

# **Ageing well with psychosis**

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Doctor of Clinical Psychology (ClinPsyD) in the Faculty of Biology,  
Medicine and Health**

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**School of Health Sciences**

**Division of Psychology and Mental Health**

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## Abstract

There are approximately 70,000 adults (aged  $\geq 50$ ) in England living with a diagnosis of schizophrenia or psychosis related disorder. With an increase in life expectancy, and an ageing population this figure is likely to double in the next decade (Vahia & Cohen, 2008). The needs of older adults change across the lifecourse for example with health co-morbidities and neurocognitive decline. As such older adults with psychosis represent a large burden to the NHS. It is therefore imperative to understand what it means for this population to 'age well' and what interventions are available to help to further support wellbeing in older age.

Paper 1 presents a systematic review of studies examining the effectiveness of psychosocial interventions for older adults with psychosis at improving social functioning. A literature search was conducted using the following electronic databases: Web of Science, PsycINFO, Embase, CINAHL and Medline. Seventeen studies were identified that satisfied inclusion criteria for the review. The review found evidence for the use of skills training interventions, both with respect to social skills and psychiatric and physical health skills training. There was not enough evidence to recommend any other psychosocial interventions. Overall, the review revealed a need for more robust research about interventions that have been shown to be effective in other age groups.

Paper 2 presents a qualitative study exploring what the concept of 'ageing well' means to mid to older aged adults with psychosis. Sixteen participants, aged 50-74 ( $M_{\text{age}} = 61$ ), diagnosed with psychosis related disorders (i.e. schizophrenia, schizoaffective disorder etc.), were interviewed about their views about ageing well, and how this can be best supported. Recordings were transcribed verbatim and then analysed using thematic analysis. Four themes were identified from the data: i) engaging with life, ii) attitude to life and ageing, iii) maintaining wellbeing and iv) having good relationships. This study showed that people with psychosis can consider themselves to be ageing well. Unlike previous literature participants also reported the importance of their relationships with professionals, developing a mastery over their mental health difficulties and the continued impact of stigma on ageing well. Therapeutic approaches that target these domains may therefore facilitate ageing well with this population.

Paper 3 is a critical reflection of the systematic review, the empirical paper and the research process as a whole. It aims to provide justification for, and explanations of key decisions that were made and outline clinical and future research implications.

Total word count: 19792 (excluding tables, figures, abstracts and references)

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# **Paper 1: A systematic review of the effects of psychosocial interventions on social functioning for middle to older aged adults with psychosis**

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Author Note: This research was submitted to the University of Manchester for the degree of Doctor of Clinical Psychology (ClinPsyD)

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Paper 1 has been prepared for submission to The Gerontologist in accordance with the guidelines for contributors (Appendix A.)

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**Abstract:**

**Background and Objectives:** The number of older adults with psychosis is likely to double in the next 20 years. It has been posited that the needs of adults diagnosed with psychosis-related disorders change across the lifecourse, and that difficulties with social functioning often persist into older age. Poorer social functioning is associated with poorer long term outcomes and has been identified as a priority for intervention by service users. The aim of this study was to systematically review studies examining the effectiveness of psychosocial interventions on social functioning for this group.

**Research Design and Methods:** A systematic review of peer-reviewed journal articles was conducted and databases were searched from inception to December 2017. The review was limited to psychosocial interventions, for mid to older aged adults ( $\geq 40$  years of age) with severe mental illness (SMI) that included a validated measure of social functioning. The databases: EMBASE, MEDLINE, CINAHL, Web of Science and PsychINFO were searched.

**Results:** Fifteen studies met inclusion criteria. There was evidence to support skills training interventions that primarily focused on social skills training or integrated mental and physical health interventions. There was not enough evidence to recommend any other interventions.

**Discussion and Implications:** The results highlight the limited nature of interventions designed specifically for older people with psychosis that target social functioning and the need for more robust, large-scale studies in the area. Current guidance recommends that CBT can be effective on social functioning but, as yet, there is insufficient evidence to recommend this for an older population.

**Key Words:** Psychosis; Severe Mental Illness; Psychosocial intervention; Social functioning

## **Background and Objectives**

The World Health Organisation (WHO) currently places schizophrenia as one of the top contributors to the world burden of disease (Vos, 2015). Psychosis related disorders, such as schizophrenia, have some of the most debilitating impact, both in terms of disability and financial burden, accounting for approximately 30% of adult mental health funding in the NHS (National Institute for Clinical Excellence; NICE, 2014). There are approximately 70,000 adults aged 50 and above currently in England living with psychosis (Public Health England, 2016). With an ageing population, this number is likely to double within the next decade, and poses a significant challenge to current services (Cohen et al., 2008).

Whilst there is some evidence about the efficacy of antipsychotics in the reduction of positive symptoms (Leucht et al., 2009), there has been little evidence demonstrating their effects on negative symptoms (Arango, Garibaldi, & Marder, 2013) or indeed functional recovery (Kern, Glynn, Horan, & Marder, 2009). Negative symptoms can be conceptualised as the absence or reduction in normal affective, behavioural and social functioning, and are one of the biggest predictors of quality of life and functional outcomes (Lutgens, Garipey, & Malla, 2017). More recently, negative symptoms have been conceptualised into two domains: experiential and expressive symptoms. Experiential negative symptoms encompass avolition (decreased motivation), anhedonia (decreased experience of pleasure) and asociality (decreased value for social contact). The expressive domain, however, captures decreased emotional expressivity and alogia (poverty of speech; Llerena, Reddy, & Kern, 2018).

Whilst positive symptoms generally recede in older age, negative symptoms often still persist (Sable & Jeste, 2002). Given that experiential symptoms include asociality, it is unsurprising that negative symptoms of schizophrenia are associated with poorer social functioning (Hunter & Barry, 2012). Indeed, recent evidence suggests that experiential negative symptoms mediate the relationship between expressive negative symptoms and social functioning in individuals with high clinical risk of developing psychosis (Schlosser et al., 2015). Furthermore, negative symptoms may be a prominent predictor of impaired social functioning among individuals in the more advanced phases of the illness (Weinberg, Shahar, Davidson, McGlashan, & Fennig, 2009).

Prior to the introduction of early intervention services it was estimated that approximately 15% of people with psychosis made a full or partial social recovery after two years, this rose to between 40-60% after these services were introduced (Fowler et al., 2018). There is evidence to suggest that persistent difficulties with social functioning, after early intervention for a first episode of psychosis, are associated with a complex array of problems including poorer engagement with services, anxiety and depression, and more treatment-resistant psychotic symptoms (Fowler et al., 2018). Persistent difficulties in these areas can lead to lifelong social withdrawal (Kam Shi, Singh Swaran, & Upthegrove, 2013) and are associated with a poor long-term course of schizophrenia (Fowler et al., 2010). There is evidence to suggest that social functioning in particular is affected across the life span, with older clients (>age 50) with schizophrenia shown to have poorer functioning compared to younger adults and same-age peers with bi-polar disorder (Martin, Ongur, Cohen, & Lewandowski, 2015). This decline in social functioning may be further impacted by co-occurring neurocognitive deficits commonly seen in people with schizophrenia; which too tends to worsen (Cohen et al., 2008; Mueser et al., 2010).

Furthermore social functioning has been cited as being an important feature of recovery and high priority for intervention among people with psychosis related diagnoses (Auslander & Jeste, 2002; Wood, Price, Morrison, & Haddock, 2010) . This evidence further highlights the importance of developing interventions that specifically target social functioning.

There is a growing body of research demonstrating the effectiveness of psychosocial interventions for improving functioning in patients experiencing psychosis (Kern et al., 2009; Pestana Santos & Amílcar Teixeira, 2016; Wykes, Steel, Everitt, & Tarrier, 2008). Wykes et al. (2008) meta-analysis reported that CBT had a mean weighted effect size of 0.38 on functioning. Indeed, NICE guidelines recommend psychological therapies, CBT and family therapy, in conjuncture with pharmacological treatment (NICE, 2014) for psychosis. However, despite evidence for the effectiveness of CBT on social functioning there are limitations. As Wykes et al. (2008) meta-analysis demonstrated the majority of RCTs reported effects on positive symptoms, with much fewer exploring other outcomes. As such, social functioning measures are not always included in research and are frequently secondary outcomes not the primary target for intervention. Further to this, the majority of evidence has been conducted in adult populations between the ages of 18-65, with comparatively limited attention focusing on the needs of older adults (Bartels & Pratt, 2009). This is important as, across a lifetime, the needs of older adults change alongside psychopathological, neuropsychological, social functioning and physical health changes (Berry & Barrowclough, 2009).

There is a need to establish the utility of psychosocial interventions on social functioning for older adults with schizophrenia as the longevity and number of this population

increases. This is essential in ensuring that we provide evidence-based and effective care to those most in need. The aim of this study was therefore to systematically review the effectiveness of psychosocial interventions for middle to older aged adults with non-affective psychotic disorders on social functioning.

## **Method**

### **Eligibility criteria**

Eligible criteria included: (i) publication in a peer-reviewed journal article, (ii) written in the English language, (iii) a quantitative methodology, (iv) evaluation of a psychosocial intervention, (v) a validated measure of social functioning, and (vi) participants with a diagnosis of a non-affective psychotic disorder aged 40 and above.

Studies were included that had examined participants with a *Diagnostic and Statistical Manual of Mental Disorders (DSM)* or *International Statistical Classification of Diseases and Related Health Problems (ICD)* diagnosis of any non-affective psychotic disorder or psychotic disorder not otherwise specified. Studies that had included people with severe mental illness (SMI) were eligible where the sample included a minimum of 20% of participants who had the aforementioned diagnoses.

Psychosocial interventions were defined as ‘*any intervention that emphasised psychological or social factors rather than biological factors*’ (Ruddy & House, 2005, p. 2). This definition allows for the inclusion of psychological interventions, health education, as well as interventions with a focus on social aspects, such as social support. Physical interventions which had included psychosocial components were not included, as the

intervention had a biological focus. Psychosocial interventions could be group or individual. Studies were excluded if they were case studies or of a qualitative design.

Social functioning can be defined as *'the interaction of an individual with their environment and the ability to fulfil their role within the environment. An individual functions daily within several environments: work, social and leisure, marital, parental, and with the extended family'* (Bosc, 2000, p. 63). Social functioning measures included in the review were defined as any measure relating to the frequency of, quality of, or satisfaction with social, academic or occupational activity. This may include socially useful activities, personal and social relationships and self-care.

### **Search Strategy**

Five databases (Medline, Web of Science, PsychINFO, Embase and CINAHL) were systematically searched from inception to December 2017. Words relating to each concept were combined using the OR operator for terms within a concept, and AND between concepts i.e. (psychosocial intervention) AND (older people) AND (psychosis). The full search strategy was initially developed for PsycINFO (*see Table.1*), then modified and dependant on specific databases.

This search resulted in 10,284 citations leaving 7,263 citations after duplicates were removed. Ten percent (n=726) were screened at title/abstract level by the lead author and an independent reviewer. A high level of agreement (98 % agreement,  $\kappa = 0.77$ ) was achieved, indicating good inter-rater reliability, and so the remaining titles and abstracts were searched by the lead author. The remaining 418 citations were screened at full text level against the specified inclusion criteria, with ten percent screened (n=42) by the



postgraduate student (88% agreement,  $\kappa=0.71$ ). Any discrepancies between raters were resolved through discussion until agreement was reached about their inclusion/exclusion. After full text articles were reviewed by the lead author, 401 articles were excluded for not meeting inclusion criteria, with agreement from the research team, resulting in 17 included articles (*see Figure 1. flow diagram*). Reference lists of papers meeting the inclusion criteria were also searched and any relevant papers were checked for eligibility.

### **Data Extraction**

Pertinent information about the studies was extracted including: (i) sample size and characteristics (ii) study design, (iii) intervention description, (iv) social functioning measure(s) used, (v) relevant statistics/findings and (vi) country. Authors were contacted for any additional information required.

### **Quality Assessment**

The quality of studies was assessed using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (*See Appendix B.*; Thomas, Ciliska, Dobbins, & Micucci, 2004) which has previously shown to have good reliability and validity (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012; Thomas et al., 2004). The lead author and a second reviewer independently rated all papers, with considerable agreement found for overall ratings (82% level of agreement,  $\kappa=0.69$ ). As above, discrepancies between raters were discussed until complete agreement was achieved.

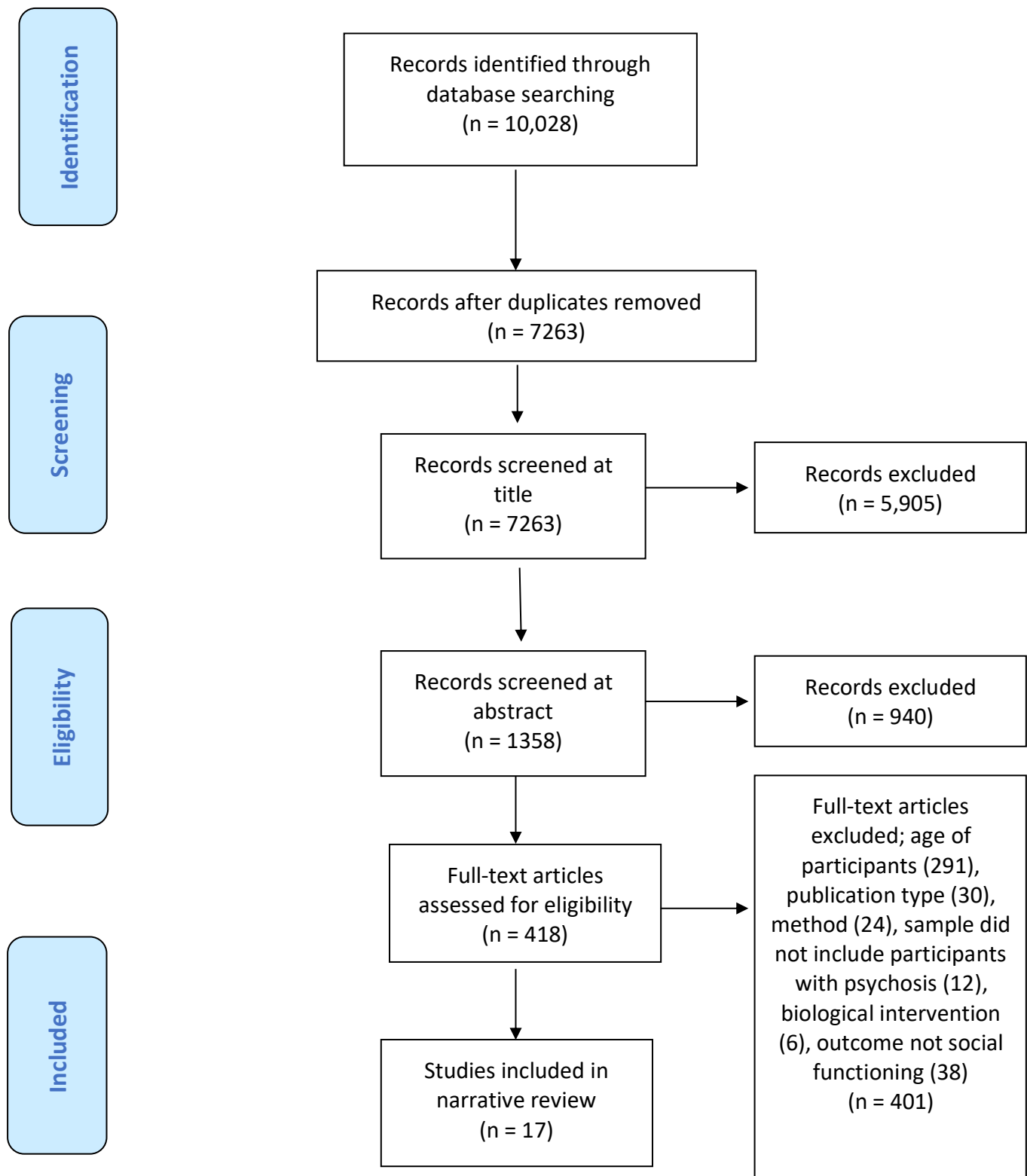
## Data Synthesis

There was a large degree of heterogeneity in the methodology of studies and type of social functioning measure used, and there were a limited number of eligible papers. Meta-analytic techniques were therefore not appropriate. A narrative synthesis of the literature was therefore conducted. Effect sizes of individual studies were calculated where possible.

**Table 1. : Search strategy tailored for PsycINFO**

<b>Keywords</b>		
<b>Psychosocial</b>	<b>Older adults</b>	<b>Psychosis</b>
psychotherap*	Old* adult*	Psychos*s
psycholog* ADJ3 (therap* OR intervention OR treatment)	Old* people	Psychotic
psychosocial ADJ3 (therap* OR intervention OR treatment)	Later life	Schizo*
counsel*	Elderly	Delusional disorder
Cognitive Behav* Therapy	Older person*	(chronic* OR serious* OR sever*) ADJ3 ((mental OR psycho*)ADJ1 (ill* OR disorder*))
CBT	middle age*	
non-pharmacologic*		
non-pharmaceutic*		
skills training		
social skills		
cognitive remediation therapy		
social support		
<b>MeSH terms</b>		
Group psychotherapy	Gerontology	Schizophrenia
Psychotherapy	Geriatrics	Psychosis
Counseling	Geriatric patients	
Cognitive Behavior Therapy	Aged "Attitudes Towards"	
Cognitive Therapy	Aging	
Online Therapy		
Computer assisted therapy		
Social Skills		
Social Skills Training		
Communication Skills Training		
Skill Learning		
Dialectical Behavior Therapy		
Psychosocial Rehabilitation		
Cognitive Rehabilitation		
Social support		
Mental health services		

**Figure 1. PRISMA diagram**



## **Results**

### **Study characteristics**

Seventeen articles, describing fifteen different studies, were included in the review. Three research groups (detailed below) represented eight of the fifteen studies and included articles were of their pilot studies, RCTs and follow-ups or adaptations of their interventions. Two studies were from Granholm and colleagues who developed the 'Cognitive Behaviour Social Skills Training' (CBSST) intervention (n=3). Three studies were from Patterson et al. who developed the Functional Adaptive Skills Training (FAST) intervention (n=3) and three studies were from Bartels and colleagues who developed the Helping Older People Experience Success (HOPES) intervention (n=4).

The study characteristics are presented in Table 1. Seven studies were randomised controlled trials (RCTs). Two studies were controlled trials, one was a matched pairs design, and the remaining five studies were within group pre-post test design. Most of the studies had small samples ranging from 10-79 participants .Two studies included larger sample sizes (n= 183-240). Nine studies included participants with SMI, which included people with schizophrenia, schizoaffective, and bipolar and major depression. Seven studies solely included participants with psychosis-related disorders. Types of intervention included were: multi component skills training (n=6), integrated mental & physical health interventions (n=5), cognitive remediation (n=1), role development (n=1), social support (n=1) and animal assisted therapy (n=1). Interventions were delivered in group (n=10) and individual (n=5) formats. The majority of studies were conducted in the USA (n= 13). Other countries of origin included the U.K (n=1) and Israel (n=1). Ten studies were delivered in clinical settings; three were delivered within the community and two studies were delivered across two sites; a research centre and community care facilities.

**Table 2. Study Characteristics**

Study	Country	Design	Sample	Intervention	Comparison group	Social functioning measure	Follow-up	Key Findings
<b>Skills training interventions:</b>								
Granholt et al. (2005) A Randomized, Controlled Trial of Cognitive Behavioral Social Skills Training for Middle-Aged and Older Outpatients With Chronic Schizophrenia	USA	RCT	n= 76 adults aged >40 with chronic schizophrenia. Schizophrenia (63%) schizoaffective (37%)	CBSST 24 x weekly 2hr sessions. The intervention integrates CBT and SST interventions and modifies these interventions for use with older patients with psychosis.	TAU	ILSS <sup>self</sup> UPSA	6M 12M	CBSST intervention group showed significant improvements on ILSS <sup>self</sup> measures as compared to TAU which were maintained at 12M (d=0.50, p<0.05). There was not a significant difference between groups on UPSA scores (d= 0.12).
Granholt et al. (2007) A Randomized, Controlled Trial of Cognitive Behavioral Social Skills Training for Older People With Schizophrenia: 12 Month Follow-Up								
Granholt, Holden, Link, McQuaid, and Jeste (2013) Randomized Controlled Trial of Cognitive Behavioral Social Skills Training for Older Consumers With Schizophrenia: Defeatist Performance Attitudes and Functional Outcome	USA	RCT	n= 79 adults aged >45 with schizophrenia or schizoaffective disorder. Schizophrenia (81%); schizoaffective (19%)	CBSST 36x 120 min group sessions. 3x 6 module sessions delivered twice over 9 months.	Goal-focused supportive contact (GFSC) 36x 120 min group contact sessions.	ILSS <sup>self</sup>	9M 13.5M	The CBSST intervention group showed significant improvements by 13.5M on ILSS <sup>self</sup> (d= 0.29 p=0.021) compared to GFSC group .Defeatist performance attitudes were shown to moderate these effects.

Patterson et al. (2003) Functional adaptation skills training (FAST): A pilot psychosocial intervention study in middle-aged and older patients with chronic psychotic disorders	USA	Pilot RCT	n= 40 adults aged >40 with psychosis related disorder. Schizophrenia (56%); schizoaffective (25%); mood disorder with psychotic features (19%)	FAST is a manualised behavioural group skills training intervention. It is a multi-component intervention covering 6 areas of functioning. 24 semi-weekly x 120 min sessions.	TAU	UPSA	12 W 24 W	FAST intervention group showed improvements on UPSA at 12W and at 24W follow-up (d= 0.11, p<0.0016) compared to TAU.
Patterson et al. (2006) Functional Adaptation Skills Training (FAST): A randomized trial of a psychosocial intervention for middle-aged and older patients with chronic psychotic disorders	USA	RCT	n= 240 adults aged > 40 with psychosis related disorders. Schizophrenia (80.6 %); schizoaffective (19.4%)	Same as above	Attentional control group (AC)	UPSA SSPA	24W	FAST group intervention showed improvements at 24W on: UPSA (d=0.32, p=0.046) & SSPA (d=0.48, p=0.003) compared to the AC group.
Patterson et al. (2005) Development and pilot testing of a new psychosocial intervention for older Latinos with chronic psychosis	USA	Pilot RCT	n= 29 adults aged with psychosis related disorders. Schizophrenia (57%) Schizoaffective Disorder 9 (43%)	The FAST program as outlined above was adapted for a Latino population 'PEDAL' and measures and materials were translated into Spanish by bi-lingual researchers and was modified to fit with culturally appropriate scenarios and roles etc.	Support group	UPSA SSPA	24W 12M 18M	PEDAL group intervention showed improvements at 24W (post-treatment) across UPSA scores (d=1.68, p=0.001) compared to the social support comparison group. There were no significant differences on UPSA scores between the groups at 6M (d=0.80) or 12M (d=0.32) There were no significant differences between the groups on SSPA scores at any time point (6M d= 0.75; 12M d=0.48)
Berry et al. (2014) A mixed-methods evaluation of a pilot psychosocial intervention group for	U.K	Pilot pre-post-test design	n=18 adults aged >55 with Schizophrenia (86%); schizoaffective – (14%)	Based on U.S manuals but adapted for U.K audience. 16 x 2hr weekly group sessions. Topics included strengths, goals, social skills, ADLS self-	n/a	ILSS <sup>self</sup> ILSS <sup>informant</sup> SBS	16W	No significant differences were found between pre and post measures of social functioning on: SBS (median= 40, U=-1.44, p=0.150); ILSS <sup>informat</sup> (median=3.29, U=-1.52, p=0.128)

older people with schizophrenia				care, increasing social contacts, planning and the future.				and ILSS <sup>self</sup> (median =0.74, U=-1.86, p=0.063).
Schindler (2008) Developing roles and skills in community-living adults with severe and persistent mental illness	USA	Pre-post-test design	n=10 adults aged >40 with SMI. Schizophrenia (80%).	Occupational therapy intervention. 9 x weekly sessions. Role Development (Schindler, 2004), a set of guidelines for clinical practice, has been developed to provide specific direction for health care practitioners to assist people diagnosed with severe and persistent mental illness to learn social roles and their underlying task and interpersonal skills.	n/a	Role functioning scale(RFS), task skills scale (TSS)and the interpersonal skills scale (ISS)	9W	Participant showed significant improvements on RFS (d=0.61, p=0.008), TSS (d= 0.63, p=0.50) and ISS scores (d= 0.84, p=0.045) post treatment.
Golas et al. (2015) Cognitive remediation for older community-dwelling individuals with schizophrenia: A pilot and feasibility study	Canada	Pre-post-test design	n=24 adults aged >60 with Schizophrenia or schizoaffective disorder (100%).	CR 8x2 hour weekly therapist guided session: (1) cognition for everyday functioning and cognitive strategies, (2) computerized drills targeting different cognitive domains, (3) monitoring to enhance metacognitive skills, and (4) how to generalise cognitive skills to daily life.	n/a	UPSA	8W	CR intervention group did not show any significant changes in social functioning post intervention on UPSA <sup>Total</sup> (d=0.23, p=0.34).
<b>Integrated mental and physical health interventions:</b>								
Bartels et al., (2004): Enhanced skills training and health care management for	USA	Pilot CT	n= 27 Adults aged > 60 with SMI. Schizophrenia	Multi-component skills training (ST): 2 x 1 hr weekly group sessions combined with a health maintenance intervention (HM)	HM intervention.	ILSS <sup>self</sup> SBS	1Y	ST+HM intervention group showed significant 1Y improvements on: ILSS <sup>self</sup> appearance (d= 0.63, p<0.10) & care of possessions (d= 0.84, p<0.05) and SBS <sup>SM</sup> measure d=0.78, p<0.10) as compared to the

older persons with severe mental illness	(54.2 %); schizoaffective (12.5 %); psychotic disorder (8.3%)	HM only control group. The control group showed no significant improvements on any measure of social functioning and scores significantly decreased for ILSS <sup>self</sup> care of possessions.
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Mueser, Pratt, Bartels, Swain, et al. (2010) Randomized trial of social rehabilitation and integrated health care for older people with severe mental illness.	USA	RCT	n = 183 adults aged > 50 with SMI. Schizophrenia (28%); schizoaffective (28%)	HOPES intervention. Multi-component social rehabilitation and health management alongside TAU. 1st year-weekly skills classes and 2x monthly 1:1 meetings with a nurse. 2nd year 1x monthly skills classes, community practice tips and meetings with nurse	TAU	UPSA, MCAS, SBS, ILSS <sup>self</sup>	1Y 2Y 3Y	HOPES intervention group significant improvements at 2Y on: ILSS <sup>total</sup> (d= 0.25, p=0.33); MCAS (d=0.26, p=0.024) and UPSA (d= 0.45, p=0.014) as compared to the TAU group.
Bartels, Pratt, Mueser, Forester, et al. (2014) Long-Term Outcomes of a Randomized Trial of Integrated Skills Training and Preventive Healthcare for Older Adults with Serious Mental Illness.								
Pratt, Mueser, Wolfe, Santos, and Bartels (2017) One Size Doesn't Fit All: A Trial of Individually Tailored Skills Training	USA	Pilot pre-post-test design	n= 47 adults aged > 50 with SMI. Schizophrenia (36%); schizoaffective (26%)	Adapted HOPES intervention for individual based program (HOPES-I). Weekly x 60 min 1:1 sessions. 5 modules were available with 10 core sessions delivered to all participants. Recommended min. 3 full modules over 12 months.	n/a	MCAS, ILSS <sup>self</sup> , SSPA, UPSA	3M 6M	HOPES-I intervention group (where participant had baseline deficits) showed significant improvements at 3M on MCAS post treatment (mean= 3.64 (0.38), t= 2.89, p=0.012) and at 6M on: ILSS <sup>LR</sup> (0.417 (0.16), F=14.31, =0.001); SSPA <sup>1</sup> (mean 3.3(1.1), F=19.88, p=0.002); SSPA <sup>2</sup> (mean= 5.0 (3.16), F=42.75, p<0.001) ; SSPA <sup>3</sup> (mean= 3.56 (0.58), F=31.01, p<0.001) and UPSA (mean=72.90(20.5), F=5.31, p=0.037)



Bartels et al. (2013) Activating older adults with serious mental illness for collaborative primary care visits	USA	Pilot pre-post-test design	n= 23 adults aged >50 with SMI and cardiovascular risk factors. Schizophrenia (41%); schizoaffective (18%).	Multi-component CAT-PC intervention. 9 x 90min group sessions delivered weekly over 2 months. Sessions were interactive skills training around physical health.	n/a	SSPA	6W	CAT-PC intervention was associated with significant improvement in patient overall communication performance (d= 0.66 p=0.02) and focus (d= 0.58 p=0.06). No other significant effects were found.
Bartels, Pratt, Mueser, Naslund, et al. (2014) Integrated IMR for psychiatric and general medical illness for adults aged 50 or older with serious mental illness	USA	RCT	n= 71 adults aged > 50 with SMI and chronic physical health condition. Schizophrenia spectrum (38%)	Integrated- Illness Management and Recovery (I-IMR). Multi-component intervention self-management skills training for psychiatric and general medical illness. 30 x weekly 1:1 sessions with IMR specialist and 15 biweekly sessions with nurse.	TAU	MCAS	10M, 14M	I-IMR intervention group did not demonstrate significantly improved MCAS scores as compared with TAU(d= 0.26, p=0.47).
<b>Other interventions:</b>								
Barak, Savorai, Mavashev, and Beni (2001) Animal-assisted therapy for elderly schizophrenic patients: A one-year controlled trial	Israel	CT	n=20 adults aged >70 with schizophrenia (100%)	Weekly 4 hr sessions of pet assisted therapy. Completed ADLs with animals and walked them outside hospital grounds. Session concluded with a summary session at end.	Group met to discuss current news	SAFE	6M, 12M	AAT intervention group showed significant improvements at 12M on: SAFE <sup>total</sup> scores (d=1.87, p=0.001) as compared to the control group. Within-group analysis showed that both AAT and control group improved on the instrumental and self-care subscale but this change was not statistically different between groups. AAT intervention group improved on SAFE <sup>total</sup> scores from baseline to 12M (p=0.001)
Gammonley (2006) A Lay Helper Intervention for Rural Elders with Severe Mental Illness	USA	Matched pairs design	n=10 adults aged >60 with SMI. Schizophrenia (20%).	A social support intervention. It was a 12-month program whereby lay helpers were trained to deliver support to older adult with SMI. Helpers	TAU	Leyman's QoL subscales: no. daily of activities and	-	Participants made significant improvements in daily activities from baseline to 6 months (mean 0.85(0.44), $\chi^2=4.92$ , p=0.23) this plateaued at 12 months and did not reach statistical significance. The number of non-

were paid to provide  
companionship and support in a  
rural community.

no. non-  
relative  
activities.

family social contacts decreased from  
baseline to 6 months, however increased  
towards baseline after 12 months  
(mean=2.90(0.91),  $\chi^2=6.22$ ,  $p=0.048$ ).

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Note: RCT= Randomised control trial; CT= controlled trial; SMI= severe/serious mental illness; CBSST=cognitive behavioural social skills training; FAST= functional adaptive skills training; PEDAL= Programa de Entrenamiento para el Desarrollo de Aptitudes para Latinos; CR= cognitive remediation; ST=skills training; HM=health management; HOPES=helping older people experience success; HOPES-I= helping older people experience success (individual format); CAT-PC= collaborative activation training for primary care; I-IMR=integrated illness management and recovery; AAT= animal assisted therapy; TAU= treatment as usual; GFSC= Goal-focused supportive contact; AC= attentional control group; ILSS<sup>self</sup>= independent living skills survey (self-report); ILSS<sup>informant</sup>= independent living skills survey (informant); ILSS<sup>LR</sup>= independent living skills survey (leisure and recreation subscale); UPSA= UCSD performance based skills assessment ; SSPA= social skills performance assessment ; SSPA<sup>1</sup>= social skills performance assessment (role play 1); SSPA<sup>2</sup>= social skills performance assessment(role play 2); SSPA<sup>3</sup>= social skills performance assessment( role play 3); SBS= social behaviour schedule; SBS<sup>SM</sup>= social behaviour schedule (social mixing subscale); RFS= Role functioning scale; TSS= task skills scale; ISS= interpersonal skills scale; MCAS= multnomah community ability scale; SAFE= social adaptive functioning evaluation; Leyman's QoL= Leyman's quality of life scale; ADLS= activities of daily living

## Measures of social functioning

Measures of social functioning varied across the studies (*Table 3.*). The most frequently reported measures were: the Independent Living Skills Survey (ILSS;  $n=8$ ; Wallace, Liberman, Tauber, & Wallace, 2000); USCD Performance-Based Skills Assessment (UPSA;  $n=8$ ; Patterson, Goldman, McKibbin, Hughs, & Jeste, 2001); the Social Skills Performance Assessment (SSPA ;  $n=4$ ; Patterson, Moscona, McKibbin, Davidson, & Jeste, 2001); the Social Behaviour Schedule (SBS;  $n=4$ ; Wykes & Sturt, 1986) and the Multnomah Community Ability Scale (MCAS;  $n= 4$ ; Barker, Barron, McFarland, & Bigelow, 1994). Functioning was measured from both self ( $n=9$ ), performance ( $n=10$ ), observer ( $n=5$ ) and informant perspectives ( $n=6$ ).

**Table 3. Description of social functioning scales**

Measure	Format	Description	Scoring
ILSS	Separate self-report & informant rated available	Measures 10 domains of basic functional living skills (e.g. self-care, leisure activities) performed during the past month.	Higher scores reflect better functioning. The self-report item scores ranges from 0–1. The informant-report measure item scores ranges from 0–4.
UPSA	Performance	Measures levels of capability of performing specific functional living skills via role play scenarios. It assesses five domains of functioning household chores, communication, finance, transportation, and planning recreational activities.	Higher scores reflect better functioning. Total score out of 100 (each subscale out of 20).
SSPA	Performance	Role-play test assessing communication skills of people with serious mental illness. Participants receive of two scenarios, followed by a 3 minute role play for each. The SSPA has also been adapted for use in a medical setting and which includes two further role plays, specific to this setting	Higher scores reflect better functioning. Rated on 5-point Likert scales of social appropriateness, ranging from 1 (low) to 5 (high).
SBS	Observational	Designed for completion by inpatient staff. Measures the severity of problematic behaviours, such as social avoidance, appropriateness of interactions, and manners	Higher scores reflect worse functioning. Scores range from 30 to 115, with Rated from 1-5.
MCAS	Informant rated	Measure of community functioning. It contains 17 items for four domains; interference with functioning, adjustment to living, social competence and behavioural problems.	Higher scores reflect better functioning.

## **Quality assessment**

See Appendix C. for full quality assessment details. Three studies were rated as having ‘strong’ quality (Patterson et al., 2003, 2006; Granholm et al., 2005, 2007); nine studies were rated ‘moderate’ (Barak et al., 2001; Bartels et al., 2004; Schindler, LaGuardia, Melchiorre, & Bailey, 2004; Patterson et al., 2005; Mueser, Pratt, Bartels, Swain, et al., 2010; Granholm et al., 2013; Bartels, Pratt, Mueser, Forester, et al., 2014; Bartels, Pratt, Mueser, Naslund, et al., 2014; Berry et al., 2014; Golas et al., 2015); and three were rated ‘weak’ (Gammonley, 2006; Bartels et al., 2013; Pratt et al., 2017). Six studies received a ‘weak’ rating for selection bias due to lack of detail about recruitment (n=1); participants self-referred (n=2); less than 60% of selected individuals consented to participate (n=5); or no details given about numbers who consented (n=1). Six studies were given ‘weak’ ratings for the blinding component due to not reporting if participants had been blind to the research questions (n=5) and assessors not being blind to participant group status (n=1). Of the eight studies which included control groups, six studies considered confounders between groups either in the design and/or analyses, and so were given ‘strong’ ratings for this criterion. Two studies received a ‘weak’ rating for confounders as they did not report controlling for confounders in their design or analyses. ‘Strong’ ratings were given to all the studies for data collection methods, as they used reliable and valid measures. All the studies (n=15) reported retention rates of > 60% at the final time point and received ‘strong’ (n=7) or ‘moderate’ (n=8) ratings for this criterion.

## **Interventions**

### **Skills Training**

Eight studies (n=9) examined different types of skills training among older adults with SMI. Six studies investigated multicomponent skills training groups (n= 7) and the other

two studies focussed on developing skills in one domain; cognitive remediation (Golas et al., 2015) and role development (Schindler et al., 2004). The FAST intervention was utilised in three studies (Patterson et al., 2003, 2005, 2006) and the CBSST intervention was used in two of the studies (n=3; Granholm et al., 2005, 2007, 2013).

Both FAST and CBSST are group-based skills training interventions that have been specifically adapted for middle to older age adults with SMI to accommodate age-related factors, such as increased cognitive impairment. The studies have included similar module topics targeting social functioning and independent living skills rather than psychiatric symptoms. Whilst Patterson et al. have primarily focused on teaching everyday living skills through a behavioural-based functional adaptation skills training intervention (Patterson et al., 2003, 2006), the CBSST program led by Granholm and colleagues has a greater focus on the use of cognitive behavioural therapy techniques in combination with social skills training (Granholm et al., 2005, 2007, 2013). Berry et al. (2014) U.K study ran a pilot group based intervention adapted from the U.S manuals. The group modules focussed on social and daily living skills and incorporated behavioural and cognitive techniques to bolster skill development and practice.

Six studies (Granholm et al., 2005, 2007, 2013; Patterson et al., 2003, 2005, 2006; Schindler et al., 2004) found significant effects of the intervention on social functioning reporting small to large effect sizes (0.11-1.68) which were maintained until long term follow-up (9-12 months; Granholm et al., 2007, 2013). Three of these studies were RCTs; one had a large sample (n= 240; Patterson et al., 2006) and the two were moderately sized (n= 76-79; Granholm et al., 2005, 2007, 2013), with 'strong' to 'moderate' quality ratings. Of the other studies to report significant effects, two were small feasibility pilot trials of

the larger RCT (n=29-40; Patterson et al., 2003, 2005) and one was a one group pre-post design (n= 10; Schindler et al., 2004) both of which had small sample sizes and so findings are not generalisable.

The large RCT (Patterson et al., 2006) reported significant improvements in performance based measures of social functioning (UPSA & SSPA) as compared to TAU and an attentional control comparison group, whilst the smaller RCTs (Granholm et al., 2005, 2007, 2013) did not find statistically significant differences on UPSA scores. However, Granholm et al. did report significant improvement in self-reported measures of social functioning (ILSS).

The two studies that did not find significant effects of intervention on social functioning (Berry et al., 2014; Golas et al., 2015) were both pilot feasibility studies so sample size was very small (Berry et al., 2014; n=7; Golas et al., 2015; n= 17) and they were underpowered to detect small effects.

### **Integrated mental and physical health interventions**

Five studies (n= 6) have developed psychosocial rehabilitation programs for older adults with SMI, which focus on the improvement of physical health skills either solely (Bartels et al., 2013) or in combination with skills training around mental health (Bartels et al., 2004; Bartels, Pratt, Mueser, Forester, et al., 2014; Bartels, Pratt, Mueser, Naslund, et al., 2014; Mueser et al., 2010; Pratt et al., 2017). The premise of these interventions are based on evidence that, alongside functional disabilities, older adults with SMI frequently have physical health co-morbidities which are often exacerbated by poor health maintenance (Druss, Bradford, Rosenheck, Radford, & Krumholz, 2001). Three studies reported on the

effectiveness of the HOPES intervention both in group (n=2) and individual (n=1) format. HOPES is an intensive 2 year program combining weekly social and health skills training groups with monthly 1:1 meetings with a nurse. This has been adapted for individuals (HOPES-I) in which only five of the seven HOPES modules are offered, individuals can select to partake in different modules based on preference. The Integrated- Illness Management and Recovery (I-IMR) intervention is a 1:1 intervention which combines a traditional self-management program with psychiatric self-management skills. Lastly, the Collaborative Activation Training for Primary Care (CAT-PC) is a group based intervention which solely focusses on physical healthcare management for people with SMI.

Four studies (n=5) found significant improvements in social functioning, reporting small to large treatment effects (0.26-0.84). One study (Bartels, Pratt, Mueser, Naslund, et al., 2014) did not find a significant effect of treatment on social functioning. However it was a feasibility study and sample was small (n= 71) which may have increased the likelihood of type ii error. It also received a 'moderate' quality rating as participants were recruited via self and clinician referral and the % of participants agreeing to take part was not reported, therefore selection bias was more likely.

Of the four studies (n=5) that reported significant results; one study was an RCT (n=2), one was the pilot study to the RCT and the other two studies were a pre-post design. All papers were rated as having a 'moderate' quality (Bartels et al., 2004, 2013; Bartels, Pratt, Mueser, Forester, et al., 2014; Mueser et al., 2010; Pratt et al., 2017). The RCT (n=183; Bartels, Pratt, Mueser, Forester, et al., 2014; Mueser et al., 2010), found improvements across a range of social functioning measures at both 2 and 3 year follow-up. These

findings were replicated across participants enrolled in another study which adapted the same intervention in an individual rather than group format (Pratt et al., 2017). In contrast to the RCT, the two pre-post-test design studies (Bartels et al., 2013; Pratt et al., 2017) measured social functioning using a performance measure of social skills (SSPA) specifically adapted to include assessment of participants' communication in a medical setting. Both studies found significant improvement in scores of social skills performance following intervention. One of the studies (Pratt et al., 2017) found significant changes to participant's performance across subscales measuring social skills and the 'reporting physical symptoms'. The other study (Bartels et al., 2013) only reported changes in regards to 'overall communication' and 'focus' but did not report significant findings in relation to any of the medical communication skills. However, this was a pilot feasibility study and underpowered to detect small effects (n=17).

## **Other**

### ***Social support***

One study (Gammonley, 2006) looked at the effects of social support (*see Table 2.*) on leisure activities and non-relative social contacts (Lehman's Quality of Life subscales). They used a matched pair design to compare participants receiving social support from companions. However, due to attrition in the comparison group, only within-group analysis was possible. They found a significant increase in daily activities from baseline to six months but this plateaued at 12 months and did not reach statistical significance. The number of non-family social contacts decreased from baseline to 6 months, although the authors reported that by 12 month follow-up this increased returning towards the baseline score. Without the results from the control group it is not possible to fully interpret the decline in social contacts. This study was, again, a very small sample (n=10) and insufficiently powered to detect small effects, thus increasing the likelihood of type ii



error. It was rated as ‘weak’ quality due to poor uptake of invited participants and not being able to ascertain if assessors were blinded to group assignment.

### ***Animal assisted therapy***

One study (Barak et al., 2001) assessed the effects of animal assisted therapy (AAT) on inpatients with chronic schizophrenia. The AAT intervention involved 4 hour weekly session whereby participants cared for the animals (i.e. grooming, petting etc.) and walked the animals within the hospital grounds. The study benefited from a comparison control group that met for a ‘current news’ group for an equivalent amount of time as the AAT group. The Social- Adaptive Functioning Evaluation (SAFE) was used to evaluate social functioning and consists of questions evaluating; social-interpersonal, instrumental and life skills functioning. Results suggested that, compared to the control group, the AAT group improved on ‘overall’ SAFE scores at 6 months ( $d=1.87$ ). The authors conducted within group analyses on separate components of the SAFE which further showed significant improvement on social factor scores in the AAT group from baseline to six months. These results were maintained at the end of the study (12 months).

Whilst the study reports preliminary evidence for AAT, it had a very small sample size ( $n=20$ ) and so the results are not generalisable. Further to this the study only assessed participants at mid and end of treatment points, so it is not possible to ascertain the long-term effects post intervention.

## **Discussion & Implications**

The aim of this systematic review was to examine the effects of psychosocial interventions on the social functioning of middle to older aged adults with psychosis. Seventeen papers representing 15 studies were identified. Broadly, these studies found improvements in social functioning for this population across the range of interventions examined, with lasting effects ( $d=0.11-1.87$ ).

The literature suggests that skills training, in particular multi-component groups may be an effective intervention for the improvement of social functioning in mid to older aged adults with psychosis. However, evidence from the higher quality RCT studies are mixed in terms of which aspects of social functioning are improved. Whilst the FAST intervention RCT reported improvement across performance measures of social functioning, this was not replicated for the CBSST intervention group, which instead only report improvements in social functioning on self-report measures that have a greater risk of response bias (Arnold & Feldman, 1981). The two CBSST studies were also much smaller than the FAST RCT and, although power calculations were not reported, are likely to have been underpowered to detect small effects.

The lack of consistency in social functioning measures was evident across the studies included in the review. Seven studies only included one measure of social functioning; two reported self-report measures, three reported performance measures, and two reported observer measures of social functioning. Eight studies included multiple measures of social functioning, which may be useful in evaluating the effect of treatment across different aspects of social functioning. The disparity of the inclusion of different measures is problematic within the literature as different measures have varying focuses, which is

reflective of the fact that there is not currently a definitive definition of social functioning. Some of the measures focus on ability or capacity to engage in life activities (ILSS<sup>self</sup>,UPSA) , whereas other measures focus on more interpersonal aspects of social functioning (SBS, SSPA) some even reporting on specific subscales within these measures. Findings should therefore be taken cautiously, as different interventions may have differing effects on more specific aspects of social functioning. Future studies would benefit from consistently using a range of measures covering these different aspects, and has previously been cited as an issue within the literature(Burns & Patrick, 2007).

Studies evaluating integrated physical and mental health interventions were shown to be effective in improving social functioning in older adults with SMI, both in group and individual formats. These effects were maintained into long term follow-up (six months-three years). However, of the five studies included in the review, four were pilot or feasibility studies which had small sample sizes and were underpowered or of less robust study designs. The largest RCT (n=183; HOPES intervention) reported promising effects of a physical and mental health intervention across self-report, performance and observer measures of social functioning. The findings were further replicated in a separate trial evaluating its effectiveness adapted for individual format, however as aforementioned, this study was a pilot study and it did not include control group for comparison.

There was encouraging preliminary evidence from the study of animal assisted therapy for improving social functioning in older adults with enduring schizophrenia. However, these results cannot be overstated, given the sample size used in the study (n= 20). Furthermore, the sample were all older adult inpatients with ‘chronic schizophrenia’ and so recruitment and participation may have been easier to regulate, and these findings may not be

replicable in other settings for example to other diagnostic and clinical groups. Indeed, evidence from a recent review (Kamioka et al. 2014) of AAT in various populations was unable to make definitive conclusions and recommended higher quality, larger scale research in this area.

In contrast to the interventions reported in the review, current NICE (2014) guidance reports that CBT has an effect on social functioning for treating adults with psychosis (Wykes et al., 2008; NICE, 2014), yet the findings of the current review suggest that there is no definitive evidence that this is true for an older adult population. There is evidence to suggest that adaptations are required to optimise CBT for older people (Evans, 2007) as was utilised by Granholm and colleagues in combining CBT techniques with social skills training. However, the CBSST intervention is in group format and targeted barriers to social functioning (i.e. negative attributions) rather than wider idiosyncratic therapy goals. There is some indication in the literature that individuals with low social functioning (Berry & Barrowclough, 2009) may benefit more from individual therapy.

### ***Methodological Limitations of Studies***

Eight of the fifteen studies included in this review were pilot or feasibility studies. Consequently, these studies had less robust designs with smaller sample sizes, which meant some were underpowered to detect significant effects or, when statistically significant results were reported, the findings may not generalise to the wider population. Additionally, of the four RCTs, two had small sample sizes (n=76-79; Granholm et al., 2005,2007,2013). Smaller sample sizes may reflect the challenges and barriers associated with recruiting participants with psychosis (Ridda, MacIntyre, Lindley, & Tan, 2010), especially older adult populations (Cassidy, Baird, & Sheikh, 2001). Contrary to this

notion, two studies had larger sample sizes ranging from 183 (Bartels, Pratt, Mueser, Forester, et al., 2014; Mueser et al., 2010) to 204 (Patterson et al., 2006).

Studies evaluating interventions had different eligibility criteria, used different types of control group (three used comparable control groups, the rest used TAU), varied in the amount of sessions offered (eight to 36 sessions) and had different follow up periods; all which may impact on effect size and outcomes. Another limitation was that the majority of the included studies were conducted in the United States and only one has been adapted for other populations (Patterson et al., 2005), thus may be open to cultural bias and not generalisable to other countries. In addition to this, there are further implications for the utility of these interventions in other countries outside of the U.S, especially as social functioning is a broad concept and may differ cross-culturally, which in turn may affect types of interventions which are developed and offered. For example, social skills training for psychosis is a more established treatment in the U.S (Kern, 2009) than in the U.K whereby NICE guidance (2014) recommends CBT. This may also be reflected in the use of measures of social functioning that include more independent living skills (i.e. self-care, leisure activities) rather than interpersonal domains, which appear to be more common place in U.S research.

### ***Limitations of current review***

The current review has a number of limitations. Firstly, it excluded studies not written in the English language and grey literature. It is possible that some evidence may have been missed. In particular, studies which do not report significant findings are less likely to be published; the so called ‘file drawer’ problem (Spellman, 2012). The search terms did not include terms for experiential domains of negative symptoms for example asociality etc.

which potentially overlap with social functioning measures and hence may have limited the literature available to the review. As there is a limited amount of research looking at older adult populations with psychosis, the review included patients with severe mental illness, including bipolar disorder, increasing the heterogeneity of the included samples. As previously mentioned, many of the studies were small pilot studies and so the proportion of people with a psychosis related disorder was sometimes limited (Bartels, Pratt, Mueser, Naslund, et al., 2014; Gammonley, 2006) as such the findings of these studies may be less pertinent for this population.

Another limitation of the current review is the use of a quality assessment tool. The use of quality assessment tools allows for comparison of studies and the evaluation of study methodology. Nevertheless, the use of a quality assessment tool inevitably involves a degree of subjectivity in the rating process (Higgins, Altman, & Sterne, 2011). Whilst, the EPHPP can be applied to a wide range of studies, it is best suited to rating RCTs and does not take sample size into account in the final quality rating. As some of the sections were not relevant to pre-post design studies (i.e. confounders between groups) the tool was modified to include 'n/a' as an option. As such, smaller, less robust study designs were scored on fewer components and some achieved 'strong' or 'moderate' ratings comparable to some of the RCTs which had a stronger design. Due to these challenges, the quality assessment ratings should be interpreted cautiously.

### ***Clinical & Research Implications***

The clinical implications are necessarily tentative given the limitations of the available literature. Existing research has indicated the benefits of FAST, CBSST and HOPES interventions. These studies have suggested that skills training, mostly in a group format,

can be an effective way of improving social outcomes for older people. However, there is a lack of research evaluating the evidence for using recommended or better established interventions in ameliorating social functioning difficulties for this group of older people.

There are yet to be any studies on NICE recommended treatments for psychosis (CBT and family therapy) that have evaluated the effectiveness on social functioning with older people, in terms of individual therapy. The lack of research with older adults therefore represents an important gap in the literature. Fowler et al. (2017; 2018) have developed 'social recovery therapy' which is an adapted form of CBT. It has been shown to be an effective treatment in improving functioning and increasing structured activity for people with psychosis (Fowler et al., 2017, 2018). Family therapy may also be useful for this population in Pharoh et al.'s (2006) Cochrane review they suggested that family therapy may be effective in helping with social impairment, however these results were limited to an adult population and further research is required to make any recommendations in this regard.

In general, further research with more robust designs is warranted to determine which elements of the above or current interventions work for older people with psychosis and for whom they work best. Future research should also specify if participants have experienced early or late onset psychosis, as the features and experiences of people with these diagnoses may qualitatively differ, which in turn could impact the effectiveness of interventions for these groups of people (Yeon & Hong, 2007). These studies should also concentrate on using consistent measures, larger sample sizes, cross-cultural validation and RCT designs to assess effects of intervention on social functioning.

## *Conclusions*

This is the first review to summarise studies investigating social functioning in psychosocial interventions for middle to older aged people with psychosis. The findings from this review suggest that future research needs to include more RCT studies with large samples using multiple and consistent well-validated measures of social functioning.

Whilst there is some evidence to support the use of skills training interventions and integrated mental and physical health interventions, there is currently insufficient evidence to determine whether psychosocial interventions improve social functioning in middle to older aged adults with psychosis. Although a number of psychosocial interventions have demonstrated some benefits to social functioning, a large portion of the research is in its infancy, as is demonstrated by the proportion of pilot feasibility studies included in this review. The paucity of high quality research and inconsistency in how social functioning is conceptualised and measured also impedes interpretation of findings across studies. Further research with a strong emphasis on study quality, clearly defined outcomes and consideration of moderator variables is required to progress understanding and inform recommendations for clinical practice. Given that the overall population of older people is increasing, and that older people with psychosis represent a greater burden to the NHS (NICE, 2014) it is vital that the identification of effective, patient-centred interventions becomes a prominent research priority.



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## Appendix A: Author Guidelines for the Gerontologist



OXFORD  
ACADEMIC



### ***The Gerontologist***

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## **Instructions to Authors**

On this page:

- Introduction
- Aims and Scope of the Journal
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- Additional Policies and Considerations
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## **INTRODUCTION**

The Gerontological Society of America (GSA), the publisher of *The Gerontologist*, was founded in 1945 to promote the scientific study of aging, to encourage exchanges among researchers and practitioners from the various disciplines related to gerontology, and to

foster the use of gerontological research in forming public policy. The organization fosters collaboration between physicians, nurses, biologists, behavioral and social scientists, psychologists, social workers, economists, policy experts, those who study the humanities and arts, and many other scholars and researchers in aging. Through networking and mentorship opportunities, GSA provides a professional "home" for 5,500 career gerontologists and students at all levels. For more information about GSA, visit [geron.org](http://geron.org).

## AIMS AND SCOPE OF THE JOURNAL

*The Gerontologist*®, published since 1961, is a bimonthly journal of [The Gerontological Society of America](#) that provides a multidisciplinary perspective on human aging by publishing research and analysis on applied social issues. It informs the broad community of disciplines and professions involved in understanding the aging process and providing care to older people. Articles should include a conceptual framework and testable hypotheses. Implications for policy or practice should be highlighted. The Gerontologist publishes quantitative and qualitative research and encourages manuscript submissions of various types including: research articles, intervention research, review articles, measurement articles, forums, and brief reports. Book and media reviews, International Spotlights, and award-winning lectures are commissioned by the editors.

Please refer below to the Types of Manuscripts Considered for additional information about all types of manuscripts.

Due to the high volume of submissions, we are unable to offer pre-screening advice. Instead, please refer to the aims and scope of the journal to determine if *The Gerontologist* is a suitable journal for your work.

## TYPES OF MANUSCRIPTS CONSIDERED

All manuscripts submitted to *The Gerontologist* should address practice and/or policy implications.

**\*The word limits listed below include abstract, text, and references.**

Tables and figures are limited to 5 Word pages for all submission types except for Review Articles, for which 10 pages are allowed.

To manage the word and page counts, authors are encouraged to submit detailed methodology, tables, and/or figures as appendixes. If your manuscript is accepted, appendixes are available to readers online only.

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a. **Intervention Research.** An Intervention Research submission describes research that spans the trajectory from intervention development to implementation. Appropriate articles include rigorous early stage development, feasibility, or pilot studies of innovative practices, RCTs, studies of the transportability of efficacious interventions, community testing or trials, and tests of dissemination and implementation strategies. Submissions may be research article length (maximum of 6000 words for quantitative, 7000 words for qualitative or mixed methods), or brief reports (maximum of 2500 words; may be most appropriate for pilot studies). Successful submissions will have the following attributes: (a) a clear theoretical or conceptual framework supporting the intervention and/or the treatment development and implementation process, (b) for implementation research, a description of evidence from rigorous research that the intervention has efficacy, (c) methodological rigor, including clear articulation of the design and analyses, and (d) integration of implementation considerations regardless of research stage. For more information, please refer to the following editorial: Meeks, S. & Pruchno R. (2017). Practice Concepts Will Become Intervention Research Effective January 2017. *The Gerontologist*. 57(2), 151-152. doi: 10.1093/geront/gnw213

b. **Research Articles.** Research Articles present the results of original research. These manuscripts may be no longer than 6,000\* (7,000\* for qualitative studies) words. The word count includes; abstract, text and references. Tables and figures are limited to 5 Word pages. The text is usually divided into sections with the headings: Introduction, Design and Methods, Results, and Discussion and Implications. Subheadings may also be needed to clarify content. Research design and analysis procedures as well as implications for practice or policy must be clearly described.

**Qualitative Manuscripts:** Qualitative manuscripts should avoid the subheading "A Qualitative Study." See Schoenberg, N., & McAuley, W. J. (2007). Promoting qualitative research. *The Gerontologist*, 47(5), 576-577 and Schoenberg, N.E., Miller, E.A., and Pruchno, R., The Qualitative Portfolio at The Gerontologist: Strong and Getting Stronger. *The Gerontologist* (2011) 51(3): 281-284.

**Humanities and Arts:** Please refer to the following editorial for additional detail with these types of submission: Kivnick, H.Q. & Pruchno, R. (2011). Bridges and Boundaries: Humanities and Arts Enhance Gerontology, *The Gerontologist*, 51(2), 142-144.

c. **Review Articles.** The Gerontologist welcomes submissions of state-of-the-art Review Articles (e.g. systematic/scoping reviews, umbrella reviews) and/or in-depth synthesis methodology reviews (e.g. meta-analyses). Manuscripts should be limited to 8,000\* words. Authors are encouraged to use and include the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist when submitting the manuscript. Please make sure to upload the appropriate checklist and flow diagram with



your review (PRISMA checklist and flow diagram is available [here](#)). Note: It is permissible to add a column or space to the checklist that specifies where in the manuscript each component has been followed. Review Articles will be published online only (title would appear in a print issue Table of Contents for the journal, but the article would appear online only). Articles will go through our usual peer review and editing processes. They will receive a DOI, be searchable, and will be available electronically.

d. **Measurement Articles.** Measurement articles describe the reporting of sophisticated scale/instrument development procedures (6,000\* words; all scales must be freely available for use by researchers). Measurement articles will be published online only (title would appear in a print issue Table of Contents for the journal, but the article would appear online only). Articles will go through our usual peer review and editing processes. They will receive a DOI, be searchable, and will be available electronically.

e. **Brief Reports.** Brief reports are encouraged for significant and innovative papers that are not as long as full research articles, but are equivalent in quality. Manuscripts should be no more than 2,500\* words. The word count includes the abstract, text and references.

f. **Forum.** Timely scholarly review articles or well-documented arguments presenting a viewpoint on a topical issue are published in this section. Total length should be no more than 5,000\* words. The word count includes the abstract, text and references.

g. **On Film and Digital Media.** Please refer to the editorial "Launching 'On Film and Digital Media.'"

h. **Book Reviews.** Book reviews are published in an essay form. Reviews are prepared at the request of the Book Review Editor and are not guaranteed for acceptance prior to submission. Unsolicited book review essays are not accepted. Books for review should be sent to Jamila Bookwala, PhD, Book Review Editor, Office of the Provost, 219 Markle Hall, Lafayette College, Easton, PA 18042.

i. **Guest Editorials.** Upon occasion, the Editor-in-Chief will invite guest editorials. Unsolicited editorials are not accepted.

*The Gerontologist* does not publish obituaries, speeches, announcements of programs, or new product information.

Supplement issues of *The Gerontologist* are additional and externally funded issues. Please contact the editorial office at [tg@geron.org](mailto:tg@geron.org) for further information. *The Gerontologist* also publishes special issues, developed by the editors of *The Gerontologist* within our regularly scheduled bimonthly issues.

## FORMATTING

Manuscripts are to be submitted in Microsoft Word or a Word-compatible program at [ScholarOne](#). Manuscripts submitted in other formats will be unsubmitted and returned to the corresponding author for correction prior to editor review. Please DO NOT submit PDF versions of your manuscript submission materials. A peer-review title page will be created by the system and will be combined with the main document file into a single PDF document. This document will be used for the peer review process. Each table should be editable and in Microsoft Word or a Word-compatible program on a separate page at the end of the main document.

*The Gerontologist* uses APA style. General guidelines follow; for more detailed information, consult the [Publication Manual of the American Psychological Association](#) (6th ed.). Please see section TYPES OF MANUSCRIPTS CONSIDERED BY THE GERONTOLOGIST above for additional information about the types of submissions and word counts. Please read "[Editorial: Science or Fishing?](#)" for valuable information about manuscript preparation.

This journal has a double-blind review policy. Therefore, we require authors to submit TWO versions of the article file, anonymous and non-anonymous (see below for additional information). Please upload ONLY these two files, the anonymous and non-anonymous manuscript files. Include your tables and/or figures and appendices, if applicable, in these documents, following APA guidelines.

**Abbreviations:** Ensure that the use of abbreviations is clear and that each one is defined in the text at its first mention only.

**In-text References and Citations.** Refer to the [Publication Manual of the American Psychological Association](#) (6th ed.) for style and see the FORMATTING section above. References in text are shown by citing in parentheses the author's surname and the year of publication. Example: "... a recent study (Jones, 1987) has shown. ..." If a reference has two authors, the citation includes the surnames of both authors each time the citation appears in the text. When a reference has more than two authors and fewer than six authors, cite all authors the first time the reference occurs. In subsequent citations, and for all citations having six or more authors, include only the surname of the first author followed by "et al." Multiple references cited at the same point in the text are in alphabetical order by author's surname.

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## COMPONENTS OF THE MANUSCRIPT

**Cover Letter (Optional).** A cover letter is not required and is optional. It should explain how the manuscript is innovative, provocative, timely, and of interest to a broad audience, and other information authors wish to share with editors. Note: The cover letter for manuscripts will NOT be shared with reviewers.

**Title page.** A title page should be a completely separate page that includes the following:

- (1) Title of the manuscript, APA recommends that a title be no more than 12 words.
- (2) All authors' full name(s), affiliations, and email addresses.
- (3) The corresponding author should be clearly designated.

**Abstract and Keywords.** On a separate page, each manuscript must include a brief abstract. Structured abstracts for Research Articles, Brief Reports, and Intervention Research, Review Articles, and Measurement Articles submissions should be approximately 250 words (the web-based system will not accept an abstract of more than 250 words), and must include the following headings: **Background and Objectives, Research Design and Methods, Results, and Discussion and Implications.** Forum manuscripts must also include an abstract of about 200 words, but may be without structured headings.

Below the abstract, authors should supply three to five keywords that are NOT in the title. Please avoid elders, older adults, or other words that would apply to all manuscripts submitted to *The Gerontologist*. Note: Three keywords must be entered to move forward in the online submission process.

**Text.** The text of Research Articles, Brief Reports, and Intervention Research, Review Articles, and Measurement Articles submissions should follow the headings included in the structured abstract (see above Abstract and Keywords). Forum manuscripts should also be divided into headings, as appropriate for the submission. Articles may need subheadings within some sections to clarify their content. The Implications should not merely restate the results but should interpret the results and specify the policy and/or practice implications.

- (1) The word counts for the different types of publications considered by the Journal are

presented above and are inclusive of the abstract, text, and references.

(2) If manuscripts greatly exceed these word count limits, your manuscript may be returned to you for correction BEFORE the peer review process can begin. If you would like to appeal the word count limit for the text of the manuscript, permission must be granted by the Editor in Chief prior to submission. When submitting, please indicate in your cover letter that permission has been granted.

**Acknowledgment (Optional).** If the authors choose to include acknowledgments recognizing funders or other individuals, they should be placed on a separate page immediately following the title page. The self-identifying acknowledgments should be removed from the anonymous version of the manuscript.

**Conflict of Interest.** At the point of submission, each author should reveal any financial interests or connections, direct or indirect, or other situations that might raise the question of bias in the work reported or the conclusions, implications, or opinions stated – including pertinent commercial or other sources of funding for the individual author(s) or for the associated department(s) or organization(s), personal relationships, or direct academic competition. When considering whether you should declare a conflicting interest or connection please consider the conflict of interest test: Is there any arrangement that would embarrass you or any of your co-authors if it was to emerge after publication and you had not declared it?

As part of the online submission process, corresponding authors are required to confirm whether they or their co-authors have any conflicts of interest to declare, and to provide details of these. It is the corresponding author's responsibility to ensure that all authors adhere to this policy. If there is no conflict of interest, please include the statement: "We have no conflict of interest to declare."

**Funding.** Details of all funding sources for the work in question should be given in a separate section labeled "Funding." This should appear before the Acknowledgements section.

The following rules should be followed:

- The sentence should begin: "This work was supported by ..."
- The full official funding agency name should be given, i.e. "National Institutes of Health," not "NIH" (full RIN-approved list of UK funding agencies) Grant numbers should be given in brackets as follows: "[grant number xxxx]"
- Multiple grant numbers should be separated by a comma as follows: "[grant numbers xxxx, yyyy]"

**Agencies should be separated by a semi-colon (plus "and" before the last funding agency)**

- Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number "to [author initials]."

An example is given here: "This work was supported by the National Institutes of Health [AA123456 to C.S., BB765432 to M.H.]; and the Alcohol & Education Research Council [hfygr667789]."

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## Appendix B: Quality Assessment Tool

### QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES



#### COMPONENT RATINGS

##### A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 - 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

##### B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted time series
- 7 Other specify \_\_\_\_\_
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

**C) CONFOUNDERS**

**(Q1) Were there important differences between groups prior to the intervention?**

- 1 Yes
- 2 No
- 3 Can't tell

**The following are examples of confounders:**

- 1 Race
- 2 Sex
- 3 Marital status/family
- 4 Age
- 5 SES (income or class)
- 6 Education
- 7 Health status
- 8 Pre-intervention score on outcome measure

**(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?**

- 1 80 – 100% (most)
- 2 60 – 79% (some)
- 3 Less than 60% (few or none)
- 4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

**D) BLINDING**

**(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?**

- 1 Yes
- 2 No
- 3 Can't tell

**(Q2) Were the study participants aware of the research question?**

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

**E) DATA COLLECTION METHODS**

**(Q1) Were data collection tools shown to be valid?**

- 1 Yes
- 2 No
- 3 Can't tell

**(Q2) Were data collection tools shown to be reliable?**

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

**F) WITHDRAWALS AND DROP-OUTS**

**(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?**

- 1 Yes
- 2 No
- 3 Can't tell
- 4 Not Applicable (i.e. one time surveys or interviews)

**(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).**

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell
- 5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

**G) INTERVENTION INTEGRITY**

**(Q1) What percentage of participants received the allocated intervention or exposure of interest?**

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell

**(Q2) Was the consistency of the intervention measured?**

- 1 Yes
- 2 No
- 3 Can't tell

**(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?**

- 4 Yes
- 5 No
- 6 Can't tell

**H) ANALYSES**

**(Q1) Indicate the unit of allocation (circle one)**

community   organization/institution   practice/office   individual

**(Q2) Indicate the unit of analysis (circle one)**

community   organization/institution   practice/office   individual

**(Q3) Are the statistical methods appropriate for the study design?**

- 1 Yes
- 2 No
- 3 Can't tell

**(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?**

- 1 Yes
- 2 No
- 3 Can't tell



**GLOBAL RATING**
**COMPONENT RATINGS**

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

<b>A</b>	<b>SELECTION BIAS</b>	<b>STRONG</b>	<b>MODERATE</b>	<b>WEAK</b>
		1	2	3
<b>B</b>	<b>STUDY DESIGN</b>	<b>STRONG</b>	<b>MODERATE</b>	<b>WEAK</b>
		1	2	3
<b>C</b>	<b>CONFOUNDERS</b>	<b>STRONG</b>	<b>MODERATE</b>	<b>WEAK</b>
		1	2	3
<b>D</b>	<b>BLINDING</b>	<b>STRONG</b>	<b>MODERATE</b>	<b>WEAK</b>
		1	2	3
<b>E</b>	<b>DATA COLLECTION METHOD</b>	<b>STRONG</b>	<b>MODERATE</b>	<b>WEAK</b>
		1	2	3
<b>F</b>	<b>WITHDRAWALS AND DROPOUTS</b>	<b>STRONG</b>	<b>MODERATE</b>	<b>WEAK</b>
		1	2	3
				Not Applicable

**GLOBAL RATING FOR THIS PAPER (circle one):**

- |   |          |                            |
|---|----------|----------------------------|
| 1 | STRONG   | (no WEAK ratings)          |
| 2 | MODERATE | (one WEAK rating)          |
| 3 | WEAK     | (two or more WEAK ratings) |

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

- |   |   |
|---|---|
| 1 | Oversight                                 |
| 2 | Differences in interpretation of criteria |
| 3 | Differences in interpretation of study    |

**Final decision of both reviewers (circle one):**

- |   |          |
|---|----------|
| 1 | STRONG   |
| 2 | MODERATE |
| 3 | WEAK     |

## Quality Assessment Tool for Quantitative Studies Dictionary



The purpose of this dictionary is to describe items in the tool thereby assisting raters to score study quality. Due to under-reporting or lack of clarity in the primary study, raters will need to make judgements about the extent that bias may be present. When making judgements about each component, raters should form their opinion based upon information contained in the study rather than making inferences about what the authors intended. Mixed methods studies can be quality assessed using this tool with the quantitative component of the study.

### A) SELECTION BIAS

**(Q1)** Participants are more likely to be representative of the target population if they are randomly selected from a comprehensive list of individuals in the target population (score very likely). They may not be representative if they are referred from a source (e.g. clinic) in a systematic manner (score somewhat likely) or self-referred (score not likely).

**(Q2)** Refers to the % of subjects in the control and intervention groups that agreed to participate in the study before they were assigned to intervention or control groups.

### B) STUDY DESIGN

In this section, raters assess the likelihood of bias due to the allocation process in an experimental study. For observational studies, raters assess the extent that assessments of exposure and outcome are likely to be independent. Generally, the type of design is a good indicator of the extent of bias. In stronger designs, an equivalent control group is present and the allocation process is such that the investigators are unable to predict the sequence.

#### Randomized Controlled Trial (RCT)

An experimental design where investigators randomly allocate eligible people to an intervention or control group. A rater should describe a study as an RCT if the randomization sequence allows each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. If the investigators do not describe the allocation process and only use the words 'random' or 'randomly', the study is described as a controlled clinical trial.

See below for more details.

#### *Was the study described as randomized?*

Score YES, if the authors used words such as random allocation, randomly assigned, and random assignment.

Score NO, if no mention of randomization is made.

#### *Was the method of randomization described?*

Score YES, if the authors describe any method used to generate a random allocation sequence.

Score NO, if the authors do not describe the allocation method or describe methods of allocation such as alternation, case record numbers, dates of birth, day of the week, and any allocation procedure that is entirely transparent before assignment, such as an open list of random numbers of assignments.

If NO is scored, then the study is a controlled clinical trial.

#### *Was the method appropriate?*

Score YES, if the randomization sequence allowed each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. Examples of appropriate approaches include assignment of subjects by a central office unaware of subject characteristics, or sequentially numbered, sealed, opaque envelopes.

Score NO, if the randomization sequence is open to the individuals responsible for recruiting and allocating participants or providing the intervention, since those individuals can influence the allocation process, either knowingly or unknowingly.

If NO is scored, then the study is a controlled clinical trial.

#### **Controlled Clinical Trial (CCT)**

An experimental study design where the method of allocating study subjects to intervention or control groups is open to individuals responsible for recruiting subjects or providing the intervention. The method of allocation is transparent before assignment, e.g. an open list of random numbers or allocation by date of birth, etc.

#### **Cohort analytic (two group pre and post)**

An observational study design where groups are assembled according to whether or not exposure to the intervention has occurred. Exposure to the intervention is not under the control of the investigators. Study groups might be non-equivalent or not comparable on some feature that affects outcome.

#### **Case control study**

A retrospective study design where the investigators gather 'cases' of people who already have the outcome of interest and 'controls' who do not. Both groups are then questioned or their records examined about whether they received the intervention exposure of interest.

#### **Cohort (one group pre + post (before and after))**

The same group is pretested, given an intervention, and tested immediately after the intervention. The intervention group, by means of the pretest, act as their own control group.

#### **Interrupted time series**

A study that uses observations at multiple time points before and after an intervention (the 'interruption'). The design attempts to detect whether the intervention has had an effect significantly greater than any underlying trend over time. Exclusion: Studies that do not have a clearly defined point in time when the intervention occurred and at least three data points before and three after the intervention

#### **Other:**

One time surveys or interviews

### **C) CONFOUNDERS**

By definition, a confounder is a variable that is associated with the intervention or exposure and causally related to the outcome of interest. Even in a robust study design, groups may not be balanced with respect to important variables prior to the intervention. The authors should indicate if confounders were controlled in the design (by stratification or matching) or in the analysis. If the allocation to intervention and control groups is randomized, the authors must report that the groups were balanced at baseline with respect to confounders (either in the text or a table).

### **D) BLINDING**

(Q1) Assessors should be described as blinded to which participants were in the control and intervention groups. The purpose of blinding the outcome assessors (who might also be the care providers) is to protect against detection bias.

(Q2) Study participants should not be aware of (i.e. blinded to) the research question. The purpose of blinding the participants is to protect against reporting bias.

**E) DATA COLLECTION METHODS**

Tools for primary outcome measures must be described as reliable and valid. If 'face' validity or 'content' validity has been demonstrated, this is acceptable. Some sources from which data may be collected are described below:

Self reported data includes data that is collected from participants in the study (e.g. completing a questionnaire, survey, answering questions during an interview, etc.).

Assessment/Screening includes objective data that is retrieved by the researchers. (e.g. observations by investigators).

Medical Records/Vital Statistics refers to the types of formal records used for the extraction of the data.

**Reliability and validity can be reported in the study or in a separate study. For example, some standard assessment tools have known reliability and validity.**

**F) WITHDRAWALS AND DROP-OUTS**

Score **YES** if the authors describe BOTH the numbers and reasons for withdrawals and drop-outs.

Score **NO** if either the numbers or reasons for withdrawals and drop-outs are not reported.

Score **NOT APPLICABLE** if the study was a one-time interview or survey where there was not follow-up data reported.

The percentage of participants completing the study refers to the % of subjects remaining in the study at the final data collection period in all groups (i.e. control and intervention groups).

**G) INTERVENTION INTEGRITY**

The number of participants receiving the intended intervention should be noted (consider both frequency and intensity). For example, the authors may have reported that at least 80 percent of the participants received the complete intervention. The authors should describe a method of measuring if the intervention was provided to all participants the same way. As well, the authors should indicate if subjects received an unintended intervention that may have influenced the outcomes. For example, co-intervention occurs when the study group receives an additional intervention (other than that intended). In this case, it is possible that the effect of the intervention may be over-estimated. Contamination refers to situations where the control group accidentally receives the study intervention. This could result in an under-estimation of the impact of the intervention.

**H) ANALYSIS APPROPRIATE TO QUESTION**

Was the quantitative analysis appropriate to the research question being asked?

An intention-to-treat analysis is one in which all the participants in a trial are analyzed according to the intervention to which they were allocated, whether they received it or not. Intention-to-treat analyses are favoured in assessments of effectiveness as they mirror the noncompliance and treatment changes that are likely to occur when the intervention is used in practice, and because of the risk of attrition bias when participants are excluded from the analysis.

#### Component Ratings of Study:

For each of the six components A – F, use the following descriptions as a roadmap.

##### **A) SELECTION BIAS**

**Good:** The selected individuals are very likely to be representative of the target population (Q1 is 1) and there is greater than 80% participation (Q2 is 1).

**Fair:** The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); and there is 60 - 79% participation (Q2 is 2). 'Moderate' may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can't tell).

**Poor:** The selected individuals are not likely to be representative of the target population (Q1 is 3); or there is less than 60% participation (Q2 is 3) or selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).

##### **B) DESIGN**

**Good:** will be assigned to those articles that described RCTs and CCTs.

**Fair:** will be assigned to those that described a cohort analytic study, a case control study, a cohort design, or an interrupted time series.

**Weak:** will be assigned to those that used any other method or did not state the method used.

##### **C) CONFOUNDERS**

**Good:** will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); or (Q2 is 1).

**Fair:** will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) and (Q2 is 2).

**Poor:** will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) and (Q2 is 3) or control of confounders was not described (Q1 is 3) and (Q2 is 4).

##### **D) BLINDING**

**Good:** The outcome assessor is not aware of the intervention status of participants (Q1 is 2); and the study participants are not aware of the research question (Q2 is 2).

**Fair:** The outcome assessor is not aware of the intervention status of participants (Q1 is 2); or the study participants are not aware of the research question (Q2 is 2).

**Poor:** The outcome assessor is aware of the intervention status of participants (Q1 is 1); and the study participants are aware of the research question (Q2 is 1); or blinding is not described (Q1 is 3 and Q2 is 3).

##### **E) DATA COLLECTION METHODS**

**Good:** The data collection tools have been shown to be valid (Q1 is 1); and the data collection tools have been shown to be reliable (Q2 is 1).

**Fair:** The data collection tools have been shown to be valid (Q1 is 1); and the data collection tools have not been shown to be reliable (Q2 is 2) or reliability is not described (Q2 is 3).

**Poor:** The data collection tools have not been shown to be valid (Q1 is 2) or both reliability and validity are not described (Q1 is 3 and Q2 is 3).

##### **F) WITHDRAWALS AND DROP-OUTS - a rating of:**

**Good:** will be assigned when the follow-up rate is 80% or greater (Q1 is 1 and Q2 is 1).

**Fair:** will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) OR Q1 is 4 or Q2 is 5.

**Poor:** will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q1 is No or Q2 is 4).

**Not Applicable:** if Q1 is 4 or Q2 is 5.

## Appendix C: Quality Assessment Ratings

*Appendix .Table of EPHPP quality ratings*

Author	Selection bias	Design	Confounders	Blinding	Measures	Retention	Global rating
Bartels et al. 2004	M	S	S	W	S	S	Moderate
Mueser et al. 2010	W	S	S	M	S	M	Moderate
Bartels et al. 2014	W	S	S	M	S	M	Moderate
Bartels et al. 2013	W	M	N/A	W	S	M	Weak
Bartels et al. 2014	W	S	S	M	S	M	Moderate
Pratt et al. 2017	W	M	N/A	W	S	M	Weak
Patterson et al. 2003	M	S	S	M	S	S	Strong
Patterson et al. 2006	M	S	S	M	S	S	Strong
Patterson et al. 2005	M	S	W	M	S	S	Moderate
Granhholm et al. 2005	M	S	S	M	S	M	Strong
Granhholm et al. 2007	M	S	S	M	S	S	Strong
Granhholm et al. 2013	W	S	S	M	S	M	Moderate
Berry et al. 2014	M	M	N/A	W	S	M	Moderate
Schindler 2008	S	M	N/A	W	S	S	Moderate
Golas et al. 2015	M	M	N/A	W	S	M	Moderate
Gammonley 2006	W	M	S	W	S	S	Weak
Barak et al. 2001	M	S	W	M	S	S	Moderate

*Note: W, weak; M, moderate; S, strong. n/a, not applicable for study design. Each domain was rated either 'weak', 'moderate' or 'strong'. Papers were assigned an overall rating of 'strong' (no 'weak' domain ratings), 'moderate' (one 'weak' domain rating) or 'weak' (more than one 'weak' domain rating).*

## **Paper 2: Exploring what it means to be ‘ageing well’ with psychosis: a thematic analysis**

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Author Note: This research was submitted to the University of Manchester for the degree of Doctor of Clinical Psychology (ClinPsyD)

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Total word count: 8668 (excluding abstract, tables, figures, bibliography and appendices)



**Abstract:**

**Background and Objectives:** With an increasingly ageing population it is imperative to better understand how best to support older aged adults with psychosis to age well. So far, much of the literature on ‘successful ageing’ has precluded this population from being defined as such. This study aimed to explore mid to older aged adults’ views about ageing well and how best to support this.

**Research Design and Methods:** Semi-structured interviews were conducted with sixteen participants (age 50-74) who were diagnosed with psychosis related disorders (i.e. schizophrenia). An inductive thematic analysis approach was used to analysis the data.

**Results:** Four themes were identified (i) engaging with life- continuing to or participating in activities that bring satisfaction and value; (ii) attitude to life and ageing- having a positive attitude and acceptance to overcome challenges in life and ageing ; (iii) maintaining wellbeing- keeping physically and mentally fit and able as is possible and having a sense of security and (iv) having good relationships- both personally and professionally, feeling heard and understood by others.

**Discussion and Implications:** The findings suggest that people can consider themselves to be ageing well with psychosis. The findings add to the existing literature on successful ageing, suggesting the importance of relationships with professionals, developing a mastery over their mental health difficulties and the continued impact of stigma on ageing well for people with psychosis. Therapeutic approaches that target these domains may therefore help this population to age well.

**Key Words:** Psychosis; Schizophrenia; Ageing well; Successful ageing; Qualitative



## **Background & Objectives**

It is estimated that the prevalence of people living with psychosis in the U.K is 31.7 per 100,000 person-years, with an ageing population means that the proportion of adults over 55 years is likely to double in the next 20 years (Cohen et al., 2008). The needs of older people with psychosis are distinct from younger populations (Berry & Barrowclough, 2009), especially in regards to specific age related issues that arise (Granholm et al., 2005). For instance older adults tend to have persistent neurocognitive deficits, which can impact on their social functioning. There is therefore a major need to understand how to support these older people to ensure they have opportunity to age well. There is an increasing focus on improving quality of life throughout the life course, which is reflected in the literature on 'successful ageing', yet, there is no clear definition of what it means to be ageing well (Cosco, Prina, Perales, Stephan, & Brayne, 2014).

One of the most prominent models of successful ageing is Rowe and Kahn's (1987) three-part biomedical model. This operationalised successful ageing as: the avoidance of disease and disability; the maintenance of cognitive and physical functioning; and continuation with social engagement. Criticism of this model argues that it: (i) does not capture the social factors that influence ageing (Riley, 1998); (ii) has disparity with self-report measures of successful ageing (Strawbridge, Wallhagen, & Cohen, 2002) and (iii) limits the number of older adults who are defined as ageing well to those with near-perfect health (McLaughlin, Connell, Heeringa, Li, & Roberts, 2010). As such, this model would not recognize people living with chronic mental health conditions as having the potential to age successfully.

More recent models of successful ageing have highlighted the need to include lay person perspectives into models of successful ageing (Martinson & Berridge, 2015). The inclusion of lay perspectives can add insights that may be otherwise overlooked by researchers, and is argued to lead to higher quality, more practically relevant and valid, models (Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998). A recent review of studies exploring lay person perspectives found the concept of successful ageing to be more multifaceted than proposed by Rowe and Kahn's biomedical model, and to focus much more on psychosocial (e.g. acceptance & engagement) and external factors (e.g. finances) than biomedical components (e.g. longevity). Furthermore, many of the components of successful ageing identified by laypersons could be applied to more practical interventions to aid individuals in old age (Cosco, Prina, Perales, Stephan, & Brayne, 2013).

Whilst there have been attempts to give voice to lay perspectives of successful ageing, there are still 'missing voices' within the literature (Martinson & Berridge, 2014), one of which is people with severe mental health conditions, such as psychosis related disorders. This is particularly important given that older adults with these conditions have significantly lower quality of life compared to age-matched peers (Folsom et al., 2009), and lower life expectancies than the general population (Chang et al., 2011; Laursen, Nordentoft, & Mortensen, 2014). Indeed, some have even suggested that schizophrenia may be considered a syndrome of accelerated ageing (Kirkpatrick, Messias, Harvey, Fernandez-Egea, & Bowie, 2007). Together with the fact that these adults are also amongst the least likely to access services (Wuthrich & Frei, 2015), this shows the importance of understanding how this population defines successful ageing, so that the right kind of support can be offered.

The aim of the current study was therefore to explore what ageing well means to mid to older age adults who have lived with psychosis throughout their lives and how this can be better promoted and supported.

## **Research Design & Methods**

### **Participants**

A convenience sample of participants were recruited via older adult and adult community mental health teams (CMHT), day centres and relevant community groups across Greater Manchester. Participants from an existing research project at the University of Manchester, who had given their consent, were also contacted about participating in the current study. Participants were eligible for the study if they (i) were age 50 years old and above, (ii) had a diagnosis of schizophrenia or psychosis related disorder that had been received prior to the age of 40, and had been confirmed by a medical professional, (iii) were capable of providing informed consent and (iv) had sufficient cognitive capacity and English language proficiency to take part in qualitative interviews. The lower limit of 50 years was used because life expectancy within this population is on average lower than in the general population (Laursen et al., 2014) and can be argued that ‘older age’ could be considered earlier than in the general population, and therefore reflected in our inclusion criteria. Purposive sampling was used to recruit people across a range of age brackets to account for variability across the sample. Participants were identified as eligible by clinicians in mental health services. Diagnosis and other eligibility criteria were confirmed by care coordinators via corroboration with the electronic note system.

## **Ethical approval**

Ethical approval was granted by the Greater Manchester East Research Ethics Committee (ref: 219388; *see Appendix A.*), and the study was registered with the relevant NHS Trust Research and Development Department

## **Procedure**

Once written informed consent (*see Appendix B.*) was obtained, participants were interviewed. A semi-structured topic guide (*see Appendix C.*) containing open-ended questions was used. This provided a consistent framework across interviews, whilst allowing for unexpected themes and leads (Maxwell, 1996). The interviews aimed to elicit participants' views on their opinions and experiences on ageing well and how this has been supported, or not, within services. For example, participants were asked to describe people who they did or did not consider to be ageing well. Given the increased likelihood of cognitive impairment within this population questioning approaches were adapted (i.e. shorter sentences) to facilitate comprehension (Bronken & Kirkevold, 2013; Luck & Rose, 2007). The topic guide was also piloted with a member of the University's community liaison group (CLG) who met inclusion criteria for the study to ensure questions and language were acceptable and accessible. Participant interviews were digitally recorded for the purpose of data analysis and lasted on average 42 minutes (range 20-90 minutes). Participants were reimbursed with a £10 high street voucher for taking part in the study.

## **Data analysis**

Interviews were transcribed verbatim, and analysed using thematic analysis (Braun & Clarke, 2006). An inductive thematic analysis was used to identify common themes.

Transcripts were systematically coded before initial themes were identified (*see Appendix*

D.). Themes were then reviewed and allocated appropriate names (Braun & Clarke, 2013). The first author undertook the initial analysis, which was finalised through discussions within the research team. The analysis was an iterative process whereby the first author and members of the supervisory team reviewed the codes, themes and data throughout to ensure the trustworthiness and rigor of the findings (Krefting, 1991).

## **Results**

### **Demographics**

Sixteen participants were recruited (*Table 1.*). Their ages ranged from 50 to 74 years old (mean age= 61). Fourteen participants had received a diagnosis of schizophrenia (n=13) or schizo-affective disorder (n= 1), the remaining two participants had a diagnosis of 'psychosis not otherwise specified'. The mean age of onset was 22 years old and average number of hospitalisations of seven (range= 1-20). A slight majority of the sample were male (56%), with all but one being from a white British ethnic background. Two participants were in active employment, and one worked voluntarily. The rest of the participants described themselves as unemployed (n=2) or retired (n=11). Nearly half of the participants identified themselves as being single (44%) All the participants were taking an antipsychotic medication (31% clozapine), with a majority (63%) taking at least one other psychiatric medication. Nine participants were recruited from community health teams (CMHT) via their care co-ordinator, five were recruited from an existing research project and two were recruited via self-referral from a local support group. Nearly all participants (n= 15) were currently receiving support from a CMHT.

**Table 1. Participant demographics**

<b>Demographics (n=16)</b>	<b>Total</b>
Age, <i>mean (range, SD)</i>	61 (50-74, 8.32)
Gender, (n, %)	
Male	9 (56%)
Female	7 (44%)
Ethnicity, (n, %)	
White British	15 (94%)
Black British	1 (6%)
Diagnosis, (n, %)	
Schizophrenia	13 (81%)
Schizoaffective	1 (6%)
Psychosis NOS <sup>b</sup>	2 (13%)
Age of onset, <i>mean (range, SD)</i>	22 (11-30, 4.92)
No. hospitalisations, <i>mean (range, SD)</i>	7 (1-20, 6.14)
Education (highest level), (n, %)	
Secondary	7 (44%)
A-Level	2 (13%)
College	4 (25%)
Undergraduate degree	2 (13%)
Postgraduate degree	1 (6%)
Marital status, (n, %)	
Single	7 (44%)
Married	3(19%)
Common Law Partner	2(13%)
Divorced	4 (25%)
Received psychotherapy, (n, %)	
Yes	12 (75%)
No	4 (25%)
Psychiatric Medication <sup>a</sup> , (n, %)	
Atypical antipsychotic	12 (75%)
Clozapine	5 (31%)
Typical antipsychotic	5 (31%)
Anti-depressants	6 (38%)
Anxiolytics	5 (31%)

*Note: <sup>a</sup> % values do not add up to 100 as some participants were taking more than one medication, <sup>b</sup>Psychosis not otherwise specified*

## Thematic analysis

Four themes and 10 sub-themes were identified (*see Table 2.*), and are described in more detail below. Additional quotes to support each theme are in Appendix E.

**Table 2. Main themes and sub themes**

Main theme	Sub-theme
Engaging with life	Activity
	Valued role & purpose
Attitude to life and ageing	Positive attitude
	Acceptance
Maintaining wellbeing	Mastering mental health
	Physical health
	Cognitive health
	Sense of security
Having good relationships	Professional relationships
	Being heard & understood

### Theme 1: Engaging with life

#### *Activity*

Participants recognised remaining active as an important element to ageing well. Activity types varied across participants, from organised activities and courses, to mental health groups, and more physical activities, such as rambling. People reported reasons for engaging with activities included keeping busy, enjoyment and satisfaction, bringing, meaning into their life, and for a sense of social connection. Nearly all participants (n=14) cited that going to groups facilitated having a connection with other people (outside of their relatives) or to the community, which kept people ageing well.

*'I enjoyed it there because... I like interacting with other people, erm, that social connection with people ...'* (Participant 9, male, age 70-75)

Six participants valued these activities because they were a space in which they could meet other people with a shared experience of mental health difficulties.

*'The Mindfulness does [keep me ageing well]. Because you've got similar people you know with the same problems'* (Participant 12, male, age 50-55)

Yet some people spoke about the barriers to accessing the community and such activities, describing difficulties either getting out of the house or struggling with the pressure of having to engage with other people and not feeling able to engage with others.

*'[Community groups] Caused me too much stress relating to people you see...I've always had difficulties with personal relationships... it's one thing I would like to improve on [to be ageing well]'* (Participant 10, male, aged 65-70)

In comparison to the more organised activities, several participants described and placed more significance on continuing to perform everyday tasks as a sign of their functioning and a sense of “normality” as an indicator of ageing well. In line with this, nearly half of the participants spoke about maintaining the ability to do things as an indicator of ageing well and to continue to manage by themselves maintaining a certain level of independence (*see Appendix E*).



*'Um I think just being able to do the things that I used to do... [Thinking of someone ageing well] ...I suppose my husband... he was ill last year but that was the first time I've ever known him being ill. He's a lot older than me but he sort of he just seems able to keep doing things.'* (Participant 14, female, age 50-55).

### ***Valued role & purpose***

Some of the younger participants stated that having a job, and support to gain employment, was important to ageing well.

*'It's just I think I am doing okay I think I'm doing better than most in terms of I'm still studying ...I'm still interested I still love my job I'm still very interested in my job y'know what I mean I read latest research...'* (Participant 1, female, age 50-55)

Similarly, others suggested having had a past career and job satisfaction was key to 'successful ageing'.

*'...and having a successful life, past life, to be honest... [a successful past life involves]...well, if you're, if you're, getting a job you, you like, enjoy doing, you're happy in it...'* (Participant 9, male, age 70-75)

Many of the participants reported being unable to pursue or continue in careers because of their mental health difficulties. In light of this, they had pursued other roles, such as voluntary jobs, that gave their life meaning or purpose (*see Appendix E.*). In keeping with this was a point that six participants raised about being able to have a continued value by helping others, passing on knowledge and wisdom and the reward this has given to them.

*'I do like helping people in the sense of it, you know, pass on knowledge, and that satisfies me, that really does... I mean that's all you can do, you know ... I could never work again, you know....'* (Participant 11, male, age 60-65)

Other participants described a dilemma of wanting more from life to feel they were ageing better, but not knowing how to achieve this.

*'But I need something more out of life and I don't know how to get something more out of life sort of to get on a more successful keel.'* (Participant 13, female, age 70-75).

## **Theme 2: Attitude to life and ageing**

### ***Positive attitude***

A part of engaging with life involved a general attitude to living and ageing well. For some this was about making the most out of life, or being grateful for the things they had. Others described ageing well as being able to 'carry on' despite difficulties that may have occurred.

*'My sister is 70 odd now ... she's ageing very well...apart from having a few bones reset all took out of her spine and that and she has a new knee and everything. She does well. Well she does, she just carries on. There's nowt stopping her.'* (Participant 6, male, age 60-65)

Linked to having a positive attitude was the idea that ageing well was about being content with yourself or life: an inner sense of satisfaction and success.

*‘...and you’re not out there trying to be a go getter, ‘cos it’s actually internal you have to feel good, not what society call it... I feel settled in myself, and I’m successful, and that’s, that’s good, and that feels nice.’* (Participant 4, female, age 50-55)

Conversely, others posited that not holding a positive attitude and letting bitterness or hate consume you was for some the epitome of not ageing well.

*‘ [people who aren’t ageing well] become embittered... they become mean individuals and they become less somehow...I know a lady in her 60s 70s probably early 70s just snarling in a corner lashing out ... There was just like I said they was just no love left I suppose. She was just this embittered husk of a woman.’*  
(Participant 1, female, age 50-55)

Two of the participants also felt that thinking about the future was not helpful and suggested living more in the moment or “one day at a time” was more important to ageing well.

*‘Well to me, success, age, ... I just go on my age as it comes. You can’t force the process, I mean, you can’t look at the future’* (Participant 15, male, age 55-60)

Some people also stated that successful ageing was being able to live life how *they* want.

*‘[asked about ageing well]...like, erm, have it all on my terms and not .. what people say ...’* (Participant 16, male, age 55-60)

However, many felt that because of their mental health difficulties this was restricted as, at least in part, their life and decisions were controlled or influenced by other people.

*'It's very difficult when they are so powerful to have your own life and lead it how you want to lead it ...My Psychiatrist sees me every six months anyway and wants to boss me around which I don't like I'm left with no alternative...'* (Participant 13, female, age 74).

### ***Acceptance***

Several participants reflected on what they may or may not have achieved in their life, and how their mental health may have affected this and in turn affected their ability to age well. Some spoke about coming to terms with or reaching a level of acceptance about their experiences. This acceptance was an element to them ageing well.

*'[what does ageing well mean?] I think about what your life's brought to you and coming to terms with that. And it's a kind of grieving process for what you may have had, when you've been mentally ill and if I hadn't have been mentally ill what could I have achieved?'* (Participant 1, female, age 50-55)

For others, reflecting on one's life was inextricably linked to comparing themselves to others without mental health difficulties and the differences and missed opportunities this had caused.

*'I'm lucky I have enough money to have my hair done if I want...but it's very much scraping the barrel when my sister has the best meat and everything that opens and shuts. And it's difficult not to be jealous of how this has brought me so low... She owns a house, I have a rented accommodation.'* (Participant 13, female, age 70-75).

Many participants posited an acceptance of physical or age related changes as a gauge of successful ageing. They suggested that not accepting these changes, or having a preoccupation with trying to be younger or more youthful, was detrimental to ageing well.

*'I know you get saddled with a few injuries here and there and ...everyone has their problems. They grow with it as in life. And the best part of that is that life can be a bitch at times like and you just have to deal'* (Participant 15, male, age 55-60)

However, many people described the importance of physical appearance, and felt that looking 'good' or 'younger' than your age was an indicator of ageing well, whereas physical signs of ageing or looking 'older' was a sign of poorer ageing (*see Appendix E.*).

*'Well, I know a couple who are my age, and who don't look it, and when I have seen 'em they look well, judging by appearance.'* (Participant 9, male, age 70-75)

For two of the participants, acceptance about ageing was linked to thinking about their mortality and preparing for death, predominantly without fear.

*'...I think um ageing and being inquisitive about death and getting older is kinda fairly key to be psychologically healthy'* (Participant 1, female, age 50-55)

### Theme 3: Maintaining wellbeing

#### *Physical health*

Most participants made reference to physical health being part of ageing well. Many also described having physical health problems, which impeded their successful ageing.

*'[do you think you're ageing well?] I'm not in my body state ...but it's my knees you see...I need brackets put on 'em, I can only walk for about five minutes have to sit down and rest.'* (Participant 4, female, age 50-55)

Despite not always being in good health, the majority of people spoke about having good fitness, and remaining physically able and active, as being important to ageing well.

*'I think I'm ageing well for me age... because I'm still fairly active you know I don't get too tired from walking or anything like that.'* (Participant 10, male, age 65-70)

For two of the participants ageing well, in regards to physical wellbeing, was more about looking after or caring about yourself enough to *want* to look after your health .

*'Well to have ill health and y'know erm let yourself go'* (Participant 6, male, age 65-70)

In line with this other people described themselves or others adjusting to their physical health problems to continue to age well with these difficulties.

*'I think of my Aunt who's a very successful person, who into her 86 87 she had a leg removed and she came to terms with that and she got herself a scooter she got herself a dog she was round the field round the back of the house 4 times a day you know.'* (Participant 1, female, age 50-55)

### ***Mastering mental health***

Participants also placed mental 'well-ness' as significant factor in ageing well. There was a paradox in that participants reported not feeling able to describe someone with mental health issues as ageing well (n=10), yet many described themselves as ageing well (n=11). For instance, participant 1 stated that she didn't feel ageing well was possible for most people with mental health problems, at least not to the same level as people without mental health issues:

*'I think that's a very difficult one because I think a vast majority don't really [age well]. Maybe I'm just being very negative but erm I think all the people that we see are or have been damaged in their childhood throughout life transitions I think all psychoses are all part of their personality damage or personality disorder...'*  
(Participant 1, female, age 50-55)

However she saw herself as an exception to this:

*'But I think I'm not doing too badly compared to my peers... I'm not your typical nutty person! You might say...'* (Participant 1, female, age 50-55)

People reported a variety of ways of coping, such as talking to other people, psychotherapy, learning different techniques and making sure they have good quality sleep. Several people described the continuous effort in managing their mental health, to ensure the maintenance of their mental stability (*see Appendix E.*). However, they also spoke about feeling more adept at coping with their mental health as they have aged, especially as they have learnt from their past experiences and what works for them.

*'No, well ... this journal is part of his ... techniques, the techniques he's used and it's meant to bring about inner growth of the person ...there's been so much inner growth that I wouldn't really call myself ill really now...I seem to be able to manage a lot better than I used to.'* (Participant 2, male, age 70-75)

However, other people felt that their illness had “progressed” as they got older. These participants often described the presence of symptoms impeding ageing well.

*'well successful ageing is, you just achieve... just ageing normally, but when you've got, erm, like a mental illness, erm, it goes a bit further on, in the sense that... I find it very, very hard, and I keep very much to myself, erm, because I'm getting older, erm, when I was younger, erm, I could cope with it much better than what I can do it now, you know'* (Participant 11, male, age 60-65).

Whilst, for many managing and coming to terms with their mental health was key to ageing well (*see Appendix E.*), for others there was an emphasis on a desire for an absence of any mental health issues or symptoms to categorise themselves as ageing well.



*'I think if I didn't have the voices it would be to get rid of the voices and to carry on living well without the voices.'* (Participant 12, female, age 50-55)

Nearly all participants were still involved in mental health services. For many, they felt this support was crucial in maintaining their mental health.

*'I suppose it's getting a lot of support from the nurses psychiatric nurses ...like some of the nurses used to take me out to various places you know and that's helped me a lot to keep me young...to age well.'* (Participant 10, male, age 65-70).

Many described that having this continued support in the background or “just in case” of crisis allowed them to continue to age well.

*'If I need to get in touch with anybody I get in touch with the crisis team so I've always got a backup plan you know when I'm not well.'* (Participant 12, female, age 50-55)

However, for some this was also a reminder that they will, perhaps, always need a certain level of additional support.

*'I can, now delegate how my illness is affecting me, and when they are called for it's for a real reason, and erm, part of me is very, very sad sometimes, that I need this help, but I need their care to get through the illness'* (Participant 4, female, age 50-55)

All participants were taking an anti-psychotic medication (*see Table 1.*). For many, medication was seen as a positive way of managing their mental health and providing stability to age well, with some even suggesting that medication was the best way to support people with psychosis to age well.

*'It just relaxes me the injection.'* (Participant 8, male, age 55-60)

Yet, for others whilst there was a degree of acceptance about 'needing' to be on some form of medication, this was not welcomed. This subset of participants described that in many ways anti-psychotic medications had been detrimental to ageing well by altering the ageing process in some way.

*'[thinking about someone who is not ageing well] ...well I don't think [X] is ageing well at all. But it's because of what he has to put up with. I mean mental health stops you ageing properly anyway that's the drugs and the psychiatric pills and what have you make you ten times worse in my opinion.'* (Participant 13, female, age 70-75)

### ***Cognitive health***

Alongside specific mental health issues, the concept of continued cognitive integrity was also discussed as being important to ageing well. In line with this, participants spoke about "keeping the mind active" as a means of staving off cognitive deterioration.

*'Keeping the mind active primarily... doing reading or colouring, doing maths puzzles things like that.'* (Participant 10, male, age 65-70)

For some there was a great deal of anxiety about losing their memory and developing dementia, which seemed to be for them an ultimate signifier of unsuccessful ageing.

*'I'm very worried about dementia, things like that, you know'* (Participant 11, male, age 60-65).

Alongside this risk of losing cognitive ability was a sense of losing any quality of life, living merely for death.

*'People in nursing homes where I see them where they are just completely cognitively wrecked and physically wrecked and they are just sitting there being fed and pooing out their bottom end and being cleaned up ... and you're there waiting and waiting and waiting for death really. Your quality of life is so reduced.'*

(Participant 1, female, age 50-55)

### ***Sense of security***

A sense of security across several aspects of life appeared to be integral to people's wellbeing and ageing well. This included feeling happy and secure within their current home environment, a personal feeling of safety, and also financial security.

*'when I got this house I got my head together for the first time in my life and so now it's peace of mind that I've got...Erm and here I'm alright now. I don't have my windows smashed or broken every day.'* (Participant 6, male, age 60-65)

Other people seemed to suggest that the best support to give older adults with psychosis was access to basic needs, without which any kind of wellbeing in ageing would not be possible.

*‘Keep ‘em busy and um well fed and they can't go wrong I suppose. There's not really much else...’* (Participant 7, male, age 60-65)

However, the presence of mental health problems that had often relapsed throughout their lives created a degree of uncertainty, and led to an often fragile sense of stability. For some, the possibility of relapse meant many areas of their lives were jeopardised, not just their mental health, but the security they had built in tangible terms in their lives.

*‘...I have lost my flat and all my property at a certain point in time... in the past but not in the recent part, and when that happened I felt that I can't let that happen again, so I have to look after my mental health, because once my mental health goes, everything, everything in here is at jeopardy straight away...’* (Participant 16, male, age 55-60)

#### **Theme 4: Having good relationships**

Participants also placed significance on the role of interpersonal relationships to the development and maintenance of successful ageing.

*‘[what does ageing well mean to you?] ...being surrounded with a loving family and friends ..and you're happy in relationship... and... you do the things you'd like*

*to do between you and help each other to get by the best way you can'* Participant 9, male, age 70-75)

These relationships were important to ageing well not least in part because of the support and understanding that a lot of the participants' families gave participants in regards to their mental health.

*'[How have family helped you to age well?] Give me plenty of support you know and understanding. Understanding the illness. I think they have got understanding about the illness really'* (Participant 10, male, age 65-70)

For some, family was their only source of social connection.

*'I haven't got many friends really, being indoors all the time. I've only got me family you know.'* (Participant 5, female, age 60-65)

It seemed that whilst those who had families often reported still having or looking forward to having a valued role as a grandparent (*see Appendix E..*), the absence of this opportunity was a reminder of a life they should or could have had, if their mental health difficulties had been different.

*'I'm single I haven't erm ever been married I've never had a child and you have to cope with your brother and sister having all the normal side life and you're stuck on your own with nothing'* (Participant 13, female, age 70-75)

Further to family relationships, many participants spoke about their friendships, and the importance of having a support network: people to ‘be there’ or ‘look out for’ them.

*‘...my friends...they, they keep a special eye on me, and I keep a special eye on them, erm, you know we gotta, we got a good system going, and if one of us drops or one of us, goes down, we all pick him up, or pick ‘em up, say, come on, off we go’* (Participant 11, male, age 60-65)

In contrast, other participants spoke about a real struggle throughout their lives to form relationships with others. These participants reflected that social isolation and loneliness was a reason for not considering themselves to be ageing as well.

*‘Well I have to socialise and I have to get... trying erm at the moment I’m being kept isolated... I want to be able to I’d like to be able to erm welcome people into me home and to be able to share what things I’ve got... I mean you could have a mansion and... if you’re the only person who goes in that mansion it’s a very lonely spot. Y’know you could have millions and still be alone. And erm that’s what I’ve found.’* (Participant 6, male, age 60-65)

### ***Professional relationships***

All participants spoke about the importance their relationships with mental health professionals for ageing well. For many, professionals had not only been a part of their lives for several years, but in the absence of other relationships, these professional relationships have provided people with much needed companionship with some even describing friendships with professionals.

*'I mean they've provided me with, I think, very often I felt very isolated and they, they used to come and give me company you know, a bit of moral support that sort of thing' (Participant 2, male, age 70-75)*

Good relationships with staff facilitated trust and honesty, and helped people to age well.

*'[Care Coordinator] he's just a really nice character. Obviously when he first started coming seeing me I weren't like I am now. So he's seen part of the worst...I kept doing things thinking I got to do this so [care coordinator] will be proud when he gets here. It's mad, innit? Sixty odd year old trying to make a fellow proud of you. But it works, and it changes. But he doesn't come as much now. So you tend to drop off again don't you?' (Participant 7, male, age 60-65)*

In contrast, a paucity of positive relationships with staff lead to dissatisfaction with the care people received and an increase in masking emotional distress and symptoms, for fear of mistreatment or unwanted repercussions. For these people not having positive relationships with staff, in some ways prevented them from ageing well.

*'[describing how staff have been unhelpful to ageing well] Well drugs number one. Not being able to talk to somebody that knows who knows what to do is two. Having very little time to talk over anything with him is three. Thinking he knows what he's talking about is four. And when there is nobody else to fall back on he thinks himself terribly clever. He doesn't help ageing well at all he's a stumbling block as far as I'm concerned.' (Participant 13, female, age 70-75)*

### ***Being heard and understood***

Many participants described situations where they had not been listened to and the effect this has had on their sense of ageing well.

*‘Well they’ve [services] not listened to me. For thirty years. And they still treated me like a paranoid schizophrenic when it was emotional trauma I was going through every day of my life... But what it was people that should have helped me in the I mean in a professional capacity let me down a bit.’* (Participant 6, male, age 60-65)

For this group of people, good relationships with friends and family, and with professionals, allowed them to be listened to, and also understood in terms of their experiences rather than just their diagnostic label. Nearly all participants cited “being understanding” or “listening to” as one of the main ways to facilitate ageing well.

*‘[Best way to support ageing well]... try to be understanding and listen to them...’*  
(Participant 16, male, age 55-60)

The majority of participants spoke about how stigma about mental health had affected their lives. Some of the older participants reflected on how this stigma had affected their ability to age well.

*‘oh, yes, made it more difficult [to age well], and people, they tend to be frightened of me, of what I don’t know .. probably ‘cos they, they’ve heard that, you know*



*certain mental illness, you know, mental illness people, they come out with knives and all that, you know, it's wrong...* (Participant 11, male, age 60-65)

Further to this, others spoke about how societal stigma becomes a “double whammy” in old age, in a society that isn’t perceived by participants to value older generations.

*‘And the lack of respect. It's been definitely the stigma of double whammy of the ageing and the psychosis is very hard for them to bear. I think for older people in particular the stigma is greater isn't it. Certainly for the over 65s they don't even tell you if they've been psychotic in the past they don't tell you.’* (Participant 1, female, age 50-55)

## **Reflexivity**

Reflexivity relates to sensitivity to the ways in which the researcher and the research process may shape the data collected, including the role of prior assumptions and experience and has been widely acknowledged as an important process within qualitative research (Berger, 2015). In the current study, all of the participants were aware that the research formed a part of the researcher’s training as a Clinical Psychologist. The first author was a white British woman in her late twenties and had not personally experienced psychosis. She had a professional interest in this area, although relatively little experience working with older adults experiencing non-organic psychosis. The second and third authors were a Clinical Psychologist and Health Psychologist respectively, with clinical expertise in working with adults and older adults with mental health difficulties and academic experience of qualitative research.

The researcher reflected on the age difference between them and the participants. Some of the participants commented on the researcher's age during the interviews and this may have caused some to feel reluctant to talk about certain aspects of their ageing. As a young woman, the researcher also wondered if this may have prevented some people talking about more taboo topics, for example sexuality and intimacy in older age. Further to this, a topic that was raised by the majority of participants regarded the effects of government austerity measures which had led to cut backs in mental health services. The researcher's professional background afforded them some experience of the effects of the cutbacks within services and it was something they felt strongly about. This made it more challenging to remain impartial throughout these discussions. The researcher was careful to remain mindful of their own biases and perspectives about the above issues, to remain impartial. The researcher also reflected on their own experience of working within current mental health services and, given the age of the participants, that it was likely they had experienced vast changes in societal understanding and stigma of mental health problems and in turn changes in mental health services as they have transitioned from more institutionalised facilities to community services. The researcher was aware of the history of mental health within society, however, hearing participant's stories of their experiences and mistreatments was very powerful and emotive to listen to. The researcher's professional background meant they were accustomed to responding empathically while listening and managing any distress. Whilst, the researcher was challenged to not go into a 'clinician' role during these times and remain caring yet impartial and curious about participants experiences, it also made them reflect on the importance of the role they held as a clinician to support and advocate for people who may not always be heard. The researcher gained feedback from supervisors throughout the analysis to ensure that both coding and themes were appropriate and not distorted by the researcher's interpretation and

direct quotes from participants were used to explicitly demonstrate how the findings were supported.

## **Discussion & Implications**

The aim of this study was to explore the meaning of ‘ageing well’ among middle and older age community dwelling adults who have lived with psychosis throughout their lives. Four themes were identified in the data. The first theme, ‘engaging with life’, described how participating with activities that bring satisfaction, meaning and value to life helped participants to age well. The theme ‘attitude to life and ageing’ outlined the importance of maintaining a positive attitude to ‘carry on’ and reach a level of acceptance about what life and age have brought. The third theme described how participants considered ‘maintaining wellbeing’ to be a key component of ageing well. This encompassed factors in regards to both mental and physical health, as well as having a sense of security with your life. The final theme illustrated how ‘having good relationships’ helped participants to age well. For these participants, this not only involved their personal, but their professional relationships.

As is consistent with much of the literature on successful ageing, (Dupuis & Alzheimer, 2008; Rowe & Kahn, 1987, 1997) participants described the importance of engaging with life to bring enjoyment and value to help them to age well. This involved both participation in more leisure type activities, as well as being able to manage more everyday tasks on their own. A longitudinal study of successful ageing has previously shown that these types of activities are related to happiness and function in older age, although more everyday activities were only associated with happiness (Menec, 2003). In the current study, these activities helped to bring meaning, enjoyment and a sense of social connection in people’s lives, which appeared to facilitate a sense of successful ageing particularly the ability to

continue to have a valued role into their older age. A unique reason that helped ageing well for this population was meeting other people with similar difficulties, and being around others who understood and accepted their mental health difficulties. One explanation for this is that being around others who understand and accept their difficulties may promote a sense of ‘social belonging’, which has previously been reported as a key domain of quality of life (Renwick & Brown, 1996).

Participants also spoke about the importance of accepting and adjusting to difficulties as being key to ageing well. Whilst participants spoke about how age or their mental health had impacted their ability to engage in life as they did before, which affected how well they perceived their ageing, many spoke about the value of accepting and adjusting to these changes, and reframing their current circumstances. Similar findings have been described in another study which examined successful ageing in people with chronic health conditions (Romo et al., 2013). Taken together, this suggests that when people cannot enter older age with the freedom of ‘chronic conditions’ their attitude can at least, in part, help them to feel as though they are ageing well.

Participants described other components of ageing well that are comparable to the current literature. For example, the maintenance of physical and psychological wellbeing, and having a sense of security (Bowling & Dieppe, 2005; Cosco et al., 2013, 2014), were reported as being important components of ageing well. However, the nuance of how people described these components revealed more unique findings. For example, participants more commonly described participating in health promoting behaviours as an indicator of ageing well and keeping physical fitness compared to complete freedom from physical health issues. In line with the higher rate of co-morbidities seen in older adults of

this population (Smith, Langan, McLean, Guthrie, & Mercer, 2013), many described that physical health difficulties were an aspect of their ageing which was less successful. Once again, participants described that having an acceptance of these difficulties helped them to continue to age well.

One of the disparities between this group and other literature related to the domain of mental health. As reported in other studies (Cosco et al., 2014), participants made reference to maintaining good mental health to qualify as ‘ageing well’. However, in this population, ageing well was conceptualised as a ‘mastery’ over mental health problems rather than a ‘freedom’ from them. For some people, this mastery had been achieved over years of learning about their illness and ways of coping with it. Whilst this knowledge was often seen as protective, the potential for relapse was also a reality. In the face of continued difficulties with their mental health, some participants still considered themselves to be ‘ageing well’ and described utilising the support of services, social support and positive attitude and acceptance of these difficulties to sustain this. Yet, others were unable to reconcile their circumstances and did not consider themselves to be ageing well. The pursuit of mental stability was not just a priority for people’s psychological wellbeing but, in fact, their financial and environmental security often depended on their ability to remain ‘well’. This ultimately left some participants with a fragile sense of security. This is important given that external factors such as financial security are known to contribute to perceptions of successful ageing (Cosco et al., 2013).

For this group, positive relationships and social networks were also integral parts of ageing well. This too has been described across the literature in other populations (Bowling & Dieppe, 2005; Gow, Pattie, Whiteman, Whalley, & Deary, 2007; Rowe & Kahn, 1987,

1997), reflecting the universality of this domain of successful ageing. Indeed, social networks and support have been shown to be strong predictors of life satisfaction in older age (Gow et al., 2007), and are associated with fewer hospitalisations and better functioning (Siette, Gulea, & Priebe, 2015), supporting the importance of these factors.

A more novel finding for this population was the importance placed on professional relationships to ageing well. For this particular group, relationships with professionals were more than just about the support or service they provide but the relationship they formed with them. Many described professional relationships providing genuine care; understanding and social connection when at times there was no one else. Clinicians should therefore be aware of the role that this relationship can have in facilitating successful ageing, adding to existing knowledge about importance of the therapeutic relationship to mental health outcomes (Ackerman & Hilsenroth, 2003). Good relationships with staff, family and friends also allowed people to be heard and understood, which many cited as the best way to support people with ageing well. This was seen as particularly important given the “double whammy” of stigma relating to mental health and ageism (Graham et al., 2003) that is associated with growing older with a mental health problem.

The literature from the adult population concerning living with psychosis, also provide an interesting comparison to the current study’s findings. For example, studies exploring service user perspectives have emphasised the role of ‘rebuilding life’ increasing social support and active participation to create a meaningful life (Pitt, Kilbride, Nothard , Welford & Morrison, 2007; Wood, Price, Morrison & Haddock, 2010; Law & Morrison, 2014). This could suggest the importance of these factors on wellbeing for people with

psychosis throughout the lifecourse as well as within ageing well. Stigma is an undeniable factor that affects people with psychosis irrelevant of age (Burke, Wood, Zabel, Clarke & Morrison, 2016). In younger adult populations the literature highlights that motivation for societal change and changing people's perspectives on mental health can be a key part of people's recovery (Pitt et al., 2007). For the current group of older adults, however, continued stigma appeared to be a hindrance to ageing well, not least in part because they also had to contend with ageism as they have grown older. As such, they spoke more passively about dealing with stigma rather than a drive to instigate change. This may be in part a generational difference as today's society is beginning to become more accepting of mental health difficulties. Lastly, the literature within the adult population suggests that learning to control symptoms of psychosis or accepting that mental health difficulties are part of the whole person are a key feature of living well with psychosis (Pitt et al, 2007; Wood et al., 2010; Law & Morrison, 2014) . Whilst, there are commonalities with the current study's findings there are also key differences, for example participants in the current study spoke more of a mastery over their mental health, which they had developed over many years. Additionally, for participants in this study acceptance appeared to be a much broader concept which reflected coming to terms with the experiences they had across their lifetime both in regards to mental health and the ageing process.

### ***Clinical & Research Implications***

These findings have important clinical implications, especially in helping service users to access support that may help them to age well. Some participants described barriers to engaging with activities, as highlighted by participant 10 (male, age 65-70) who described not feeling fully able to engage because of his social anxiety and the stress this caused him. Others described lacking motivation to engage in the things they used to. Interventions that

seek to ameliorate these difficulties in social functioning could therefore promote successful ageing in this population. One example of this is the integrated CBT and social skills training intervention which has been shown to be effective in improving social functioning in older people with SMI (Granholm et al., 2005, 2007; Granholm, Holden, Link, McQuaid, & Jeste, 2013). Interventions in adult populations with enduring mental health conditions have also sought to improve engagement by supported socialisation (Sheridan et al., 2015), social recovery therapy (Fowler et al., 2017, 2018) and Interpersonal Community Psychiatric Treatment (ICPT; Koekkoek et al., 2012) which utilised community nurses to engage service users by helping to build therapeutic relationships, develop goals using motivational interviewing techniques and increasing levels of activity. Future research is needed to establish if these or other interventions focusing on social functioning or engagement could help older generations.

As highlighted in theme 2 ‘Attitude to life and ageing’, acceptance of one’s circumstances had an important role in ageing well. Acceptance and Commitment Therapy (ACT), has as a core message: to accept what is out of your control, and commit to action that improves and enriches your life (Hayes, Strosahl, & Wilson, 2011). ACT has been successfully used with younger adults with schizophrenia (Bach, Hayes, & Gallop, 2012; Johns et al., 2016). Future research into how ACT could be adapted for older adults with psychosis may help to facilitate a positive attitude and acceptance both in regards to ageing and mental health difficulties. In regards to the sub-theme of ‘Physical Health’ one study in the U.S ‘Helping Older People Experiences Success’ (HOPES) has developed a multi-component skills training group which combines both psychiatric and physical health self-management training (Bartels et al., 2014). The HOPES group was associated with a greater acquisition of preventive healthcare. It may therefore be beneficial to include social skills and



education pertinent to physical co-morbidities in treatment plans with middle and older clients with psychosis to improve physical health outcomes.

Many of the participants spoke about the ongoing impact of stigma in their lives and the impact this continued to have on their ageing and others spoke about societal ageism affecting how ageing well is perceived. An interesting finding that arose was that often participants did not feel able to describe someone with mental health problems as ageing well, yet the majority of participants felt that they were ageing well, perhaps reflecting once again the “double” societal stigma of ageing with a mental health difficulty. That is, that it may be a pervasive societal expectation that people with mental health problems do not age well, despite this not necessarily being the perception of those with such difficulties. As a whole the participants often cited ‘looking younger’ as an indicator of ageing well perhaps reflecting societal believes the onus and culture of pressure to appear youthful. Future interventions and clinicians should be aware of this when working this population and potentially work with older people to challenge internalised stigma they may hold. Granholm et al.’s intervention also includes components focussed on challenging internal stigma, which could help to ameliorate the effects of stigma that participants described.

In spite of the importance placed on engagement with life and the support received by mental health services to ageing well, changes to health and social care and subsequent cuts has caused a disproportionate impact on older adult’s services (Humphries, Thorlby, Holder, Hall & Charles, 2016). In the last five years there has been a £160 million cut in total public spending on older people’s social care despite a rapidly increasing demand (NHS, 2016). These cutbacks to local authorities and services directly jeopardise

opportunities for people to obtain the level of support they not only require for daily life (Age U.K, 2017), but furthermore the services and support they need to achieve continued wellbeing in old age. In addition to this the decline in access to care places more pressure on family and unpaid carers, which could in turn disproportionately disadvantage older adults with psychotic disorders, who may be more likely to have smaller social networks and be socially isolated (Berry & Barrowclough, 2009).

Finally, whilst the current study focussed on exploring people with lived experience's opinions on ageing well future research could benefit from including other perspectives. It may be beneficial to recruit relatives or carers and mental health professionals to explore their opinions about how to better support people with psychosis to age well, or interview people with late onset psychoses. Indeed, further research is also warranted to specifically explore what ageing well means to older people from different cultures and minority groups, especially those who are at a higher risk of psychosis i.e. Black Afro-Caribbean.

### ***Study limitations***

There were some limitations to this study. Whilst there was diversity in terms of participant age, education, and social background, participants were recruited from one area of England, and the majority of the sample were ethnically white British. Therefore the findings may not be transferable to other ethnic groups. It was not possible to recruit any participants in an older age bracket (75+), which means that the voices of the oldest older adults are not heard. However, the current findings still provide valuable knowledge about the perceptions of ageing well in a younger old sample, which is particularly relevant given the lower life expectancies of older adults with psychosis (Chang et al., 2011; Laursen et al., 2014). Additionally, it has been recognised that member verification or

member checking is an important process in improving credibility and validity within qualitative research (Thomas, 2017), not including this within the current study therefore represents a key limitation of the study. Triangulation methods were not used due the limited scope of this study, however, the analysis was iteratively checked by members of the research team as a way of increasing the credibility and trustworthiness of the findings.

### ***Conclusion***

Older adults who experience psychosis can still perceive themselves as ‘ageing well’, by engaging with valued activities, developing a sense of acceptance, managing their symptoms and physical health, and maintaining good relationships with other people. Unlike previous work examining lay perceptions of successful ageing, participants also reported the importance of their relationships with professionals, developing a mastery over their mental health difficulties and the continued impact of stigma on ageing well. The findings of this study contribute to existing research, and offer key clinical implications about therapeutic approaches and future research that is needed to facilitate ageing well with this population. Importantly, the study has given a voice within the literature to those who often aren’t afforded this opportunity.

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## Appendix A: NHS ethics REC and HRA letters of approval



North West - Greater Manchester East Research Ethics Committee  
3rd Floor, Barlow House  
4 Minshull Street  
Manchester  
M1 3DZ

**Please note:** This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

27 March 2017

Ms Emily Smart  
Trainee Clinical Psychologist  
Manchester Mental Health and Social Care Trust  
2.01, 2nd Floor, Zochonis Building  
Brunswick Street  
M13 9PL

Dear Ms Smart

Study title: What does it mean to be 'ageing well' with psychosis?  
REC reference: 17/NW/0116  
Protocol number: 2  
IRAS project ID: 219388

Thank you for your emails of 16 March 2017 and 22 March 2017. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 07 March 2017

### Documents received

The documents received were as follows:

Document	Version	Date
Participant consent form	3	15 March 2017
Participant information sheet (PIS)	3	15 March 2017
Response to Additional Conditions Met [email]		16 March 2017

### Approved documents

The final list of approved documentation for the study is therefore as follows:

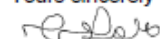
A Research Ethics Committee established by the Health Research Authority

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	2	18 January 2017
Copies of advertisement materials for research participants [Condensed Poster]	2	18 January 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		23 January 2017
GP/consultant information sheets or letters	1	16 December 2016
Interview schedules or topic guides for participants	2	18 January 2017
IRAS Application Form [IRAS_Form_09022017]		09 February 2017
Letter from sponsor		23 January 2017
Other [University Research Subcommittee Approval Letter]	1	21 November 2016
Other [Demographics questions]	2	18 January 2017
Other [Distress Protocol]	1	18 January 2017
Other [Protocol Disclosure of Risk]	2	18 January 2017
Participant consent form	3	15 March 2017
Participant information sheet (PIS)	3	15 March 2017
Research protocol or project proposal	2	18 January 2017
Response to Additional Conditions Met [email]		16 March 2017
Summary CV for Chief Investigator (CI)	1	13 December 2016
Summary CV for supervisor (student research) [Katherine Berry CV]		01 September 2015
Summary CV for supervisor (student research) [Laura Brown CV]		09 December 2016

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

17/NW/0116	Please quote this number on all correspondence
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Yours sincerely



**Rinat Jibli**  
REC Manager

E-mail: [nrescommittee.northwest-qmeast@nhs.net](mailto:nrescommittee.northwest-qmeast@nhs.net)

Copy to: Ms Lynne Macrae Ms Julia Foster, Manchester Mental Health and Social Care Trust

Ms Emily Smart  
Trainee Clinical Psychologist  
Manchester Mental Health and Social Care Trust  
2.01, 2nd Floor, Zochonis Building  
Brunswick Street  
M13 9PL

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

27 March 2017

Dear Ms Smart

**Letter of HRA Approval**

Study title:	What does it mean to be 'ageing well' with psychosis?
IRAS project ID:	219388
REC reference:	17/NW/0116
Sponsor	University of Manchester

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

## Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

## After HRA Approval

The document *“After Ethical Review – guidance for sponsors and investigators”*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

## Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

## User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.



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#### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 219388. Please quote this on all correspondence.

Yours sincerely

Beverley Mashegede  
Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: Ms Lynne Macrae, Sponsor Contact  
Ms Julia Foster, Lead NHS R&D Contact

## Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Contract/Study Agreement [Statement of Activities -Trust sites]		21 February 2017
Contract/Study Agreement [Statement of Activities -GP sites]		21 February 2017
Copies of advertisement materials for research participants [Poster]	2	18 January 2017
Copies of advertisement materials for research participants [Condensed Poster]	2	18 January 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		23 January 2017
GP/consultant information sheets or letters	1	16 December 2016
Interview schedules or topic guides for participants	2	18 January 2017
IRAS Application Form [IRAS_Form_09022017]		09 February 2017
IRAS Application Form XML file [IRAS_Form_09022017]		09 February 2017
IRAS Checklist XML [Checklist_09022017]		09 February 2017
Letter from sponsor		23 January 2017
Other [Schedule of Events - Trusts]		21 February 2017
Other [Schedule of Events - GP sites]		21 February 2017
Other [University Research Sub-committee Approval Letter]		21 November 2016
Other [Demographics questions]	2	18 January 2017
Other [Distress Protocol]	1	18 January 2017
Other [Protocol Disclosure of Risk]	2	18 January 2017
Participant consent form	3	15 March 2017
Participant information sheet (PIS)	3	15 March 2017
Research protocol or project proposal	2	18 January 2017
Response to Additional Conditions Met [email]		16 March 2017
Summary CV for Chief Investigator (CI)	1	13 December 2016
Summary CV for student [Emily Smart CV]	1	13 December 2016
Summary CV for supervisor (student research) [Katherine Berry CV]		01 September 2015
Summary CV for supervisor (student research) [Laura Brown CV]		09 December 2016

## Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

**For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.**

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Lynne Macrae

Tel: 01612755436

Email: [fmhsethics@manchester.ac.uk](mailto:fmhsethics@manchester.ac.uk)

### HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor intends to use a Statement of Activities as the form of agreement with the participating NHS organisations in England.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			research study.
4.3	Financial arrangements assessed	Yes	No application for external funding made. No funds will be provided to sites to support this study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	Favourable Opinion with conditions issued 07 March 2017.  Acknowledgement of conditions met issued 27 March 2017.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

## Participating NHS Organisations in England

*This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.*

This is a non-commercial student (Doctorate in Clinical Psychology - ClinPsyD) study and there is one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). The HRA will work with these organisations to achieve a consistent approach to information provision.

## Confirmation of Capacity and Capability

*This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.*

Participating NHS organisations in England will be expected to formally confirm their capacity and capability to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

## Principal Investigator Suitability

*This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).*

A Local Collaborator is expected at each participating organisation.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

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## HR Good Practice Resource Pack Expectations

*This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken*

Where arrangements are not already in place, network staff (or similar) undertaking any research activities that may impact on the quality of care of the participant, would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance. For research team members undertaking activities that do not impact on the quality of care of the participant (for example, administering questionnaires), a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

## Other Information to Aid Study Set-up

*This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.*

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

## Appendix B: participant consent form



### CONSENT FORM

Participant Identification Number for this study: .....

Title of Project: Ageing well with severe mental health difficulties

Please initial box

1. I confirm that I have read and understood the participant information sheet dated .....(version .....) for the above study and have had at least 24 hours to consider it and been given the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I give my consent for the interview to be audio-recorded and written out in full (transcribed).	
4. I give permission for direct quotes from my interview which do not identify me to be used in reports about the research.	
5. I agree to my healthcare team (where applicable) or GP being informed of my participation in the study.	
6. I understand that data collected during the study, may be looked at by individuals from The University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	
7. I give my consent to be contacted by other researchers about being involved in other related studies at the University of Manchester (optional) Y/N	
8. I wish to receive a summary of the findings of the study (optional) Y/N	
9. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.	
10. I agree to take part in the study	

_____ Name of participant	_____ Date	_____ Signature
_____ Name of person taking consent	_____ Date	_____ Signature

1 copy of the signed form will be retained by the research team  
1 copy of the signed form will be given to the research participants  
1 copy of the signed form will be placed in service user participants' clinical notes.

## Appendix C: Interview topic guide



Topic Guide: What does it mean to be 'ageing well' with psychosis?

1. We are interested in finding out what people think it means to 'age successfully', or to 'age well'. Can you tell me, what do the words 'successful ageing', or 'ageing well' mean to **you personally**?

Prompt - What do you think it involves?

2. Think of someone who you would describe as ageing successfully/well. What is it about them that make you think they are ageing successfully/well?

3. What do you think it means to age unsuccessfully, or to not age well?

Prompt: - What do you think it involves?

- What other things do you think would mean that someone is not ageing successfully/well?

4. Think of someone, who you think is not ageing successfully. What is it about them that mean they are not ageing successfully?

I

5. Do you think that you are ageing well/ 'successfully'?

- Which areas of your life do you think are better or more 'successful'? Why?
- Which areas of your life do you think aren't as good or 'successful'? Why?

6. Could you tell me about any things that you do to help you age successfully/well?

- What would you change about yourself or your life to make you feel you were ageing more successfully/well?

**\*break\***



For the next questions, I want you to think about mental health services, this can be in the community like the hearing voice group etc. or in the NHS; you may be or have been involved with.

7. What do you think services have done or do for you that are helpful to ageing well/ successfully?
8. What do you think mental health services have done or do for you that are unhelpful to ageing well/ successfully?
9. How do the staff in mental health services help you to age successfully/well?
  - a. What other things could staff do to help you age successfully/well?
  - b. Do they make it more difficult for you to age successfully/well?
10. What could a 'perfect service' do to help support people who have lived with schizophrenia or psychosis throughout their life
11. How do your family or friends help you to age successfully/well?
  - a. What other things could your family or friends do to help you age successfully/well?
  - b. Do they make it more difficult for you to age successfully/well?
12. What do you believe is the most important way to help people, who have lived with schizophrenia or psychosis throughout their life, to age successfully/well

## Appendix D: Example coding spreadsheet

Participant	Excerpt	Code	Initial theme	Main theme	Subtheme	comments
9	erm .. so if I'm really stressed I'll do a, tense to relax .. I'll massage me neck, me temples, er ... .. breathing .. exercising, to relax meself and er 190	learning ways to cope with mental health difficulties	Mental health	Maintaing wellbeing	Mastering mental health	
2	I've got one of two friends who have had a history of mental illness, erm, one of them in particular doesn't seem to be coping all that marvellously suffers a lot from insomnia 47	Not managing mental health	Mental health	Maintaing wellbeing	Mastering mental health	
3	um I mean I'm to blame there because I don't tell them you know. 242	Not sharing my mental health difficulties stops me ageing well	Mental health	Maintaing wellbeing	Mastering mental health	
1	I was able to get on top of that quite quickly take the medication and sleep. Um and get back well again quite quickly 21	Sleep	Mental health	Maintaing wellbeing	Mastering mental health	
16	so I accept somebody can like shake that person (inaudible: 0.02.42) look, what you saying, nobody knows and cares about it, and it, it did not happen or that belief that you hold at that time is not a reality 33	Support to question beliefs	Mental health	Maintaing wellbeing	Mastering mental health	
13	Perhaps I shouldn't be so negative I don't know sometimes it helps to talk it over and get some.. a problem halved is sometimes a problem sorted out instead of bottling it up in your head. 96	Talking to people about my difficulties	Mental health	Maintaing wellbeing	Mastering mental health	
13	it helps to talk over things and air them occasionally which helps you sleep better its er um. 185	Talking to people about my difficulties	Mental health	Maintaing wellbeing	Mastering mental health	

## Appendix E: Table of additional quotes

### Table of quotes for main themes and subthemes

#### Theme 1: Engaging with life

##### Activities

*'... Just maintaining a good quality of life... Pushing myself to do the things...I suppose everyday things like um ironing washing cleaning making dinner looking after personal needs and what not.'* (Participant 14, female age 50-55)

*'...just being able to cope with things normally, you know .. and .. I get out most days, see friends and .. erm .. I'm a catholic and there's a Mass at 12:15 at the church in town which I go to, and usually do some shopping first, maybe go to the library for a bit ...'* (Participant 2, male age 70-75)

*'... I relate it to myself, like not doing the things you used to do. Yes it can become quite isolating really...Erm It's this age group in your seventies it's harder. Really, cos you haven't got the energy or the willpower to do things like I did. Like I drive but I don't drive far...and yeh I don't go out like I used to do, so that really gets me down in a way.'* (Participant 3, female age 70-75)

##### Valued Role & Purpose

*'[How can staff support ageing well?]'Help them help those who want to go to work and that remember what it is what they want to do.'* (Participant 7, male age 60-65)

*'I think it's, people who have been in a hospital, erm they'd quite like to go back there and be a carer, they always want to feed back to the hospital, ...I received the care and I've now got the care for myself and perhaps a little bit for other people, and they'd like to go in there and they just come in with some fruit or something like that and they sit down and anyone want a conversation... that's what would be good in the future.'* (participant 4, female age 50-55)

*'And I realise, I realise now, if you do voluntary work though ... are you really appreciated because you're indispensable'* (Participant 9, male age 70-75)

*'... I had nothing to do meself y'know cos I was lost so it [helping neighbour] gave me something to live for, to help others. So that's one thing'* (Participant 6, male age 60-65)

#### Theme 2: Attitude to Life and Ageing

##### Positive Attitude

*'People to go not all like me but some sicker or some healthier ...to go through just getting on keeping on the courage to carrying on with it for the best part.'* (Participant 15, age 55-60)

*'I'm amazed I look back and I think I never thought I could do this and I always try to learn from... I never really... I might lose situations but I never I never really I always learn from what takes place I always try to find a reason or a meaning or a purpose for things'* (Participant 1, age 50-55)

*'I think just force myself to not give in to the problems and keep doing the things that I'm struggling to do to keep them in a stable place.'* (Participant 14, female age 50-55)

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## Acceptance

*'They're just looking their age. You know in their face. Like I said about all that business.'* (Participant 7, male age 60-65)

*[What does not ageing well mean?] 'er, I think you panic about how you look you panic how you look, and you try all sorts of things to make yourself younger...'* (Participant 4, female age 50-55)

*'No not in mine there has been no. I'm like anybody just going through life from the life that I was given. No one knows how it's going to change could be better or worse or mortifying or great or rich no one knows. That's the best part about not [caring about] ageing, gotta keep in your heart that you're not ...but it's just a bitter thing that you've got to cope with.'* (Participant 15, male age 55-60)

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## Theme 3: Maintaining Wellbeing

### Physical Health

*'I don't know I think that I'm going downhill. I've just got a lot of problems. I've got physical problems like in my neck and my ankles'* (Participant 14, age 50-55)

*'Well I got a relation called [X] and she's 97...And she's ageing well and she's still alive. And she's still in good condition. Yeh...in good condition how do you mean? She's pretty fit for her age'* (Participant 8, male age 55-60)

*'[ageing well] what does it involve, it's just that you don't care about yourself'* (Participant 9, male age 70-55)

*'[describing husband who is ageing well] Erm well he's keeping fit he's going on his bike all the time and doing a lot of exercises and goes to work on his bike. He keeps fit yeh...Physically'* (Participant 5, female age 60-65)

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### Mastering Mental Health

*'... well the illness has got such a grip on so many people, that they can't manage on their own, they've got to, they need the help, you know'* (Participant 2, age 71)

*'But now I'm actually here on this plateau where I can go right you know it's not so bad. And I've worked very hard my whole life for it and to earn it and I think I deserve it really! ... It's been blumming hard work but I've got here so!'* (Participant 1, female age 50-55)

*'My schizophrenia has been very good. Over the last few years. I've been doing well... Seems to be since I've got older... I'm just not hearing any voices'* (Participant 5, female age 60-65)

*'Well if you say about mentally, er, mental health, I suffer from depression as well as anxiety mainly. I could be happier... if things would have been different in the past, but... But I do try that's why I went to mindfulness, so hopefully I could learn some ways of dealing more with my problems.'* (participant 9, male age 70-75)

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	<p><i>'[What would you change to be ageing better?]'No I mean if I could I'd change the way my mental state can be bad but in a way not really no....Yeh could I would like to but I know it will never be it's not Gods work and it's God's work within God's work and my own problem and me families problem which I don't blame cos [there's] no fault... It's the way it is the way life has got to be no matter how hard it may be. But sometimes you've got to continue through that that foggy bloody mess. And that's the best part of it.[growing older]'</i>(Participant 15, age 65-70)</p> <p><i>I like my tablets now, I like to feel good, like to take them then I feel successful[in my ageing] I'm taking them this time'</i>(Participant 4,female age 50-55)</p> <p><i>'erm .. erm, erm, their illnesses, and that, the mental illnesses that you know, I think when you take, take a lot of tablets, you basically deteriorate in age'</i>(Participant 11,male age 65-70)</p>
<b>Cognitive Health</b>	<p><i>'...age well, yeah, oh yeah, yeah, erm by occupying your mind, erm, age well, yes, to occupy your mind because if you didn't have anything to do, erm .. I think you would fall the wayside'</i> (Participant 11, male age 62)</p> <p><i>[Age unsuccessfully is] 'I think like when your mind starts going when you can't remember things like people and what not.'</i> (Participant 14, female age 50-55)</p> <p><i>'Well, ageing well, could may be, having my memory and be able to be ... behaving in a certain way that accepted in society'</i> (Participant 16, male age 55-60)</p>
<b>Sense of Security</b>	<p><i>'I'm always looking over me shoulder because I've had a few good hidings on this estate through drunks and what have you'</i> (Participant 7, male age 60-65)</p> <p><i>'...and I get that pension, state pension, and I can manage comfortably off that, but I've got [Does it help you age well?] yeah ... gives you a certain amount of peace of mind, you know'</i>(Participant 2,male age 70-75)</p> <p><i>'The fact I got out of a horrible hellhole of a place called [previous residence] and came up to this beautiful part of the country is I think ...'</i> (Participant 1, female age 50-55)</p> <p><i>'Well make sure their standard of living is good for starters...'</i> (Participant 6, male age 60-65)</p> <p><i>'...and erm when you age successfully, you, you've got a certain amount of everything, you feel, yeah, this is what I get for, erm, not being too crazy, and I've built it back up again and I don't want to lose what I've got again, you see, I've built it all up and this time.'</i> (Participant 4, female age 50-55)</p>

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**Theme 4: Having Good Relationships****Having Good Relationships**

*'If I didn't have a partner I'd be so I'd be much poorer if you like emotionally in every sense of the word.'* (Participant 1, female age 50-55)

*'[Family help to age well]...because they are there for me if I'm unwell and if things are getting me down and things like that.'* (Participant 3, female age 70-74)

*'[describing a friend who is not ageing well] And erm got nobody to fight his corner at all and if he's not careful he'll be put back into hospital so he has to do what he, he has to go along with the treatment which is absolutely barbaric and there's nothing anybody will do for him at all and he has to be brave he has to put on a face and fight the world and erm nobody takes his corner at all.'* (Participant 13, female age 70-75)

*'I walk to my sons um two or three times a week and see grandkids and what have you any other time I've had my daughters, so I'm always getting to see them. Otherwise I wouldn't see anybody I wouldn't think'* (Participant 7, male age 60-65)

*'So I mean whereas before for forty or fifty years I have I've been on my own erm isolated, [now] I'm in a family in families that erm say 'oh can you just babysit today?' and you know I would go there for a week and babysit y'know what I mean?'* (Participant 6, male age 60-65)

*'...and it's not easy living on your own ... I don't find it easy, you know...and a lot of me friends are married anyway, so, erm, they're not on their own, you know ...'* (Participant 2, male age 70-75)

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**Professional Relationships**

*'But he's [Psychiatrist] just genuinely kinda alright. You get scared don't you? You know you're going seeing somebody you get on your guard. And before you know it with him I'm telling him things I weren't very sure I was going to tell him. You walk out of there thinking how the heck did he get that out of you then...'* (Participant 7, male age 60-65)

*'I don't know if you know [X]? She's a nurse. We used to have a great friendship together it helped me a lot... you know.'* (Participant 10, male age 65-70)

*'They aren't I don't feel I have that problem really because I have support workers you know. I'd be lost if I didn't have them.'* (Participant 3, female age 70-75)

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**Being Heard & Understood**

*'...because you know people, erm who've got a mental illness ... didn't ask for it, you know, and that's where it, you know, families don't, erm, understand, they don't understand, they just think, well, you know, he's off his head him, and it's not that at all, so you, you've got, you know, there's, when you actually, there is a stigma within the family, you know'* (Participant 11, male age 60-65)

*'[Best support for ageing well]Erm I suppose again it's about getting people involved that's part of your life that have an understanding about what schizophrenia's about'* (Participant 3, female age 70-75)

*'Just by talking to me and listening, and just see how I'm doing...Just by being there someone to listen to[you]'* (Participant 12, female age 50-55)

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*I suppose if you had a lifetime of being judged and if you tell people I've told friends I've been mentally ill and it's kinda 'oh right, don't want the kiddies, can't bring the kiddies round' and it's been that kind of experience.'* (Participant 1, female age 50-55)

*'[discussing people not ageing well] Well not doing alright some have more problems some are very poor some are really downtrodden. Because I think they're saying 'oh well you're useless you're no good you're just a senile old man.'* (Participant 15, male age 55-60)

*'[stigma of diagnosis] it's been like four life sentences, because if you commit a murder it's 15 year sentence but I have four life sentences because of my age.'* (Participant 6, male age 65-70)

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## **Paper 3: Critical Evaluation**

Word count: 5380 (excluding references)



## **1. Introduction**

The following paper presents a critical appraisal of the research presented within the current thesis. This appraisal includes a critical evaluation of the planning, implementation and interpretation of the systematic review and empirical study respectively. The strengths and limitations of the research are discussed. Critical reflections of the research process as a whole are also offered.

## **2. Paper 1: Systematic review**

### **2.1 Topic selection**

Berry and Barrowclough (2009) conducted a systematic review examining the needs of older people with schizophrenia. The review's aims were to explore the potential differences in the needs of older people with this diagnosis compared to younger people; examine what factors may account for these differences; as well as identify future direction of psychosocial interventions for this population. Whilst, the authors concluded that older adults had similar needs to younger people, for example with regards to cognitive functioning, social functioning, and quality of life, there was a lack of evidence comparing the needs of older and younger populations directly and assessing the effectiveness of interventions designed to address these needs in older populations.

An initial scoping search of the literature (post 2009), was conducted based on the search terms used in Berry & Barrowclough's (2009) review, as it was evident that there was sufficient relevant research available to update the review. Further to this the research team agreed that an updated version would benefit from more extensive search terms than were used in the original review. As the review had searched a broad area of the literature the research team decided that a narrower focus would be more appropriate to undertake. The

initial scoping search revealed 30 intervention studies for this population, given the findings of the Berry and Barrowclough (2009) review that there was a lack of studies assessing interventions for older populations the trainee decided that there was a need for a focussed review on the effectiveness of interventions. This topic also complemented the empirical paper, which was exploring what ageing well meant to middle to older adults with psychosis and how best to support this.

Social functioning was specifically chosen as the outcome measure to examine for two reasons. Firstly, social functioning is widely documented as a difficulty among people with schizophrenia and psychosis, with persistent problems with social functioning associated with more severe symptoms and poorer longer term outcomes (Fowler et al., 2010). Furthermore there is evidence to suggest that older adults with schizophrenia have poorer social functioning compared to younger adults and same-age peers with bi-polar disorder (Martin, Ongur, Cohen, & Lewandowski, 2015) and this may, in part, be due to additional neurocognitive decline (Mueser et al., 2010). Secondly, research of lay perspectives suggests that improving social functioning is a high priority in interventions for people with psychosis related disorders (Auslander & Jeste, 2002). The final research question for the review was therefore to systematically review the literature of the effectiveness of psychosocial interventions on social functioning for mid to older age adults with psychosis.

## **2.2 Search terms**

The starting point for developing the search terms was the list used in the Berry and Barrowclough (2009) review. These included ‘old age’ OR ‘elderly’ OR ‘older people’ OR ‘geriatric’ AND ‘psychosis’ OR ‘schizophrenia’. These terms were then expanded to develop more thorough search sets. At the search stage and after consultation with the

library systematic review service it was also decided to include the term ‘middle-aged’ into the age group search set, as inclusion criteria was set at including samples aged forty and above (see below). The specificity of the search was also increased by including a search set for ‘psychosocial interventions’. The trainee therefore decided on three search sets (1) psychosocial interventions, (2) older and middle aged people and (3) psychosis. Synonyms were generated for each search set and were added to further with appropriate MeSH terms identified whilst running test searches. Further to this, terms used in previous reviews for (Frederiksen, Farver-Vestergaard, Skovgård, Ingerslev, & Zachariae, 2015; Kok, Williams, & Zhao, 2015) these concepts were examined for any other terms that may have been overlooked. Appropriate use of truncation was considered for different spellings, singular/plural and noun/adjective forms of the search terms.

Once a comprehensive list of search terms was generated it was reviewed by the research team. One of the challenges of conducting a systematic review was finding the balance between sensitivity (needed for completeness) and specificity (needed for efficiency) and decisions were made with these issues in mind when conducting test searches. MeSH terms were not exploded and the term ‘old age’ was excluded as they added an excessive number of hits, and after reviewing one of the databases (PsycINFO) the trainee found that these terms did not add any further studies that were not already captured. Furthermore the trainee was confident with the search strategy as no further studies were identified from hand searched reference lists.

### 2.3 Inclusion and exclusion criteria

When setting the eligibility criteria it was crucial to develop clear definitions for each concept i.e. older people, psychosocial interventions and social functioning. Rationale and definitions are detailed below.

Firstly, the trainee sought to establish existing definitions of psychosocial interventions within the literature. An initial search revealed several definitions, ranging from any non-pharmacological intervention (Dagnan, 2007) to *‘A psychosocial intervention aims to reduce complaints and improve functioning related to mental disorders and/or social problems (e.g., problems with personal relationships, work, or school) by addressing the different psychological and social factors influencing the individual’* (Cummings & Kropf, 2013). The definition used by Ruddy and House (2005, p. 2) of *‘any intervention that emphasised psychological or social factors rather than biological factors’* was deemed the most appropriate, and used for the review because this allowed for the inclusion of all psychological and social interventions such as social support and befriending. In their Cochrane review Ruddy and House (2005) chose to include studies that had a biological focus if there was a psychosocial element included, as their primary aim was reviewing psychosocial interventions for conversion disorder which has a greater physical health emphasis. However, as the focus of the current review was on psychosocial interventions, it was decided to exclude any biological interventions with these components (i.e. exercise groups, medications with support groups) to be sure that any improvements in social functioning were clearly due to a primarily psychosocial intervention.

The concept of social functioning was also challenging to define for the review, as there are several conceptualisations in the literature. Further to this, it became apparent whilst

scoping the literature that there were a multitude of different measures which have been used by different studies to measure social functioning. Overall it was decided to use the Bosc (2000) definition of social functioning, *'the interaction of an individual with their environment and the ability to fulfil their role within the environment. An individual functions daily within several environments: work, social and leisure, marital, parental, and with the extended family'*. The research team reviewed several of the measures used in the studies identified to assess what they were measuring i.e. activities of daily living, leisure activities, social communication etc. One of the issues with these disparities was the inclusion in some of the scales of activities of daily living which are not necessarily social in nature i.e. self-care. The Handbook of Social Functioning in Schizophrenia defines impairment in social functioning as, *'the inability of individuals to meet societal defined roles such as homemaker, worker, student, spouse, family member or friend. In addition, individual's satisfaction with their ability to meet these roles, their ability to care for themselves and the extent of their leisure and recreational activities are often subsumed under the rubric of social functioning'* (Mueser & Tarrier, 1998). It has been argued that these skills are essential for a person's ability to engage within social roles or settings (Patterson, Goldman, McKibbin, Hughs, & Jeste, 2001). It was therefore decided that a broad definition of measures pertaining to the above definitions would be included. Social functioning measures included in the review were defined as any measure relating to the frequency of, quality of, or satisfaction with social, academic or occupational activity. This may include socially useful activities, personal and social relationships and self-care.

The inclusion criterion for age was set at forty and above for this review. This was because issues of ageing for this population may also encompass midlife issues. It has been posited that the definition of "older" for people with psychosis related disorders may differ from

how it is normally defined (Jeste & Maglione, 2013). Factors such as increased likelihood of neurocognitive difficulties (Kurtz, 2005) and potentially accelerated physical ageing (Kirkpatrick, Messias, Harvey, Fernandez-Egea, & Bowie, 2007), including premature morbidity and mortality compared with the overall population (Tiihonen et al., 2009), may contribute to this. Thus, people with psychosis related disorders in their 40s and 50s may be more comparable with those in their 60s and 70s in the general population. Furthermore, to have set the inclusion criteria for an age any higher would have narrowed the usefulness of clinical implications.

The inclusion criteria relating to diagnosis included a DSM or ICD diagnosis of a psychosis-related disorder. Samples that included severe mental illness (SMI) were also included. This was because preliminary searches revealed that studies using SMI samples generally included a proportion of people with psychosis related disorders. Given the limited nature of literature, and the high number of pilot studies in the scoping search it seemed appropriate to include studies that utilised samples of people with SMI so as not to minimise the evidence available to review and be inclusive of psychosocial interventions that are currently researched for use with this population. Therefore, studies that examined interventions for people with SMI were included so long as they had included people with psychosis related disorders in the sample. For the majority of studies included in the review (n=13) the proportion of the sample was greater than 50% (54-100%). However for two studies (Bartels et al., 2014; Gammonley, 2006), both of which had very small sample, proportions of people with psychosis related disorders were lower (20-38%). As briefly outlined in the discussion, the generalisability of this evidence in relation to people with psychosis should therefore be interpreted cautiously.

Given the scope and time-limited nature of the thesis, only peer-reviewed journal articles were included in the review; books or dissertations were excluded. While the inclusion of only peer-reviewed papers may be of a higher standard, there has been some controversy about excluding other publications, especially 'grey literature' as there is an increased chance of overlooking potentially relevant evidence (Benzies, Premji, Hayden, & Serrett, 2006). Further to this the 'file drawer' phenomenon has also been acknowledged in the literature, in that statistically significant findings are more likely to be published than studies which report non-significant findings (Spellman, 2012). There are many challenges of including 'grey literature' not least, that it is not readily available on standard electronic databases (MEDLINE, PsycINFO etc.), it can be more time consuming to extract and synthesise the data and there may more risk of bias (Adams et al., 2016). The exclusion of such literature may therefore have led to an over-optimistic summary of the effectiveness of these interventions. In addition, the review only included studies written in the English language. It is acknowledged that this may have limited the comprehensiveness of the review; however given the timeframe and limited resources it was not possible to translate articles.

## **2.4 Contacting authors**

A number of papers (n=9) which were retrieved appeared to be potentially relevant to the review but as the articles only reported average age of the participants without any inclusion criteria or age ranges being reported it was not clear if they met inclusion criteria. In an attempt to be as systematic as possible, if the average age of participants was within the inclusion criteria for the current review authors were contacted to establish this information. Overall only two authors replied (Atkinson, Coia, Gilmour, & Harper, 1996; Farhall & Cotton, 2002) both of whom had included participants younger than forty in

their studies. It is therefore possible that these studies met inclusion criteria and were missed from the review. However, contacting these authors was testament to the fact that every effort was made to ensure the review was as systematic as possible.

## **2.5 Quality assessment**

Systematic reviews should involve “a systematic approach to minimizing biases and random errors which is documented in a materials and methods section” (Chalmers, Altman, & Gotzsche, 1995). Whilst it is therefore important to include standardised quality assessments in systematic reviews, others have highlighted that there is a risk of bias across raters using quality assessment tools and low inter-rater reliability (Sanderson, Tatt, & Higgins, 2007). It is therefore important to include a second rater to assess this when using a quality assessment tool.

The Effective Public Health Practice Project tool (EPHPP; Thomas, Ciliska, Dobbins, & Micucci, 2004) was chosen as it allows for quality assessment across a range of study designs. As noted in the review, it also has previously been shown to have good reliability and validity (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012). For the current review all papers were rated for quality by another post-graduate student independent from the research team. There was a moderate level of inter-rater reliability (82% agreement,  $\kappa = 0.69$ ). Discrepancies on three of the papers were discussed until agreement was achieved. Two of the discrepancies were due to the second rater overlooking information reported in papers, such as details about randomisation. The other discrepancy was due to the second rater scoring ‘could not tell’ for counfounders being controlled for between groups which led to a ‘weak’ rating for this component when actually the study was a pre-post-test design and so this component was not relevant to the study. A strength of the EPHPP was the



‘dictionary’ that is provided to clarify the requirements for each component, and the trainee reflected this helped to obtain a good level of agreement between ratings. The trainee found it very useful to have a second rater during this process to discuss the papers and interpretation of each component of the tool and to have confidence in the final ratings given.

There were some challenges and limitations to using the EPHPP. Firstly, while the EPHPP has been designed to evaluate a range of study designs, the components are skewed towards RCT or control trial designs. Some of the items were not applicable to the pre-post design studies that were included in the review, and so the scoring had to be altered for such cases to include ‘n/a’. As such RCT or control trials were rated on more items than the pre-post studies. Furthermore, whilst study design is included in the rating, the number of participants was not. This was particularly important as several of the studies included were pilot or feasibility studies, with very small numbers of participants. Global ratings for studies with less robust designs may therefore have been overinflated and were interpreted cautiously when weighting the studies in the narrative synthesis. Sample sizes were also considered throughout the result, for example if studies were underpowered to detect statistically significant results and the generalizability of studies with smaller sample sizes.

## **2.6 Synthesising the data**

Given the heterogeneity of study designs and measures used across the papers a meta-analysis was not appropriate, and so a narrative synthesis was conducted. Two of the biggest challenges in writing the review was firstly how to synthesise the data across the range of studies included in the review, and secondly how to organise the results section in a way that was coherent. It was decided that dividing the results section by intervention type would be the most sensible and accessible way of creating a narrative for the review.

Whilst, broadly speaking, the interventions could be divided into two main types: ‘skills training’ and ‘integrated mental and physical health interventions’, there was a degree of overlap between the two. However the trainee felt that there was enough distinction to discuss separately. Upon reflection the trainee felt that the organisation of the systematic review worked well and that it was possible to make useful conclusions about each of the intervention types.

A further challenge of synthesising the data was the disparity of social functioning measures used across the studies, both in terms of how and what they measured. As previously discussed, ‘social functioning’ is not well defined in the literature, and clarification of these differences has been attempted to be highlighted where possible within the review. The review highlighted the need for more consistent use of multiple measures of social functioning in future; to capture different aspects of functioning that may be improved and to better assess the effectiveness of different interventions.

## **2.7 Clinical implications and Future Research**

Overall, the review found that there is evidence for skills training and integrated mental physical health interventions for improving social functioning in middle to older adults with psychosis. However it was difficult to make more specific conclusions as much of the research is in its infancy, and so evidence available is limited and often low in quality (e.g. No control groups, small samples). There is therefore a need for future research to use higher quality designs (i.e. RCT) with larger sample sizes, and to investigate possible moderator variables to clarify what elements of interventions work and for whom. Future research should also evaluate currently established, well evidenced, and recommended

interventions (CBT and family therapy; NICE, 2014) on social functioning for this population. Given the effectiveness on social functioning for this population is, as yet, unestablished it is not clear that the NICE recommendations, particularly with adults in an older age bracket (age >65), are appropriate.

## **Paper 2: Empirical paper**

### **2.8 Developing the research question**

It was initially posited that exploring which factors promote resilience in older with psychosis would be an important area of research, based on evidence that people with psychosis may actually improve in managing their symptoms as they grow older (Berry & Barrowclough, 2009). The trainee spent time conducting a scoping search of the literature and from this further explored the literature on ‘successful ageing’ a concept closely related to resilience, in that some studies have found that people consider themselves to be ageing well in the context of disadvantage and adversity (Pruchno & Carr, 2017). Two reviews of this area (Cosco, Prina, Perales, Stephan, & Brayne, 2013; Martinson & Berridge, 2015) both highlighted the gaps in the literature, particularly that current definitions of successful ageing limit the number of people classified as ageing well. Further critiques of current definitions of successful ageing are that there is a ‘missing voice’ of lay perspectives in the literature. Furthermore, whilst other studies have sought to remedy this by gathering the perspectives of people with chronic physical health conditions (Romo et al., 2013); the literature search suggested there was a lack of research exploring what successful ageing means to those with chronic mental health difficulties. In particular, to the trainee’s knowledge, there were no studies that had examined what ageing well or successful ageing meant to older people with psychosis. With agreement from the research team it was therefore decided to explore this further and set this as the research question.

Early on in the planning, the research team set specific inclusion and exclusion criteria for recruitment. An inclusion criterion of note was the age of participants to be recruited. We decided to recruit people age 50 and above (rather than more typical age boundaries for older adult research of 60 or 65 years) for two main reasons. Firstly, as life expectancy within this population is on average lower than in the general population, it is argued that ‘older age’ could be considered earlier than in the general population (Jeste & Maglione, 2013), and as such it was decided that this should be reflected in our inclusion criteria. One limitation to this may be that early life expectancy does not necessarily mean *everyone* will feel this is an appropriate label for them. However, we believe that the concept of ageing and ‘ageing well’ is a topic that people can discuss irrespective of age. Thus, whilst people across the age ranges may not feel ‘old’ themselves they will likely have an opinion of what they want from later life and what the ageing process may look like to them. Indeed, studies examining views on successful ageing have previously been conducted in people as young as 18 (Bowling, 2007). The research team also believed that it was important to include people with a variety of experiences who may highlight aspects of support or resilience that may benefit others. The second reason for using a lower age cut-off was, that including people age 50 and above would enable us to ascertain the opinions of what good support should look like from the next generation of people who will become eligible for ‘later life’ services. Participant age was also considered when interpreting data for thematic analysis, for example younger participants spoke about being able to keep working as an important aspect of ageing well.

## **2.9 Recruitment and sample**

The recruitment of clinical populations (Bucci et al., 2015), especially older adult populations can be challenging for many reasons including mistrust, increased facility and health conditions, and indifference (Cassidy, Baird, & Sheikh, 2001). In the first instance, and following guidance outlining recruitment in mental health settings (Bucci et al., 2015), the trainee spent time engaging services, attending meetings to present the study. The trainee found that recruitment was greatly facilitated when they allocated time at the end of the meeting to ask individual clinicians to review caseloads and contact participants when the trainee was still there. Overall, the trainee reflected that this maximised recruitment by minimising the burden on clinicians. Monetary reimbursement (high street voucher) was given to all participants that took part in the study, which also helped to facilitate recruitment.

Some services were more difficult to recruit from. In particular, two of the local trusts had merged prior the start of recruitment, leading to changes within services and team leadership. The trainee reflected that this influx in disruption across the trust may have reduced some teams' capacity to engage with the current study. Efforts were therefore concentrated in teams where recruitment had been more successful. Another key source of participants was those who had taken part in a previous study with similar inclusion criteria. These participants had been asked within the consent forms if they would agree to be contacted by other University research projects.

One of the limitations of the study was the low number of participants who did not identify as white British. The trainee made every effort to recruit people from a range of backgrounds for example by specifically asking clinicians from mental health teams to

consider adults that met criteria who were from different ethnicities. However, this proved to be challenging, as has been previously reported in other research (Areán, Alvidrez, Nery, Estes, & Linkins, 2003; Areán & Gallagher-Thompson, 1996). As such it is possible that the findings of the study may not be generalisable across other cultures and ethnicities. In future, the trainee reflected that it would be beneficial to make additional effort to make links with ethnically or culturally specific community groups to increase recruitment across a range of populations.

In addition to participant ethnicity, other demographic variables were collected to help maximize variation amongst participants and facilitate purposive sampling (Patton, 1990). After an initial sample of five participants was recruited, targets were developed to ensure that the sample was representative across the following variables: age ranges 50-60, 61-70, and 71-80, (at least one in each age bracket), gender, previous experience of Psychological therapy, number of hospitalisations, current involvement with primary/secondary services and having an identified carer.

Although qualitative sample size should be directed by data saturation (Marshall, 1996), a preliminary aim of recruiting a sample of 20 people was set. This target was determined on the basis that previous studies that have recruited a similar sample have recruited a range of sample sizes ( $n=28$ ; Leutwyler, Hubbard, Jeste, & Vinogradov, 2013;  $n=16$ ; Leutwyler, Hubbard, Slater, & Jeste, 2014;  $n=7$ ; Ogden, 2014). In addition, some researchers have argued that the concept of ‘data sufficiency’ may be more appropriate than data saturation in applied research. Data sufficiency is the idea that new ideas do not add anything to the overall story (Dey, 1999; Strauss & Corbin, 1990) and this was considered when interviewing participants.

The trainee managed to ascertain 21 referrals for the study with a final sample size of 16. Unfortunately, the final five participants were unable to take part for various reasons: two were experiencing a relapse with their mental health; two participants were not reachable to arrange interviews and one other decided to withdraw from the study prior to being interviewed. The trainee attempted to recruit a further four participants but, after reviewing the completed interviews, and discussing with the research team the decision was made to conclude recruitment at 16 participants. On completion of data collection from the 16 interviews there was evidence of a rich data set, with no evidence of new themes emerging after the 11th interview. This is in keeping with guidelines for thematic analysis which argue that six to ten participants are usually sufficient to identify patterns across data gathered from interviews (Braun & Clarke, 2013).

## **2.10 Qualitative analysis**

The majority (75%) of the transcription was undertaken by the trainee. The remaining recordings were transcribed by an experienced transcriber, independent to the research team. All interviews were checked for accuracy alongside the audio-recordings. Whilst this allowed more time to focus on data analysis the trainee found that personally transcribing interviews facilitated familiarisation with the data.

All the interviews were coded and analysed by the trainee following the guidelines outlined by (Braun & Clarke, 2006). The first stage of analysis was familiarising with the data through reading and then rereading transcripts on several occasions. As the trainee had transcribed the majority of interviews this increased familiarity with the data. Data was then coded line by line. This was a time consuming and laborious process especially as this

was the first time the trainee had undertaken qualitative analysis. One of the challenges of analysis that the trainee reflected upon was that analysis often generated codes unrelated to the research aims. Whilst many of these were interesting, the trainee had to be careful to focus on codes and themes directly related to the research question. As previously mentioned qualitative analysis was a new experience for the trainee, and as for many novices, found the experience initially daunting. However, this approach captured rich data that would have been lost in quantitative methods such as questionnaires, and was a process the trainee found to be very rewarding.

## **2.11 Reflexivity**

It has been widely acknowledged that reflexivity is an important process within qualitative research (Berger, 2015). That is, it is important for a researcher to reflect not just on their own background and bias that may influence the research (prospective reflexivity), but also how the research has concurrently shaped and influenced themselves (retrospective reflexivity; Attia & Edge, 2017). Evidence suggests that the professional background of the researcher can also influence participants' responses during research interviews (Richards & Emslie, 2000). In the current study, all of the participants were aware that the research formed a part of the researcher's training as a trainee clinical psychologist. The trainee is a white British woman in her late twenties and had not personally experienced psychosis. She had a professional interest in this area, although relatively little experience working with older adults experiencing non-organic psychosis. Some of the participants commented on the researcher's age during the interviews and this may have caused some to feel reluctant to talk about certain aspects of their ageing. The researcher found hearing the narratives of this population was very powerful and made them reflect on their own views



of ageing, mental health and the importance of the role of the clinician in supporting and advocating for people who may not always be heard.

## **2.12 Clinical Implications and Future Research**

Overall the findings suggested implications both for clinical practice and future research.

Firstly that older adults should be supported to engage in activities that are appropriate for their preferences and skills, to add enjoyment and value to their lives. It should be further recognised that there can be barriers to facilitating these activities (for example difficulties with social functioning) and these should be ameliorated either by specific intervention or choice of group to bolster engagement. Further research in different types of interventions, such as social recovery therapy, may help to establish usefulness for this population.

Importantly, supporting older people with psychosis to have good relationships is key both personally and with professionals. Whilst facilitating engagement with groups may help to create wider social network, systemic or family interventions should be explored as means of strengthening familial relationships. As previously mentioned clinicians should not underestimate the experience that having positive, trusting relationships that allow people to feel understood and heard may have on a person's sense of ageing well.

Stigma about mental health and societal ageism are ongoing difficulties for this group of adults with psychosis. It may be key for clinicians to challenge these beliefs, where possible, especially as these can become internalised and potentially act as a barrier to people engaging with services.

## **Personal reflections**

At the start of the clinical psychology doctorate, the trainee hoped to complete a research project that would contribute to clinical practice and to develop their research skills to further continue contributing to research, following qualification. The trainee's previous research experience was in quantitative designs. As an undergraduate and, following this, a research assistant, she was involved in a longitudinal study of cognitive ageing. The trainee was enthusiastic about gaining experience in using qualitative methods, and especially about continuing to work with older adults. The trainee initially had some reservations regarding her research competence in the project, as she had no prior clinical or research experience working in the area of psychosis or using qualitative methods. Throughout recruitment and conducting the interviews with participants, the trainee felt incredibly privileged to hear the stories and bear witness to the triumphs and challenges they have faced throughout their lives. The trainee reflected, as they worked with older adults previously, that the research project had reinvigorated their passion for researching and working with this sometimes undervalued population. One challenge they found about conducting the interviews was separating out the 'clinician' and 'researcher' roles. Throughout some interviews the trainee felt drawn to ask more clinically appropriate questions and to help and support the participants out with the research context. The trainee had to be conscientious not to conflate her role and with help from supervisors reflected about this in supervision.

The trainee found that being involved with designing the empirical study from the start helped her to have a sense of personal ownership of the project and furthered their drive going forward with the project. The trainee found supervision with research supervisors very valuable and reflected upon the skills and knowledge they imparted. One of the main

challenges the trainee faced was managing competing demands of the course both clinically and academically while needing to devote time to the research project, in particular engaging clinical teams for recruitment. Challenges in the trainee's personal life further added to the demands placed on her. The trainee managed this by seeking support from her clinical tutor and peers and felt fortunate to have good supportive relationships with both her supervisors.

The trainee was pleased to be given the opportunity to develop transferable skills throughout the research project. These included: developing formative writing skills and writing concisely for publication; managing a research budget; critically appraising research studies; recruiting from clinical populations; and analysing qualitative data. The trainee intends to carry forward these skills post qualification and promote the importance of conducting research at her workplace gaining further opportunities to conduct research.

In conclusion, conducting the research was at times challenging but a highly valuable and enjoyable process. The trainee gained a great sense of achievement and satisfaction from completing a research project that will contribute to the understanding of ageing well for adults with psychosis.

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