involvement of people with dementia as peer researchers. The study also identified for the first time an array of factors, other than impairment, perceived by researchers, gatekeepers and people with dementia as both facilitating and

inhibiting this activity. Dementia-related impairments were seen as barriers by some, while others emphasised the importance of tailoring the research to the person's abilities. Accessibility in terms of transport provision and communication was also important, as were limited time and resources. In addition to these 'practicalities', different assumptions about, and ways of conceptualising dementia and research were more or less facilitative of peer research. A range of emotional factors also came into play: a perception, often by gatekeepers, that peer research was threatening, or dangerous, led some participants to reject the idea, while many said that being at ease with oneself, and the opportunity to get to know and trust a researcher in familiar surroundings were facilitative. Many participants identified wanting to make a difference or just to carry on engaging with life as important motivations. Unlike the biological effects of dementia, many of these factors are modifiable; the implication of this is that peer research, designed with them in mind, may have a greater chance of success.

## References

- Bartlett, R. (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, 29, 1291-1304.
- Beresford, P., & Croft, S. (2001). Service users' knowledges and the social construction of social work. *Journal of Social Work*, 1, 295–316.
- Bradbury-Jones, C., & Taylor, J. (2015). Engaging with children as co-researchers: challenges, counter-challenges and solutions. *International Journal of Social Research Methodology*, 18, 161-173.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Candace, L. (2007). The power of adolescent voices: co-researchers in mental health promotion. *Education Action Research*, 15, 371-383.

- Caress, A.L., Ford, A., Roberts., L., Turner, K., Ward, & D., Williamson. (2012). *Briefing notes for researchers. Involving the public in NHS, public health, and social care research.* Eastleigh, INVOLVE.
- Clough, R., Green, B., Hawkes, B., Raymond, G., & Bright, L. (2006). *Older people as researchers: evaluating a participative project.* York: Joseph Rowntree Foundation.
- Cohen, M., Werner, P., & Azaiza, F. (2009). Emotional reactions of Arab laypersons to a person with Alzheimer's disease. *Aging Mental Health*, 13, 31–37.
- Connell, C. M., Shaw, B. A., Holmes, S. B., & Foster, N. L. (2001). Caregivers' attitudes toward their family members' participation in Alzheimer disease research: implications for recruitment and retention. *Alzheimer Disease and Associated Disorders*, 15, 137–145.
- Corrigan, J. D., Bogner, J., Pretz, C., Mellick, D., Kreider, S., Whiteneck, G. G. & Heinemann, A. W. (2012). Use of neighborhood characteristics to improve prediction of psychosocial outcomes: a traumatic brain injury model systems investigation. *Archives of Physical Medicine and Rehabilitation*, 93, 1350-1358.
- Crook, B., Tomlins, R., Bancroft, A. (2015). 'So often they do not get recruited': exploring service user and staff perspectives on participation in learning disability research and the barriers that inhibit it. *British Journal of Learning Disabilities*, 44, 130-137.
- Dewing, J. (2002). From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, 1, 157–171.
- Di Lorito, C., Birt, L, Poland, F., Csipke, E., Gove, D., Diaz-Ponce, A., & Orrell, M. (2017). A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia. *International Journal of Geriatric Psychiatry*, 32, 58-67.

- Downs, M. (1997). The emergence of the person in dementia research. *Ageing Society*, 17, 597–607.
- Fleming, J. (2012). Moving to the inside: employing young people as researchers. In Fleming, J. & Boeck, T. (Eds.), *Involving children and young people in health and social care research*. London: Routledge.
- Frankham, J. (2009). *Partnership Research: A review of approaches and challenges in conducting research in partnership with service users*. Swindon: ESRC National Centre for Research Methods.
- Fudge, N., Wolfe, C.D.A., & McKeivitt, C. (2007). Involving older people in health research. *Age and Ageing*, 36, 492-500.
- Gilleard, C., Higgs, P. (2013). The fourth age and the concept of a 'social imaginary': a theoretical excursus. *Journal of Ageing Studies*, 27, 368-376.
- Griffen, J. A., Rapport, L. J., Coleman Bryer, R., & Scott, C. A. (2009). Driving status and community integration after stroke. *Topics in Stroke Rehabilitation*, 16, 212-221.
- Hanley, B. (1999). *Involvement works: the second report of the standing group on consumers in NHS research*. London: NHS Executive.
- Hammersley, M. (1992). *What is wrong with ethnography?* London: Routledge.
- Holstein, M. (2011). Cultural ideals, ethics, and agelessness: a critical perspective on the third age. In Carr, D.C., & Komp.K. (Eds.), *Gerontology in the Era of the Third Age* (225–243). New York: Springer.
- Hubbard, G., Downs, M.G., Tester, S. (2003). Including older people with dementia in research: challenges and strategies. *Ageing & Mental Health*, 7, 351-361.
- Kessler, E., Bowen, C., Baer, M., Froelich, L., & Wahl, H. (2012). Dementia worry: a psychological examination of an unexplored phenomenon. *European Journal of Ageing*, 9, 275-284.
- Littlechild, R., Tanner, D., & Hall, K. (2015). Co-research with older people: perspectives on impact. *Qualitative Social Work*, 14, 18-35.



- Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D.M, Boyle, F. (2005).  
Beating the barriers: recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research*, 49, 296-305.
- March, J., Steingold, B., Justice, S., & Mitchell, P. (1997). Follow the yellow brick road! People with learning disabilities as co-researchers. *British Journal of Learning Disabilities*, 25, 77-80.
- Michie.S., van Stralen., M.M., & West.R. (2011). The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation Science*, 6, 1-11.
- Miller, E., Cook, A., & Alexander, H. (2006). Challenges and strategies in collaborative working with service user researchers: reflections from the academic researcher. *Research Policy and Planning*, 24, 198–208.
- Macrae, H. (2010). Managing identity while living with Alzheimer’s disease. *Qualitative Health Research*, 20, 293-305.
- Mockford, C., Murray, M., Seers, K., Oyebode, J., Grant, G., Boex, S., Staniszewska, S., Diment, Y., Leach., J., Sharma, U., Clarke, R., & Suleman., R. (2016). A SHARED study-the benefits and costs of setting up a health research study involving lay co-researchers and how we overcame the challenges. *Research Involvement and Engagement*, 2, 1-12.
- Mockford, C., Staniszewska, S., Griffiths.F., & Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal for Quality in Health Care*, 24, 28–38.
- Moore, T., Hollett, J. (2003). Giving voice to persons living with dementia: the researcher's opportunities and challenges. *Nursing Science Quarterly*, 16, 163–167.
- Moore, J.E., Mascarenhas, A., Marquez, C., Almaawiy, U., Chan, W., D’Souza, J., Liu, B., & Sharon, E.S and The MOVE ON Team. (2014). Mapping barriers

- and intervention activities to behaviour change theory for mobilization of vulnerable elders in Ontario (MOVE ON), a multi-site implementation intervention in acute care hospitals. *Implementation Science*, 9, 1-9.
- Newlands, R., Duncan, E.M., Prior, M., Elouafkaoui, Elders, A., Young, L., Clarkson, J.E, Ramsay, C.R, & TRIadDS Research Methodology Group. (2016). Barriers and facilitators of evidence- based management of patients with bacterial infections among general dental practitioners: a theory-informed interview study. *Implementation Science*, 11, 1-12.
- Nicholson, L., Colyer, M., & Cooper., S.A. (2013). Recruitment to intellectual disability research: a qualitative study. *Journal of Intellectual Disability Research*, 57, 647-656.
- O'Brien, P., McConkey, R., & Garcia-Iriarte, E. (2014). Co-researching with people who have intellectual disabilities: insights from a national survey. *Journal of Applied Research in Intellectual Disabilities*, 27, 65-75.
- Page, S., & Keady, J. (2010). Sharing stories: a meta-ethnographic analysis of 12 autobiographies written by people with dementia between 1989 and 2007. *Ageing and Society*, 30, 511-526.
- Powell, M. A. (2011). *International literature review: ethical issues in undertaking research with children and young people*. Lismore/Dunedin: Southern Cross University, Centre for Children and Young People/University of Otago, Centre for Research on Children and Families.
- Rapport, L. J., Hanks, R. A., & Bryer, R. C. (2006). Barriers to driving and community integration after traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 21, 34-44.
- Rapport, L. J., Bryer, R. C., & Hanks, R. A. (2008). Driving and community integration after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 89, 922-930.
- Ritchie, J., Lewis, McNaughton-Nicholls, C., & Ormston, R. (2014). Qualitative

- research practice. London: Sage.
- Rose, D. (2003). Collaborative research between users and professionals: peaks and pitfalls. *Psychiatric Bulletin*, 27, 404–406.
- Russell, C.G., Taki, S., Campbell, K.J., Laws, R., Elliot, R., & Denney-Wilson, E. (2016). A qualitative study of the infant feeding beliefs and behaviours of mothers with low educational attainment, *BMC Pediatrics*, 16, 1-14.
- Staley, K. (2009). *Exploring impact: public involvement in NHS, public health and social care research*. Eastleigh: INVOLVE.
- Shields, G., Wainwright, R., & Grant, G. (2007). Doing user research: narratives of mental health service user researchers. In Nolan, M., Hanson, E., Grant, G., Keady, J (Eds). *User Participation in Health and Social Care Research*. Open University Press: Maidenhead.
- Stevenson, M. (2014). Participatory analysis alongside co-researchers who have Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, 27, 23-33.
- Stevenson, M., & Taylor, B.J. (2017). Involving individuals with dementia as co-researchers in analysis of findings from qualitative study. *Dementia: The International Journal of Social Research and Practice*, 14, 788-799.
- Tanner, D. (2012). Co-research with older people with dementia: experience and reflections. *Journal of Mental Health*, 21, 296–306.
- Turner, M., & Beresford, P. (2005). *User controlled research: its meanings and potential. Final Report*. Eastleigh: INVOLVE.
- Walmsley, J. (2004). Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research. *Nursing Inquiry*, 11, 54–64.
- Wolverson, E.L., Clarke, C., & Moniz-Cook, E. (2010). Remaining hopeful in early stage dementia: a qualitative study. *Ageing and Mental Health*, 14, 450-460.

## **Part 3: Critical Appraisal**

## **Introduction**

In this section, I will reflect on theoretical and methodological issues that I encountered while planning and conducting my literature review and empirical project. I would also like to discuss the implications of some of the findings.

### **Personhood versus Citizenship**

One of the most striking findings from the literature review was the near total absence of papers examining community integration/social participation (CI/SP) in individuals with dementia. The only paper identified used a very limited measure of social participation (asking how often the individuals with dementia received visitors, how often s/he visited others, and how often s/he participated in social activities outside the home), completed by caregivers as part of a larger study (Sørensen, Waldorff, & Waldemar, 2008). The scores from this measure were analysed in relation to demographic factors, symptom severity and activities of daily living. The study found that symptom severity and impaired activities of daily living were associated with low CI/SP, a similar finding to many studies in other populations with acquired cognitive impairment. The lack of studies about CI/SP in dementia need not mean that there are no other quantitative findings regarding CI/SP in the literature. It is possible that searches focussing on the separate domains of CI/SP rather than the overall construct would produce a greater number of hits. But this does not explain why so few researchers have deemed the question of what might predict CI/SP in those with dementia worth asking, given that so many have asked the same question of populations with stroke and traumatic brain injury. Research and clinical practice in the field of dementia may have been somewhat limited by Kitwood's influential concept of personhood (Bartlett & O'Connor, 2007). The concept focuses on the role of the immediate care environment in maintaining personhood, thus largely ignoring wider social structures, and implicitly seeing a person with dementia as passive rather than as a social actor capable of exerting

power and influence. It may be that the pervasiveness of Kitwood's influence partly explains why it has not occurred to more researchers to ask questions about the social participation or community integration of people with dementia, both constructs which conceive of the individual as an active member of his or her social world. Conceiving of people with dementia not merely as persons but as citizens is an alternative, which might overcome these limitations (Bartlett & O'Connor, 2007). It is something of a cliché to talk about how people participate in research because they 'want to make a difference' but I was struck by how precious having the power to make a difference (and to know what difference you have made) was to several of my participants with dementia, even when that difference was something as modest as suggestions being listened to and acted on. The experience appeared to be precious because of its novelty, set against the much more familiar experience of being treated as an irrelevance because of social stigma, including when this takes the form of a tokenistic pretence at involvement, or a researcher who does not share results. This made me reflect that, it is important not only that we do not exclude people with dementia from research on CI/SP but also that when we engage them in research we enact the principles of truly including and valuing the individual that underpin this construct.

### **Insider Research**

An unfamiliar aspect of this research was that some of my participants were members of the PRIDE research team. As a DClinpsy student, one of my worries at the outset of my project was around having enough interviewees. In the context of this worry, the idea of having easy access to some interviewees with relevant experience was reassuring and I did not think much beyond that. In the event, only a small number of participants were recruited from the PRIDE team. Nevertheless, as the project developed, I came to find some aspects of this situation ethically challenging. Although I knew none well my internal supervisor, who is a senior

member of the PRIDE team, knew all of them. One of the participants was directly responsible for recruiting peer researchers to the project and, outside of our interview, I was often in touch with her to ask about potential participants for my project. One of the advantages, which is sometimes claimed for insider research, is that because the interviewee has a relationship with the researcher they are more likely to feel comfortable enough to speak freely (Hockey, 1993). In my position as a slightly familiar person, or an outsider/insider, I think the opposite may have been the case. Although all participants were free not to participate, I was not always confident that those whom I recruited from PRIDE felt entirely free; I sometimes sensed that, while participants wanted to speak freely and openly in the spirit of contributing helpfully to the research, they also felt slightly constrained by the knowledge that their words would end up, albeit anonymously, in a report that their boss was going to read. Some openly expressed concern about how it was going to be possible truly to anonymise their data, given team-members familiarity with their verbal mannerisms. I offered to show them quotes that I was thinking of using in the report but, having done this, worried that I was implicitly offering to edit their words, which compromised the integrity of the research. In retrospect some of the dilemmas I faced were predictable, and it might have been helpful to talk this through explicitly right at the beginning of planning the research.

There were more practical difficulties too. Participants were in some cases aware of the COM-B model that informed my topic guide. It was sometimes noticeable that participants talked in terms of capabilities, opportunities and motivations, even though in my questions I generally used less formal vocabulary to ask about these different areas. I had a feeling that people were trying to give me what they thought I wanted and wondered if the end result was a less reflective, flatter account than might have come about otherwise. Reflecting on this now, other than having ensured my insider-participants were less well-informed about my research, I am

not sure that this was avoidable, but the experience has reinforced for me the importance in qualitative research of thinking carefully about the impact on the data of the context within which the interview is carried out (Ritchie, McNaughton-Nicholls, & Ormston, 2014).

Finally, I think being an 'insider' may also have made it more likely that I would position myself in a certain way in relation to the topic of peer research with people with dementia. Knowing that I was, in some sense, a part of a team that was attempting to do this made me, I found, want to believe that this new and relatively unproven approach was a good thing, perhaps as a way of avoiding 'cognitive dissonance'. When interviewees expressed scepticism about the value of people with dementia interviewing others with dementia, although I did my best to remain neutral and open-minded in the conversation, I noticed that internally I was feeling as though I was on the opposite side of an argument. I am not sure exactly what impact this had, but wonder whether, at times, it slightly blunted my curiosity and meant that I explored a perspective less thoroughly than I might have done otherwise. Similarly, my knowledge that within the PRIDE team, recruitment of people with dementia to this role was proving problematic, meant that I was more inclined to think that it was problematic because of obstacles out there in the world, outside of my team, rather than considering that at least some of the obstacles could just as easily be seen as a result of constraints imposed by PRIDE.

### **Topic Guide**

One of the most important tasks in developing my project's design was to decide on method, or methods, of data collection. Observation did not feel like an option because I had no guarantee that, within my timeframe, there would be anything very much to observe (i.e. peer research with people with dementia is a very rare activity). It seemed likely, then, that data would be generated by asking individuals



to reflect on previous as well as current experience of the topic. While focus groups were one possible way of doing this, I did not spend much time thinking about this; even at this early stage I knew my participants would be geographically widely dispersed so, on the basis of practicalities alone, focus groups were ruled out. This meant that the main choice was between a semi-structured interview, where the interviewer is committed to asking specific questions, and a topic guide, where the interviewer explores specific areas but is flexible in the questions used to do this (Ritchie et al., 2014). I opted for a topic guide, thinking that the flexibility this offered would make it easier to construct something that would work for three groups of participants, whose experiences were likely to be very different from each other. Whilst I do think a topic guide was the right choice I did at times, during data collection, miss the security of knowing that I had asked the questions that I was 'supposed to' have asked. As someone with little experience of qualitative research, having a fixed list of questions might have helped allay anxieties I periodically had about whether there was 'enough' consistency in the way I was doing things, and whether I was 'getting it right'. In the main I think I did a reasonable job of finding a balance between ensuring my participant could express themselves, and guiding the interview towards topics of relevance to the research question. However, feeling slightly insecure in my method occasionally reduced the extent to which I was able really to listen to my interviewees and ask relevant follow-up questions; my attention was slightly distracted by doubts about whether I had covered an area sufficiently.

Not unrelated to the challenge of tolerating a degree of uncertainty around knowing what the 'right questions' were, was the challenge of adapting my topic guide in view of what I learnt from the initial interviews. It is an accepted feature of qualitative research that the researcher may need to adapt aspects of study design in light of emerging data (Mason, 2002) but this was new to me. My initial reaction when I

needed to depart from the original topic guide for one of the early interviews was to think something had gone wrong rather than to see this as useful new information. Once I was able to think more reflectively about this, I revised the topic guide so that it could be applied more flexibly. The original topic guide had focussed on the capabilities, opportunities and motivations of the person with dementia, slightly neglecting these areas in other people involved in the process. This meant I had overestimated the extent to which all participants would feel able meaningfully to comment on what, once they were invited, might influence the person with dementia to take up the role and underestimated the importance of factors that influenced decisions and actions that took place before any person with dementia was even invited to take part in peer research; for example, one of my early interviewees had little to say about what had led people with dementia to decide against becoming peer researchers when she invited them, but quite a lot to say about what had led her to plan, at least initially, only to recruit carers as co-researchers. Reflecting on this experience, I decided that I needed first to obtain a narrative of whatever dementia-peer research experience my participant had before then asking questions about what helped and what got in the way at key points in this narrative.

Another area of difficulty I experienced in relation to the topic guide concerned epistemology. The discipline of trying to be consistently aware of one's own epistemological assumptions, when asking questions of others and thinking about their answers, is something relatively new to me. Although I identified early that I wanted to use a 'critical realist' or 'subtle realist' approach, this was largely because I had seen this defined (Hammersley, 1992; Ritchie et al., 2014) as an approach which assumed that it was possible to have multiple, mutually contradictory but valid accounts of the phenomena under investigation. What I had not resolved was how I was using these accounts, which is a central question for those using this approach (Hammersley, 1992). Was I interested in my participants' views as

sources of information about peer research by people with dementia, or as social phenomena (i.e. the phenomena of people's attitudes towards the topic), which I was interested in understanding? Or was I interested in both of these? Shortly after beginning data collection, I realised that I was sometimes avoiding questions about things that I knew my participants did not have direct experience of; for example, if a participant had not, in the end, worked with peer researchers with dementia, I sometimes had not asked them about the motivations of people with dementia to do, or not to do peer research. My actions in doing this suggested that I was only interested in my participants' accounts as sources of information rather than as social phenomena. This was not the case. I was interested in both. This reflection was important in freeing me up to ask about motivations, knowing that in some cases I would be more interested in these answers as evidence of actual motivations, while in other cases I would be interested in them more as evidence of a particular set of assumptions and beliefs, produced within a particular context.

### **Defining Peer Research**

Something I had to think through, as the research developed, was the issue of defining my topic. Despite having started out with what I felt was a fairly clear definition (i.e. research carried out by people with the condition under study, working alongside academic researchers) before long this definition began to feel insufficient. There were large variations among the activities described by the six academic researchers I interviewed, in terms of duration (they ranged from a one-off session to a commitment lasting several years); what was done (in some projects people with dementia did interviews, in others they did just analysis, in one they had the option of doing a range of service-user involvement activities, including analysis, but could do more or less depending on their preferences; in terms of when they were recruited and how much involvement they had in designing the interview (some were recruited early, before any participants, and had a role in designing the

interview schedule, some were recruited after many interviews had already been carried out, and the interview schedule had been designed). This was less of an issue when interviewing the researchers because I could allow each of them to define peer research as the activity they carried out. However, when it came to interviewing participants who had not done peer research, and to whom I had to explain what peer research was, it was difficult to know how to do this. I thought that having a complicated definition that included references to the different variables (duration, extent of involvement in design etc...), which had emerged during the course of the researcher interviews, was likely to be confusing, especially for people with various cognitive impairments. Another thing that might have been lost through having an over elaborate definition of peer research was the opportunity to see what assumptions different people would make about what peer research involved, and how this might affect their attitude towards it. With these considerations in mind, the definition I gave of peer research was limited to saying that it involved people with dementia interviewing people with dementia with support from an academic researcher and/or helping the researcher in thinking about what the interviews meant. To leave it at that, though, also seemed to throw away the opportunity to find out about how things like the duration of the project, or extent of involvement in design, might affect individuals' attitudes to the topic. Therefore, although I did not ask participants about these variables irrespective of what their main concerns were, in line with qualitative research methodology I did use prompts (Ritchie et al., 2014) if what they said suggested this might be a relevant area to them; for instance, where participants talked about having limited time, I saw this as providing justification for mentioning that different peer research projects would run for different lengths of time, and asking what difference project duration would make to someone's inclination to participate.

While I think these solutions to the problem of defining peer research were reasonable and, in the case of my use of prompts, had a basis in qualitative research theory, I found the difference between how peer research was defined in interviews with those who had experience of it, and in those where they did not, uncomfortable. Perhaps, this discomfort is the discomfort of someone who, previously, had been used to doing quantitative research where procedures were standardised and who, as a result, had come to equate standardisation with scientific rigour, and the lack of standardisation with the opposite. There is something reassuring about having a very fixed set of procedures, and something quite unnerving about having a much more fluid set of procedures, which the researcher must continuously reflect upon. Another reason for my discomfort was, I think, connected to how this piece of research differed from my limited previous experience of qualitative research. This had generally involved exercises looking at interviews where people had talked about their experiences of being something (e.g. their experience of being a clinical psychology student). In such cases there is never a need to define what is meant by 'a clinical psychology student' because the interviewee would have their own idiosyncratic understanding of the term, which the interviewer would seek to elicit. For this reason, having to provide definitions of the thing that I was then asking them about felt slightly jarring.

## **Conclusions**

Overall, I finished both my literature review and my empirical research project feeling that I had learnt a lot about research methodology, at the same time as producing some interesting findings. In particular, I hoped that the themes and subthemes identified in the empirical paper would be of value to people, who consider carrying out peer research with people with dementia in the future. Although at times I felt slightly overwhelmed by having to carry out two tasks, which in many different aspects were quite new to me, at other times I was able to enjoy

the different challenges and opportunities they both presented. If there is one theme that pulls together what I will take forward from this process, it is maybe a renewed appreciation of the importance of being able to reflect regularly upon your decisions and actions at the same time as accepting and learning to tolerate that this means that your decisions and actions will always be performed without you being completely certain about their rightness or wrongness. It is possible that a difficulty tolerating this kind of uncertainty is part of the explanation for the relative lack of dementia research in CI/SP; maybe it feels a bit safer to contribute research to an area with a well-established literature. This tolerating of uncertainty also has parallels in clinical work, where as a clinician you use a formulation to guide interventions, knowing that this formulation is never definitive.

### References

- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: broadening the lens for dementia practice and research, *Journal of Aging Studies*, 21, 107–118
- Hammersley, M. (1992). *What is wrong with ethnography?* London: Routledge.
- Hockey, J. (1993). Research methods – researching peers and familiar settings, *Research Papers in Education*, 8, 199-225
- Mason, J. (2002). *Qualitative researching*. London: Sage.
- Ritchie, J., Lewis, McNaughton-Nicholls, C., & Ormston, R. (2014). *Qualitative Research Practice*. London: Sage.
- Sørensen, L. V., Waldorff, F. B., & Waldemar, G. (2008). Social participation in home-living patients with mild Alzheimer's disease. *Archives of Gerontology and Geriatrics*, 47, 291-301.

# Appendices

## Appendix 1:1 The used search strategy and results in PsycInfo

Limits	Hits	Combination	
		OR	AND
1990 to 2016, English Language			
<b>Outcome</b>			
1. Participation/ or Participation.mp	74368		
2. Social Participation.mp	1638		
3. Community Participation.mp	1342		
4. Community Involvement.mp	4989		
5. Community Integration.mp	1019		
6. Community Reintegration.mp	315		
7. Social Integration.mp	5052		
8. Social Reintegration.mp	203		
9. Social Engagement.mp	1306		
10. Consumer Participation.mp	257		
11. Community Engagement.mp	1095		
12. Civic Engagement.mp	1333		
13. Social involvement.mp	392		
		82255	
<b>Design</b>			
14. Prediction/ or Predict*.mp	320402		
15. Factor*.mp	560868		
16. Correlat*.mp	258929		
17. Determinant*.mp	35664		
18. Relat*.mp	1211563		
19. Associat*.mp	594470		
20. Variable*.mp	217099		
21. Psychosocial Factors/ or psychosocial factor*.mp	31281		
22. Influen*.mp	354930		
23. Lever*.mp	10819		
24. Barrier*.mp	51998		
25. Facilitat*.mp	113943		
26. Effect*.mp	950641		
		2214981	
<b>Population</b>			
27. Dementia*.mp or Dementia/ or Senile Dementia or Aids Dementia Complex or Semantic Dementia or Dementia with Lewy Bodies or Vascular Dementia	74477		
28. Alzheimer's disease.mp or Alzheimer's disease	47001		
29. Traumatic Brain Injury	15239		
30. Traumatic Brain Injur*.mp	16970		
31. Acquired Brain Injur*.mp	1585		
32. Brain Injur*.mp	22233		
33. TBI.mp	8394		
34. ABI.mp	934		
35. Cerebrovascular Accident/ or stroke*.mp	29102		
36. Cerebrovascular accident*.mp	17064		
37. Cognitive impairment/ mild cognitive impairment.mp	30816		
38. Cognitive impairment*.mp	41423		
		142736	
			2624



## Appendix 1:2 QualSyst scoring checklist

Criteria	Yes (2)	Partial (1)	No (0)	N/A
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				

## Appendix 2:1 UCL Research Ethics Committee approval letter for the recruitment of people with dementia

UCL RESEARCH ETHICS COMMITTEE  
ACADEMIC SERVICES



25<sup>th</sup> January 2017

Dr Georgina Charlesworth  
UCL Department of Clinical, Educational and Health Psychology

Dear Dr Charlesworth

### Notification of Ethical Approval

**Re: Ethics Application 8635/001: What helps people with dementia become peer researchers? What gets in the way?**

I am pleased to confirm in my capacity as interim Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC until 25<sup>th</sup> January 2018 on condition that only people with the mental capacity to give informed consent are included in the study.

Approval is also subject to the following conditions:

### Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form':

<http://ethics.grad.ucl.ac.uk/responsibilities.php>

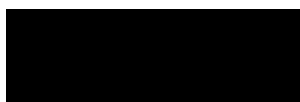
### Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

### Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

Yours sincerely,  
Professor Michael Heinrich  
Interim Chair, UCL Research Ethics Committee



cc. Jacob Waite

## Appendix 2:2 Information Sheet for Healthy Volunteers

UCL DIVISION OF PSYCHOLOGY  
AND LANGUAGE SCIENCES



### Information Sheet for Participants

Title of Project: **Recruiting peer researchers: factors influencing decisions made about individuals with dementia.**

This study has been approved by UCL Clinical, Educational and Health Psychology Research Department's Ethics Chair (Project ID No: **CEHP\_2015\_529**): Dr John King

Name, Address and Contact Details of Investigators:	Principal investigator: Dr Georgina Charlesworth Department of Clinical Educational and Health Psychology UCL Gower Street London WC1E 6BT Tel. 0207679 1897 g.charlesworth@ucl.ac.uk
Jacob Waite Department of Clinical Educational and Health Psychology UCL Gower Street London WC1E 6BT Tel. 0787078747 jacob.waite.14@ucl.ac.uk	

In this study we are interviewing people who have played a part in making decisions about whether people with dementia take part in research as 'peer researchers\*'. The research project is being run by researchers at University College London.

If you choose to take part, you will be contacted by the researcher, Jacob Waite, to arrange a time to meet, or to speak over the phone. The interviews are designed to be informal and conversational, and will last for up to an hour. There are no written questionnaires to complete. Jacob will ask your views on: the opportunities that people with dementia have to be research collaborators; the abilities needed to be a peer researcher; and which people with dementia would like to take up the peer researcher role. The interview will take place somewhere that is convenient for you (e.g. your place of work), or over the phone, and will be recorded on a digital voice-recorder.

Information from interviews will be handled according to the Data Protection Act 1998 and will be kept anonymous. Jacob will transcribe the recorded interviews and then look for themes. If you are willing and interested, Jacob will re-contact you to gather your opinion on the identified themes. Individuals will not be identified in any research reports, unless they choose to identify themselves.

It is completely up to you whether you chose to take part. If you choose not to, you will not be disadvantaged in any way. To help you make up your mind, please read this information sheet carefully. You might want to discuss it with a friend or colleague too. Please get in touch with Jacob Waite (details above), if something is not clear or if you want to know more.

If you decide to take part, please keep this information sheet. We will ask you to sign a consent form. You will still be free to change your mind at any time without giving a reason. You can also ask us to destroy any information you have shared with us, and we will do that.

\* **Peer researchers** are people with lived experience of the issue being studied

## Appendix 2:3 Information sheet for people with dementia

### Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Title of Project: What helps people with dementia become peer researchers? What gets in the way?

Committee (Project ID Number): 8635/001

Names	Jacob Waite (Researcher)
	Dr Georgina Charlesworth (Principal Investigator)
Work Address	Department of Clinical Educational and Health Psychology UCL Gower Street London WC1E 6BT
Contact Details	<a href="mailto:jacob.waite.14@ucl.ac.uk">jacob.waite.14@ucl.ac.uk</a> Tel. 0787078747 <a href="mailto:g.charlesworth@ucl.ac.uk">g.charlesworth@ucl.ac.uk</a> Tel. 02076791897

We would like to invite you to participate in this research project.

**Details of Study:** In this study we are interviewing people with dementia who have been invited to become peer researchers ('peer researchers' are people with lived experience of the issue being studied). We are also interviewing people without dementia who have been involved with dementia peer research. We want to find out what you believe helps or gets in the way of individuals with dementia becoming peer researchers. We hope that what we learn will help increase the opportunities for individuals with dementia (who want to) to become peer researchers.

The research project is being run by researchers at University College London.

If you choose to take part, the researcher, Jacob Waite, will get in touch. He will arrange a time to meet with you, or to speak over the phone. The interviews are designed to feel like a relaxed chat. They will last for up to an hour. Jacob will ask you what you think helps people with dementia to become peer researchers, and what you think might get in the way. He will arrange the interview somewhere that is convenient for you (e.g. your place of work or your phone), or over the phone. He will record your chat on a digital voice-recorder.

*Your personal details will be handled according to the Data Protection Act 1998. This means that Jacob will not share your details with anyone. He will listen to the recorded interview and write down what you both said in a transcript. Anything that you say in the interview that might identify you will be removed. Jacob will then look in the interview transcript for themes. If you are willing and interested, Jacob will re-contact you to ask what you think about the themes he finds. He will also offer you a copy of the final report. Individuals will not be identified in any research reports, unless they chose to be.*

We hope that those who participate will enjoy the experience. In the unlikely event that a participant becomes upset during the interview, Jacob will deal with this in a sensitive way.

It is completely up to you whether you choose to take part. If you choose not to, you will not be disadvantaged in any way. To help you make up your mind, please read this information sheet carefully. You might want to discuss it with a friend or colleague too. Please get in touch with Jacob Waite (details above), if something is not clear or if you want to know more. If you have additional concerns about your rights as research participants please contact Dr Georgina Charlesworth (details above).

If you decide to take part, please keep this information sheet. We will ask you to sign a consent form. You will still be free to change your mind at any time without giving a reason. You can also ask us to destroy any information you have shared with us, and we will do that.

THANKYOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

## Appendix 2:4 Consent form for use with healthy volunteers

UCL DIVISION OF PSYCHOLOGY AND LANGUAGE SCIENCES



### Consent Form

#### Informed Consent Form for Participants in Research Studies

*(This form is to be completed independently by the participant after reading the Information Sheet and/or having listened to an explanation about the research.)*

Title of Project: **Recruiting peer researchers: factors influencing decisions made about individuals with dementia.**

This study has been approved by UCL Clinical, Educational and Health Psychology Research Department's Ethics Chair (Project ID No.): Dr John King

#### Participant's Statement

I ..... agree that I have

- read the information sheet
- had a chance to ask questions and discuss the study
- been given clear answers to all my questions (or have been given contact details for someone who can answer questions about the research and about my rights and whom to contact in the event of a research-related injury).
- I understand that my interview will be recorded and I am aware of, and consent to, the analysis of the recordings.

**For the following, please circle "Yes" or "No" and initial each point.**

- I agree for the quotations from my interview to be used by the researchers for teaching, conferences, presentations, publications, and/or thesis work  
YES / NO initial: \_\_\_\_\_
- I agree for the anonymised, transcribed material to be used by researchers in further research studies  
YES / NO initial: \_\_\_\_\_

I understand that I am free to withdraw from the study if I want, and that this will not disadvantage me in any way. I understand that I consent to the use of my personal information for this study only. I understand that all my information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

Signed:

Date:

#### Investigator's Statement

I ..... confirm that I have carefully explained the aims of the study to the participant and outlined any foreseeable risks or benefits (where applicable).

Signed:

Date:

## Appendix 2:5 Consent form for people with dementia

<p><b>Informed Consent Form for Participants in Research Studies</b></p> <p>Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.</p> <p><b>Title of Project: What helps people with dementia become peer researchers? What gets in the way?</b></p> <p>This study has been approved by the UCL Research Ethics Committee (Project ID Number): 8635/001</p> <p><i>Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.</i></p> <p><i>The researcher will give you an information sheet and will explain the research to you. If, after this, you still have questions, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.</i></p> <p><b>Participant's Statement</b></p> <p>I ..... agree that I have:</p> <ul style="list-style-type: none"><li>• read the information sheet</li><li>• had a chance to ask questions and discuss the study</li><li>• been given clear answers to all my questions (or the name for someone who can answer my questions about the research and about my rights, and for someone to contact in the even of a research-related injury).</li><li>• I understand that my participation will be recorded. I consent to use of this material as part of the project.</li></ul> <p>For the following, please circle 'Yes' or 'No' and initial each point.</p> <p>- I agree for the quotations from my interview to be used by the researchers for teaching, conferences, presentations, publications, and/or thesis work</p> <p>YES / NO initial:</p> <p>- I agree for the anonymised, transcribed material to be used by researchers in further research studies</p> <p>YES / NO initial:</p> <p><b>Investigator's Statement</b></p> <p>I .....confirm that I have carefully explained the aims of the study to the participant and outlined any foreseeable risks or benefits (where applicable).</p> <p>Signed: _____ Date: _____</p>
---



## Appendix 2:6 Topic Guide – Original Version

### 1. Introduction

- Introduction to researcher
- Explain study topic, aims & objectives
- Explain confidentiality
- Explain recording, length & nature of discussion, reporting, data storage
- Go through consent issues explaining they can withdraw at any time
- Check whether any questions
- Check happy to continue

### 2. Background

*Aims: to elicit demographics, get participant talking and find out about their relationship to dementia and research:*

- How old are they?
- What do they do in life?
- How would they describe their ethnicity?
- What is their educational background? What experience of research do they have.
- Where does dementia fit in their life?

### 3. Core interview

*Aims: to learn participants views on what leads to someone with dementia becoming (or not becoming) a peer researcher.*

#### a) Capabilities

- Recruiters/Gatekeepers: *what do they look for? what rules people out?*
- Individuals with dementia: *why did they think they could/could not do it?*
- **Probe for:**
  - Skills, Abilities, Experiences, Qualities
  - Physical & Psychological

#### b) Opportunities

- Recruiters: *how did they approach potential participants? how did they support them to become peer researchers?*
- Individuals with dementia: *how did they find out? what was helpful about the researcher's approach?*
- **Probe for:**
  - Practical facilitators and barriers
  - Attitudes and assumptions of others

#### c) Motivations:

- Recruiters/Gatekeepers: *what do they think makes someone want to be a peer researcher? what's their kneejerk reaction to the idea?*
- Individuals with dementia: *what makes you (not) want to be a peer researcher? what is your gut instinct about it?*

#### d) Anything not covered

### 4. Winding Down:

- Summarize

- Thank participant & reiterate that interview will remain confidential



## Appendix 2:7 Topic Guide – Revised Version

### 1 Introduction

- Script: *Very few people with dementia have become peer researchers. By talking to people who have been involved at different stages of the research process, I want learn different perspectives about things that help or get in the way of people with dementia becoming peer researchers. (N.B. for participants without any experience of peer research give definition: Peer research involves people with dementia doing interviews with people with dementia, supported by an academic researcher. It also sometimes involves helping researchers think about what interviews with people with dementia mean.)*
- Explain confidentiality, recording, length & nature of discussion, reporting, data storage, go through consent issues, explaining they can withdraw at any time.
- Check whether they have any further questions & are happy to continue.
- Obtain participant's age, ethnicity and highest educational qualification.

### 2 Background. Aim: To get participant talking & obtain relevant context.

- *Where does dementia fit in their life (personal, professional)?*
- *Where does research fit into their life?*

### 3 Map of relevant experience. Aim: To obtain a detailed narrative of the participant's experience of peer research with people with dementia.

- Please talk me through your experience of peer research with people with dementia from the beginning.
- Use mapping questions (Ritchie et al., 2014) (e.g. when did you first start thinking about this? what happened next?) to build up detailed picture.

### 4 Participant perspective. Aim: To obtain participant's perspective as to what things helped or got in the way at different points in their narrative.

- What do you think helped at that point? What else? What helped most? What got in the way? What else? What got in the way most?

Sub-questions, to be used flexibly:

- How do you think this was different from co-research with any other population? Any other activity (other than peer research)?
- Prompt around capabilities (e.g. what skills/abilities/qualities helped?), opportunities (e.g. what approach was helpful? what support was important?), motivations (e.g. why did they (not) want (the PWD) to do it? what is your knee jerk reactions to the idea?).
- Have an eye out and prompt for themes, which emerged in previous interviews.

### VARIATIONS:

**For peer researchers who are carers, use section 3 but for section 4 ask hypothetical questions** (e.g. 'you say that you were approached by e-mail, how would that work for the person you care for? what would work better?').

**For participants with dementia without experience of peer research, or gatekeepers with limited memory of their experience, do not use section 3 and for section 4 ask hypothetical questions** (e.g. Imagine a researcher asks you to become a peer researcher. How would they need to ask you? What would you say? Why? What do you think would help or get in the way?).

## **5 Winding Down**

- Ask participant if there's anything they want to add.
- Thank participant, explain what happens next, answer any questions.

