

# Self-report measures assessing aspects of personal recovery in relatives and other informal carers of those with psychosis: a systematic review

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9 **Keywords: Caregivers<sup>1</sup>, Psychosis<sup>2</sup>, Schizophrenia<sup>3</sup>, Recovery Approach<sup>4</sup>, Self-report  
10 measures<sup>5</sup>, COSMIN checklist<sup>6</sup>**

## 11 **Abstract**

12 **Background:** Providing long-term care for a family member with psychosis can cause significant  
13 distress for informal carers due to the trauma of seeing their loved one in crisis, dealing with the  
14 difficult symptoms of psychosis and the burden of providing care. An important aspect of carers'  
15 adjustment can be construed as their personal recovery in relation to having a relative affected by  
16 psychosis. Self-report measures are increasingly used to assess personal recovery in service users,  
17 but less is known about the utility of such tools for carers.

18 **Aims:** This review aimed to identify all self-report measures assessing aspects of carers' personal  
19 recovery, and to quality appraise them.

20 **Methods:** Academic Search Ultimate, CINAHL, MEDLINE, PsychINFO and PubMed were searched  
21 for articles that reported the development of self-report measures created for carers of those with  
22 psychosis. Studies were appraised using the Consensus-based Standards for the Selection of health  
23 status Measurement INstruments (COSMIN) checklist. A Levels of Evidence synthesis provided  
24 overall quality scores for each measure.

25 **Results:** The search identified 3,154 articles for initial screening. From a total of 322 full text  
26 articles, 95 self-report measures were identified with a final 10 measures included for the quality  
27 assessment showing varying levels of psychometric rigor.

28 **Conclusions:** The results show that no single self-report measure is currently available for use to  
29 comprehensively assess personal recovery for carers, highlighting the need for further research in this  
30 area and the development of a new measure.

## 31 **1 Introduction**

32 Taking on a long-term caring role for a family member who experiences psychosis or schizophrenia  
33 is associated with diminished psychological health, grief, social isolation and a poorer quality of life

34 (Awad and Voruganti, 2008, Mulligan et al., 2013, Poon et al., 2017). The prevalence of psychosis is  
35 relatively common, with 7% of the adult population experiencing psychosis before their 75<sup>th</sup> birthday  
36 and 50% of these cases occurring before the age of 23 (McGrath et al. 2016). The Schizophrenia  
37 Commission (2012) have estimated that carers save £1.24 billion of public health funding per year,  
38 so it is essential to provide good support to carers. Family carers are also more likely to have  
39 financial problems and suffer from interpersonal stress (Mueser and Fox, 2002, Rose et al., 2002).  
40 The initial acute phase of treatment for psychosis can be overwhelming and has been compared to a  
41 bereavement for the relatives of the service user (Patterson et al., 2005). Carers of those with first  
42 episode psychosis have been found to burnt out – feeling exhausted, inadequate, and generally having  
43 negative appraisals of their caregiving ability (Onwumere et al., 2018). Carers have described  
44 feeling hopeless, depressed, and anxious and this has been conceptualised as a form of secondary  
45 trauma that is caused by the ongoing stress of providing long-term care (Wyder and Bland, 2014,  
46 Shiraishi and Reilly, 2019). Carers have been found to show symptoms of posttraumatic stress  
47 (PTSS) (Hanzawa et al., 2013) such as having intrusive thoughts about the event, feeling alert or on  
48 edge a lot of the time, and avoiding difficult thoughts and feelings about their loved ones mental  
49 health difficulties. Kingston et al. 2016 found that 44% of carers met the threshold for posttraumatic  
50 stress symptoms which was strongly related to negative thinking about themselves, self-blame, and  
51 trauma in relation to taking on a caring role. Poon et al. (2017) argue that it is important to  
52 acknowledge that families may be struggling with their caring role, and carers often feel isolated and  
53 alienated from their usual social support systems (Bland et al., 2009, Hayes et al., 2015). Carers  
54 often put their own needs last, but research suggests that when carers attend to their own physical,  
55 emotional, and spiritual health that many of their own problems become more manageable (O’Grady  
56 and Skinner, 2012). There has been a call for more supportive interventions to be provided for carers  
57 (Poon et al., 2019, Wyder and Bland, 2014) both for their own health and well-being but also to  
58 allow them to provide effective care for the service user (Reine et al., 2002, Testart et al., 2013). For  
59 example, recent novel eHealth interventions incorporating psychoeducation and peer support for  
60 carers have shown to have a positive impact on carer wellbeing (Batchelor et al., 2022; Sin et al.  
61 2019; Lobban et al. 2019). Taking on a long-term caring role can also alter carers views of self-  
62 efficacy and in turn their coping capacity (Rowe, 2012, Wilkinson and McAndrew, 2008), which  
63 may negatively affect both their caring abilities and personal lives (Wyder and Bland, 2014). To  
64 better understand and develop more targeted support for carers, it is important to understand their  
65 personal experiences (Zendjidjian and Boyer, 2014). Assessing carers experiences is also important  
66 in evaluating the treatment and management of care for the service user, as well as evaluating the  
67 well-being of the carer (Boyer et al., 2016).

68 An effective method of assessing the experiences of carers is through the use of self-report measures  
69 (Richieri et al., 2011) as they are relatively quick to administer and cost effective, which increases the  
70 feasibility of incorporating them into routine clinical practice. Self-report measures can also be used  
71 to measure the effectiveness of psychosocial and family interventions and can be a useful clinical  
72 tool, enabling carers a chance to reflect on their progress over time. The EUFAMI (2014) survey  
73 found that assessment of carers experiences was crucial in order to effectively support them,  
74 however, despite this need, self-report measures for carers are routinely underutilised in mental  
75 health services (Boyer et al., 2016). There are a plethora of measures to assess various aspects of  
76 carer experience (Harvey et al., 2005, Harvey et al., 2008, Testart et al., 2013) with the majority of  
77 measures focusing on the negative aspects of caregiving such as burden, strain, reduced social  
78 networks and stigma. There are a few measures that investigate carer coping strategies, perception of  
79 need and quality of life (Zendjidjian and Boyer, 2014) and even fewer measures looking at the  
80 positive aspects of caring such as, developing great compassion, finding greater meaning and  
81 purpose, and strengthened interpersonal relationships. Understanding the positive aspects of caring

82 has been argued to be an important area to investigate to provide a holistic view of the caring process  
 83 and to assess what progress is being made (Fulton Picot et al., 1997, Kate, 2012, Onwumere et al.,  
 84 2018). A further important aspect of carer wellbeing that is linked to the positive aspects to caring is  
 85 the concept of ‘personal recovery’, conceptualised as living alongside the trauma, burden, stress of  
 86 caring for a loved one experiencing a psychotic crisis. This is a facet of carers experience that is not  
 87 assessed by any available measures used for carers but is now widely assessed for service users  
 88 (Sklar et al., 2013).

89 The recovery approach has now become a guiding principle in mental health care delivery in most  
 90 English-speaking countries across the globe (Slade et al., 2014, Tew et al., 2012, Price-Robertson et  
 91 al., 2017) with the recovery approach being a key UK policy recommendation made by the  
 92 Department of Health (2011). Personal recovery has been defined as “a deeply personal, unique  
 93 process of changing one’s attitudes, values, feelings, goals, skills and/or roles” and “a way of living a  
 94 satisfying, hopeful, and contributing life even within the limitations caused by illness” (Anthony,  
 95 1993). Personal recovery differs from clinical recovery in that it focuses on the unique personal  
 96 journey that an individual with a mental health condition goes through in order to find new meaning  
 97 and purpose in their lives, even in the presence of clinical symptoms (Anthony, 1993, Slade, 2009).  
 98 There has been very limited research about the recovery approach and carers (Jacob et al., 2017,  
 99 Scottish Recovery Network, 2016) and recovery informed practice has largely overlooked carers  
 100 (Hungerford and Richardson, 2013). The bulk of current research has focused on service user  
 101 recovery, however there is now increasing recognition of ‘family recovery’ (Price-Robertson et al.,  
 102 2017, Norton and Cuskelly, 2021). Recovery for service users does not happen in isolation and that  
 103 it is dependent on family support (Wyder and Bland, 2014), and there is a need to understand and  
 104 support families in their own recovery journey as distinct from the recovery of the service user  
 105 (Norton and Cuskelly, 2021). It has been argued that carers are on a parallel journey of recovery  
 106 (Lovelock, 2016, Wyder and Bland, 2014), and that the family recovery journey is intrinsically  
 107 linked to the service user’s journey thus neither can be understood in isolation (Wyder and Bland,  
 108 2014). Increasingly there is a call for more recovery focused support for carers and family members  
 109 (Deane et al., 2015, Estrada, 2016, Poon et al., 2017, Norton and Cuskelly, 2021) and it is seen as  
 110 important to support the carers recovery journey to assist them in moving forward with their lives by  
 111 helping them to develop a sense of meaning and purpose despite ongoing challenges (Deane et al.,  
 112 2015). In supporting carers to identify their own recovery journey, it is also more likely to deepen  
 113 their understanding of their relatives’ experiences of mental health problems by understanding their  
 114 recovery journey (Lovelock, 2016), which may ultimately lead to improved relationships and a  
 115 reciprocal support system within the family (Chen and Greenberg, 2004). Supporting the carer’s  
 116 recovery journey may also indirectly support service user’s recovery because greater understanding  
 117 of personal recovery processes gives carers greater confidence in their own ‘expertise-by-caring’  
 118 (Fox et al., 2015). There are increasingly more recovery focused family interventions being  
 119 developed and trialled (Deane et al., 2015, Estrada, 2016, Rue et al., 2016) and there are strong  
 120 recommendations that carers must be included in recovery oriented social work practice (Poon et al.,  
 121 2019) and in care planning with mental health professionals (Fox et al., 2015).

122 In light of the recommendations to provide more recovery-oriented support for carers, there is a  
 123 requirement to identify self-report measures that may be used to assess personal recovery for carers.  
 124 However, there are potential challenges in both defining and measuring personal recovery for carers.  
 125 The primary challenge is that there is a limited literature on what personal recovery may mean for  
 126 relatives themselves (Lovelock, 2016, Wyder and Bland, 2014). Despite recent systematic reviews of  
 127 qualitative research examining carers’ experiences (Mui et al., 2019; Shiraishi and Reilly, 2019), to  
 128 date there is no qualitative research exploring specifically what personal recovery means for carers.

129 This presents a potential challenge for this review, as the conceptual understanding of personal  
130 recovery will necessarily rely on personal recovery for service users as opposed to their carers.  
131 Because of the lack of conceptual literature on personal recovery for carers, there might also be a  
132 lack of measures assessing recovery for carers. To the authors' knowledge, there is currently only  
133 one measure, that is in the process of development, that focuses on family recovery in particular (Rue  
134 et al., 2016; [email] Personal correspondence with K, MacKinnon, 17 August 2016). This has  
135 presented a core conceptual problem for this systematic review in that if there is only one specific  
136 measures of recovery for carers, is there a need for the review? The authors felt that because of the  
137 compelling argument that personal recovery is an important aspect of carer wellbeing then a review  
138 looking at measures of various singular dimensions of recovery would reveal which outcome  
139 measures could be used together to assess the multi-dimensional nature of personal recovery.  
140 Previous systematic reviews looking at carer self-report measures have focused on measures that  
141 mainly assess the negative impacts of caring (Harvey et al., 2005; Harvey et al., 2008; Testart et al.,  
142 2013), with many of the measures reviewed having been developed for the general population. This  
143 calls into question the validity of many of the measures in current use because it is difficult to  
144 adequately assess the experience of carers from the general population (Hilton, 2016). It is generally  
145 accepted to be good practice for self-report measures to be developed using the perceptions of the  
146 population they evaluate, to improve the relevance and validity of the measure (Slevin et al., 1988,  
147 Testart et al., 2013). In addition, previous reviews (Harvey et al., 2005; Harvey et al., 2008; Testart  
148 et al., 2013) found a limited amount of self-report measures related to positive outcomes, such as  
149 quality of life, however, none of the reviews identified a measure that related to the concept of  
150 recovery. Therefore, there is a need for a more up to date review that focuses on aspects related to  
151 the recovery concept, and where the self-report measures reviewed have been developed specifically  
152 for the carer population.

153 The primary aim of this review was to identify all self-report measures that have been developed for  
154 use with carers of those with psychosis or schizophrenia, and that assess aspects of personal  
155 recovery. A quality appraisal of the psychometric properties of the self-report measures was carried  
156 out using the COSMIN checklist (Mokkink et al., 2010). This review had two further aims: to  
157 investigate and assess the level of carer involvement in the development of each self-report measure,  
158 and to explore how well personal recovery was assessed by each self-report measure.

## 159 **2 Methods**

### 160 **2.1 Protocol and registration**

161 This systematic review was registered on 22<sup>nd</sup> May 2018 with PROSPERO (CRD42018096020), and  
162 followed the PRISMA (Moher et al., 2009) guidelines.

### 163 **2.2 Eligibility criteria**

164 Quantitative and mixed method studies that used a self-report measure(s) to assess the health and  
165 wellbeing of carers of those with psychosis or schizophrenia, were included. Carers included:  
166 parents, spouses, partners, grandparents, siblings, adult children, extended family and close friends in  
167 a caring role. Studies assessing paid carers, in-patient care staff and relatives under the age of 18  
168 (young carers) were excluded. It was thought likely that adults and adolescents/children would have  
169 substantially different experiences because of varying levels of responsibility and role expectations.  
170 The clinical group of interest were service users who had received a diagnosis of psychosis (acute,  
171 chronic, first episode) or schizophrenia (all types). Service users who have experienced an episode of  
172 psychosis as part of another serious mental illness such as bipolar disorder or personality disorder

173 were also included in this review, but only if the psychotic episode was the main focus of the article.  
174 See Appendix A for a full list of inclusion and exclusion criteria.

175 The self-report measures included any formally tested measure such as questionnaires, surveys,  
176 outcome assessments, instruments, and rating scales. Only self-report measures developed and  
177 validated in the English language and designed specifically to assess carers of those with a mental  
178 health diagnosis were included. There was no limitation on the date range of publication. Modified  
179 and brief versions of self-report measures were excluded from this review.

180 The conceptual challenge of this review has been the fact that there is limited research on personal  
181 recovery for carers, so particular attention was paid to operationalise this concept. Since there are no  
182 available self-report measures that primarily assess personal recovery for carers, several linguistic  
183 terms of recovery were collated from key authors on the topic of personal recovery (Anthony, 1993,  
184 Leamy et al., 2011, Resnick et al., 2005, Slade, 2009). These linguistic terms were discussed by the  
185 research team and a checklist of terms was created and incorporated as part of the search strategy for  
186 this review. (See supplementary material for a copy of the checklist).

### 187 **2.3 Information sources**

188 The following databases were searched in September 2017 with an updated search in March 2022:  
189 Academic Search Ultimate, CINAHL, MEDLINE, PsychINFO and PubMed. Additional searching  
190 strategies included checking the reference lists and citation tracking (using Web of Science) of the  
191 final papers. The search strategy involved setting out three distinct categories related to the key  
192 elements of the review: population, type of instrument and construct. Database specific search  
193 strategies were developed utilising tools such as MESH headings (MEDLINE) and thesaurus terms  
194 (PsychINFO). See Appendix B for an example search strategy.

195 The following key word search terms were used to search all databases: [POPULATION] carer\*,  
196 caregiver\*, relative\*, families, family caregiver\*, psychosis, psychoses, psychotic, psychotic  
197 disorder, schizophren\*, [TYPE OF INSTRUMENT] outcome measure, instrument\*, assessment,  
198 measurement scale, rating scale, survey, questionnaire, patient reported outcome measure, self-report  
199 measure, [CONSTRUCT] recovery, mental health recovery, hope, optimism, goals, relationships,  
200 identity, meaning, personal responsibility, full engagement with life, empowerment, knowledge, life  
201 satisfaction, self-direction, full potential, person-driven, peer support, support groups, community,  
202 strengths, respect, motivation to change, positive thinking, valuing success, aspirations, positive  
203 sense of identity, quality of life, meaningful life, meaningful social roles, rebuilding life,  
204 employment, self-efficacy, coping, and adaptability.

### 205 **2.4 Quality appraisal**

206 The COSMIN checklist (Mokkink et al., 2010) was used for this review as the gold standard for  
207 providing a comprehensive assessing the psychometric properties of self-report measures  
208 (Rosenkoetter and Tate, 2018). The COSMIN checklist was developed by expert consensus  
209 (Mokkink et al., 2010), is freely available and includes a thorough user manual and scoring sheet and  
210 as such provides a consistent and transparent approach to systematic reviews of self-report measures.

### 211 **2.5 Data extraction**

212 Online data extraction forms were created on DistillerSR (Evidence Partners, 2011) for the title and  
213 abstract screening and full text screening. Two independent reviewers (CH and NA) assessed all the

214 title and abstracts against the inclusion criteria. Separate scoring sheets were used for the COSMIN  
 215 4-point checklist results, and for the assessment of quality of measurement properties per measure.  
 216 CH carried out the COSMIN assessment, and then NA carried out a 20% check of the COSMIN  
 217 results. Data were extracted by CH from the final 15 measure development or validation papers that  
 218 related to: 1.) details about the measures 2.) characteristics of the study participants 3.) details about  
 219 the development of the measure and the psychometric properties required for the COSMIN  
 220 assessment.

## 221 **2.6 Synthesis of results**

222 The results of the COSMIN checklist were synthesized into two main results tables. The first table  
 223 summarised the methodological quality of each study per measurement property (Table 3). Due to the  
 224 comprehensive nature of the psychometric properties assessed, the COSMIN checklist does not  
 225 provide one single overall score for each measure. Therefore, a second table (Table 4) was created to  
 226 provide an overall assessment of the measurement properties for each outcome measure. The main  
 227 psychometric properties assessed by the COSMIN checklist are: internal consistency, reliability (test  
 228 re-test), content validity, structural validity and hypothesis testing. Certain psychometric properties  
 229 assessed using the COSMIN checklist, such as cross-cultural validity, were not included in this  
 230 review as no data were reported in the measure development papers.

## 231 **3 Results**

### 232 **3.1 Study Selection**

233 The electronic database search identified 3,154 records with an additional 24 records identified  
 234 through other search methods. The title and abstracts were screened by two reviewers independently  
 235 (CH and NA) with good inter-rater reliability (Cohen's  $\kappa = .78$ ). A total of 322 full text articles were  
 236 selected based on the title and abstract screening. Of the 322 full text articles, 179 were excluded  
 237 because they were based on a translated version of a measure, did not assess the psychometric  
 238 properties of a measure or did not assess an aspect of recovery. This resulted in a total of 143 full  
 239 text articles being screened to identify any potentially relevant outcome measures, of which 95 self-  
 240 report measures were identified. Only 15 studies, covering ten measures, fulfilled the inclusion  
 241 criteria. The main reasons for exclusion at full text are presented in Figure 1.

242 [Insert Figure 1 here]

243 Table 1 shows that characteristics of the included studies, Table 2 shows the characteristics of the  
 244 included measures, and Table 3 details the COSMIN review carried out on the included studies to  
 245 assess their methodological quality. No study was excluded based on methodological quality. A  
 246 synthesis of the COSMIN results of all studies is summarised in a levels of evidence table (Table 4)  
 247 where an assessment of all the measurement properties was carried out per measure. Table 5 details  
 248 the quality criteria used to assess the levels of evidence for each measure in Table 4 and is based on  
 249 Terwee et al. (2007) and DeVet et al. (2011) (See Appendix C).

250 [Tables 1-3 here]

### 251 **3.2 Results of Individual Studies**

252 Presented below are the summary findings of each measure, listed in alphabetical order by title of the  
 253 measure. Each summary provides an overview of the constructs assessed by the measure, whether

254 the constructs are based on theoretical model(s) and a summary of the theoretical model(s) used, the  
 255 overall structure of the measure (domains and sub-scales), the response options, an assessment of the  
 256 psychometric quality of the measure based on the COSMIN checklist, the level of public  
 257 involvement in the development of the measure, and finally how the measure relates to the concept of  
 258 personal recovery. All outcome measures assessed in this review have been specifically created for  
 259 use with carers of those with psychosis and schizophrenia.

### 260 **3.2.1 Carer Coping Style Questionnaire (CCSQ) - (Budd et al., 1998)**

261 The Carer Coping Style Questionnaire (CCSQ) was designed to assess the coping styles of carers of  
 262 those with schizophrenia and was based on two theoretical models; assessing the four dimensions of  
 263 expressed emotion (Leff and Vaughan, 1985), and the seven coping styles identified by Birchwood  
 264 and Cochrane (1990). The CCSQ has 89 items divided into nine subscales (collusion, reassurance,  
 265 emotional over-involvement, constructive, resignation, passive, warmth, criticism/coercion and over-  
 266 protectiveness). The response format of the CCSQ is a 5-point Likert scale. The CCSQ was tested  
 267 on 91 carers of those with schizophrenia in the United Kingdom. It scored 'poor' for internal  
 268 consistency on the COSMIN checklist because the authors did not conduct a factor analysis or  
 269 principal components analysis on the results despite a good alpha score for each subscale  
 270 (Cronbach's alpha ranged between 0.69 to 0.87). Even if the authors had carried out a factor  
 271 analysis, according to the COSMIN criteria, the CCSQ has a poor sample size ( $n = 91$ ) for testing the  
 272 unidimensionality of the factors as the population was below five times the number of items on the  
 273 scale (89 items). The CCSQ scored 'poor' on content validity because they did not involve carers in  
 274 the development of the measure, meaning it is not possible to say that the items were relevant to the  
 275 study population. The authors generated an item pool based on the theoretical models and then  
 276 carried out a Q-sort with a team of health professionals to classify the items into discrete categories  
 277 with the final item similarity matrix being subjected to a cluster analysis. Because no principal  
 278 components analysis or factor analysis was carried out the CCSQ scored 'poor' on structural validity.  
 279 The CCSQ demonstrates 'fair' hypothesis testing as the authors did not make it explicit how missing  
 280 items were handled and it was unclear what a priori hypotheses were made. The CCSQ showed  
 281 concurrent validity compared to the General Health Questionnaire (GHQ-28) (Goldberg, 1978), the  
 282 Cost of Care Scale (CCS) (Kosberg and Cairl, 1992), and the Symptom-Related Behavioural  
 283 Disturbance Scale (SBDS) (Birchwood, 1983).

284 The CCSQ does not seem to assess many aspects related to carer's personal recovery as the items  
 285 assess carer coping styles in relation to their interactions with the service user and how this relates to  
 286 expressed emotion. The CCSQ does not focus on the personal experiences of the carers, rather their  
 287 interactions with the service user and because of this the CCSQ does not seem to fit well with the  
 288 recovery framework.

### 289 **3.2.2 Carer Well-being and Support Questionnaire (CWS) - (Quirk et al., 2009)**

290 The CWS assesses the well-being and support of carers of those with serious mental illness and  
 291 dementia and was based on a pre-existing measure called the Carers' and users' expectations of  
 292 services - carers' version (CUES-C) (Lelliott et al., 2003). The CWS consists of 49 items and is  
 293 divided into two subscales: the carer well-being scale with 10 domains (your day-to-day life; your  
 294 relationship with the person you care for; your relationships with family and friends; your financial  
 295 situation; your physical health; your emotional well-being; stigma and discrimination; your own  
 296 safety; the safety of the person you care for; your role as a carer), and the carer support scale with 5  
 297 domains (information and advice for carers; your involvement in treatment and care planning;  
 298 support from medical and/or care staff; support from other carers; and taking a break (respite). The

299 CWS sub-scales are scored using either a 4 or 5-point Likert scale depending on the specific  
 300 subscale. The CWS was also validated with a large population sample of 361 carers from various  
 301 centres across the United Kingdom. The CWS scored ‘excellent’ on the COSMIN checklist for  
 302 internal consistency as they reported high Cronbach’s alpha scores for each subscale (0.96 and 0.97  
 303 respectively). The CWS scored ‘fair’ for reliability on the COSMIN checklist only because the  
 304 authors did not state the time interval between the two administrations of the test. The intra-class  
 305 correlations for both subscales were high:  $r = .92$  ( $n=91$ ) for the carer well-being scale and  $r = .88$   
 306 ( $n=92$ ) for the carer support scale which demonstrates good test-retest reliability. The CWS showed  
 307 ‘excellent’ content validity as the measure went through a rigorous three phase construction process  
 308 to make sure items were relevant to the constructs being assessed, and relevant for the target  
 309 population. Carers were consulted regularly throughout the development and validation stages of the  
 310 CWS construction which demonstrates excellent face validity and follows current good practice  
 311 guidelines for questionnaire construction (Streiner et al., 2015). The CWS demonstrated ‘excellent’  
 312 structural validity as the two-factor model accounted for over 50.8% of the variance. The CWS also  
 313 showed ‘good’ construct validity with all convergent hypotheses supported by moderately high  
 314 correlations with the General Health Questionnaire (GHQ-12) (Goldberg, 1988) ( $r = -.66$ ,  $n = 194$ )  
 315 and the Involvement evaluation questionnaire – European version (IEQ-EU) (van Wijngaarden,  
 316 2003) ( $r = -.70$ ,  $n = 122$ ).

317 The CWS covers a broad range of issues for carers and fits well with the recovery framework. The  
 318 first sub-scale (Carer Well-being) is particularly relevant to the recovery framework as it covers  
 319 carers personal experiences and looks at the various aspects of well-being such as physical health,  
 320 mental health, financial resources, social networks, the carers own needs and how the carers view the  
 321 future. The second sub-scale (Carer Support) is more focused on the level and quality of support that  
 322 carers receive from mental health services and is not as directly relevant to the recovery framework  
 323 as it focuses more on the practical aspects of caring and not how the carer perceives or finds meaning  
 324 in their role. The authors do suggest that the CWS can be used as in mix-and-match combinations  
 325 and that the validated well-being and support subscales can be administered separately, which could  
 326 mean that just the well-being sub-scale could be used to measure those aspects of recovery.

### 327 **3.2.3 Care-related Quality of Life (CarerQol) - (Brouwer et al., 2006)**

328 The CarerQol was developed to measure the quality of life of carers of those with physical and  
 329 mental health problems. Eight items are divided into two subscales, with seven items relating to  
 330 burden (fulfilment, relational, mental health, social, financial, support, physical) and one item to  
 331 assess happiness. The response format is mixed, with single choice answers for the burden subscale,  
 332 and a visual analogue scale (VAS) for the happiness item. The CarerQol has been well validated for  
 333 content and construct validity with three validation studies (Brouwer et al., 2006, Hoefman et al.,  
 334 2013, Hoefman et al., 2011) all based on data from carer populations in the Netherlands. It is unclear  
 335 as to whether the data were collected using the English or Dutch version of the CarerQol, however, it  
 336 was decided to include this measure in the review as the measure is available online in the English  
 337 language. All three studies had large sample sizes (Brouwer et al., 2006,  $n = 175$ ; Hoefman et al.,  
 338 2011,  $n = 1244$ ; Hoefman et al., 2013,  $n = 275$ ). Based on the COSMIN criteria two out of the three  
 339 studies scored ‘excellent’ for content validity (Brouwer et al., 2006; Hoefman et al., 2013). The  
 340 CarerQol scored less well for hypothesis testing with all three studies scoring ‘fair’, the main reason  
 341 being that the studies either failed to provide a description of how the missing items were handled or  
 342 they failed to report on whether any a priori hypotheses were formulated. Even though three  
 343 validation studies were carried out, there was no assessment of the measure’s internal consistency,  
 344 reliability or structural validity. The CarerQol did show some level of carer input in the development



345 of the measure which is positive in terms of participant involvement. Carers were involved in some  
 346 initial pilot testing and in commenting on the wording of the items, however, the researchers were  
 347 solely responsible for devising the initial item pool.

348 The CarerQoL does not fit well within the recovery framework despite purporting to assess carer  
 349 quality of life. The bulk of the items relate to aspects of carer burden with only one item relating to  
 350 happiness.

351 **3.2.4 Carers' and users' expectations of services - carer version (CUES-C) - (Lelliott et al.,**  
 352 **2003)**

353 The CUES-C assesses the experience of caregiving based around 13 items (help and advice,  
 354 information about care workers, information about mental illness, involvement and planning of care,  
 355 support for carers, own life, relationships, family and friends, money, well-being, stigma and  
 356 discrimination, risk and safety, choice to care). The response format involves three questions per  
 357 item (which is worded as a normative statement). Part A questions ask whether the carers experiences  
 358 matches the items normative statement, part B questions ask if the carer would like further support in  
 359 that area, part C is a free text box for comments on that item. It was developed for use with carers of  
 360 those with mental health problems in the United Kingdom. It is worth noting that this measure was  
 361 deconstructed and used as the basis for the development of the CWS. The CUES-C was validated  
 362 with a good size sample of 243 participants; however, it did not score well on the COSMIN checklist.  
 363 The CUES-C scored 'fair' for reliability on the COSMIN checklist because the authors did not?  
 364 report on how missing items were handled. Interclass coefficients were calculated for test-re-test  
 365 reliability and were moderately good for both parts of the measure ( $r = .61$ ,  $n = 97$ ). The CUES-C  
 366 was not based on any kind of theoretical model and as such it would be difficult to assess if all items  
 367 together adequately reflect the construct being measured, which relates to content validity. Despite  
 368 of this, the CUES-C scored 'good' for content validity because they showed a very good level of  
 369 carer involvement at all stages of the questionnaire development. An advisory panel worked with the  
 370 authors throughout the development process providing feedback on the measure and the authors  
 371 conducted focus groups and individual interviews on the draft measure. The CUES-C scored 'fair'  
 372 for structural validity on the COSMIN checklist because there was no description of how missing  
 373 items were handled. The authors did carry out a comprehensive principal components analysis on  
 374 both parts of the measure, part A includes 3 factors that account for 49% of the variance and part B  
 375 includes 2 factors that account for 51% of the variance.

376 The CUES-C has several items that fit with the recovery framework, such as the statements about the  
 377 carer's own lives, relationships with the service user, relationships with family and friends, their own  
 378 wellbeing that includes both positive and negative elements, and their personal choice to care.

379 **3.2.5 Experience of Caregiving Inventory (ECI) - (Szmukler et al., 1996)**

380 The ECI was the most commonly used measure in this review, being used in 20 of the 95 studies  
 381 reviewed. The ECI provides a very broad view of the experiences of caregiving and is based on the  
 382 stress-appraisal-coping framework (Lazarus and Folkman, 1984). It assesses both negative and  
 383 positive aspects of caring with 66 items divided across 10 domains. There are eight domains  
 384 covering the negative aspects of caring (difficult behaviours, negative symptoms, stigma, problems  
 385 with services, effects on family, the need to provide backup, dependency, and loss), and two domains  
 386 covering the positive aspects of caring (rewarding personal experiences, and good aspects of the  
 387 relationship with the patient). The response format for the ECI is a 5-point Likert scale and it was  
 388 developed by a team of researchers in the United Kingdom and Australia. The ECI has been

389 validated by two studies, the original by Szmukler et al. (1996) that provided a good overall  
 390 assessment of most of the psychometric properties of the measure, and a subsequent study by Joyce  
 391 et al. (2000) that assessed hypothesis testing. On the COSMIN checklist, the ECI showed ‘excellent’  
 392 internal consistency (Szmukler et al., 1996) as it had a large sample size (n = 626) and good  
 393 Cronbach’s alpha scores that were calculated for each dimension (ranging from 0.74 to 0.91). The  
 394 ECI also demonstrates ‘excellent’ content validity as it went through a rigorous five stage  
 395 development process where carers had a high level of input at every stage of its development. For  
 396 example, items were devised through a series of one-to-one interviews and focus groups with 120  
 397 carers. Szmukler et al. (1996) also ensured that the items were validated within the stress-coping  
 398 model and found that the ECI predicted psychological morbidity. The ECI also scored ‘excellent’  
 399 for structural validity because the authors carried out a comprehensive principal components analysis  
 400 on a large sample of 626 carers. The initial 14 factor model accounted for 60% of the variance, and  
 401 this was refined down to 10 factors for the final measure. The ECI scored ‘good’ on the Szmukler et  
 402 al. (1996) study and ‘fair’ on the Joyce et al. (2000) study for hypothesis testing. This was because  
 403 they did not state the expected magnitude of correlations or differences in the Szmukler et al. (1996)  
 404 paper, and because only limited information was provided on the measurement properties of the  
 405 comparator instruments in the Joyce et al.(2000) paper.

406 The ECI partially fits with the recovery framework because there are two dimensions that focus on  
 407 the positive aspects of caring: ‘positive personal experiences’ that assesses learning about oneself,  
 408 having greater confidence, and being more understanding of others with problems; and ‘good aspects  
 409 of the relationship’ that assesses the relationship with the service user and whether the carer feels a  
 410 sense of self efficacy in their care provision. However, a large portion of the ECI looks more at the  
 411 burden of caring, such as stigma, dependency, and loss, and dealing with difficult behaviours and  
 412 negative symptoms, which does not fit with the recovery framework.

413 The Brief Experience of Caregiving Inventory (BECI) (O’Driscoll et al., 2018) provides a shortened  
 414 19-item version of the ECI, which aims to provide a quicker and less burdensome version for carers  
 415 to complete. The BECI was reviewed but excluded from the final COSMIN assessment for two  
 416 reasons. First, the BECI has not been validated using a new sample population, as the authors carried  
 417 out a Multidimensional Item Response Theory (MIRT) on the original data collected for the  
 418 validation of the ECI in 1996. It is not possible to carry out a COSMIN assessment without a full  
 419 validation paper with data collected from a relevant sample population. Secondly, part of the  
 420 exclusion criteria for this review was to exclude modified versions of self-report measures.

### 421 **3.2.6 Family Mental Health Recovery Evaluation Tool (provisional title) - (Rue et al., 2016)**

422 The Family Mental Health Recovery Evaluation Tool (FMHRET) was developed to assess the well-  
 423 being and recovery of family members who were taking part in an online family recovery  
 424 intervention (Families Healing Together, 2018) in the USA and was validated by Rue et al., 2016.  
 425 The intervention is based on the stress-appraisal-coping framework (Lazarus & Folkman, 1984) and  
 426 the constructs assessed are the positive aspects of caregiving and family recovery. The measure  
 427 contains 46 items divided into six domains (capacity to support family member, hopefulness toward  
 428 recovery, mental health coping skills, boundaries and role clarification, communication, self-efficacy  
 429 toward recovery). The response options are divided into a mixture of 3 and 5-point Likert scales.  
 430 The FMHRET did not score well overall on the COSMIN checklist mainly because of the small  
 431 sample size used to validate the measure. The authors used a sample of 108 carers, which is less than  
 432 five times the number of items on the measure. To score anything above ‘poor’ on the checklist, the  
 433 measure should have had a sample size of more than 230 carers. The FMHRET scored ‘poor’ for  
 434 internal consistency but did demonstrate strong alpha values ( $\alpha = 0.76$  to  $0.86$ ). It scored ‘poor’ for

435 its structural validation because of the small sample size. It should be noted that the authors only  
 436 intended to carry out an exploratory factor analysis for this study, which may have been one of the  
 437 reasons for the small sample size. The exploratory factor analysis of the FMHRET showed a five-  
 438 factor model that accounted for 47% of the variance. The FMHRET scored ‘fair’ for content  
 439 validity, again because of the small sample size and because they didn’t employ robust participant  
 440 involvement in the development of the measure. According to the authors, the initial items were  
 441 developed through a qualitative analysis of blog post entries from the ‘Families Healing Together’  
 442 intervention, with a subsequent construct validity assessment with five ‘experts’ to refine the  
 443 conceptual definitions. It is not made clear who the ‘experts’ were but following personal  
 444 communication with K. MacKinnon (2016) it was clarified that only one of the ‘experts’ was a carer.

445 Of all the measures assessed in this review, the FMHRET is the most well positioned within the  
 446 recovery framework because it was developed to assess family recovery specifically. It looks at the  
 447 positive aspects of caring as its primary construct but also includes other aspects such as coping skills  
 448 and self-efficacy. Unfortunately, at the time of writing this review, the measure was not available for  
 449 use outside of the ‘Families Healing Together’ intervention.

450 **3.2.7 Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLLISS)**  
 451 **- (Friedrich et al., 2002)**

452 The FLLISS measures the stress of caregiving for siblings of those with schizophrenia and is based  
 453 on the stress model of caregiving (Pearlin et al., 1990). The FLLISS was developed in the USA. It  
 454 consists of 256 items across five domains that cover primary stressors, such as: caregiving roles,  
 455 disturbing behaviours and their relationship to the ill sibling; secondary stressors such as:  
 456 relationships with friends and family, work performance and career; the mediators of stress such as:  
 457 coping strategies and social support; and outcomes such as: effect on health and view of self; and  
 458 some demographic questions. The FLLISS uses a mixture of Likert scales, multiple and single  
 459 choice answers. The FLLISS was validated in two parts, the first part reporting how the measure was  
 460 devised (Friedrich et al., 2002) and the second part reporting the validation of the psychometric  
 461 properties of the FLLISS (Rubenstein et al., 2002). The FLLISS scored ‘excellent’ on the COSMIN  
 462 checklist for content validity as the authors had a very rigorous approach in the development of the  
 463 measure, basing the content of the items on a qualitative content analysis of interview data from 30  
 464 siblings. The authors also used some of the direct wording from the interview statements in the  
 465 wording of the items which the authors claim increased the ecological validity and relevance of the  
 466 measure for siblings, unfortunately they do not indicate which items are based on the interview  
 467 statements in their published article. Siblings were also invited to comment on the final version of  
 468 the measure before testing. The FLLISS scored ‘poor’ for internal consistency because the sample  
 469 size used was less than five times the number of items on the measure despite having a large sample  
 470 of 761 participants. The FLLISS is the longest measure in this review with 256 items and the study  
 471 would have needed a sample of over 1280 to score over a ‘poor’ rating on the COSMIN checklist.  
 472 This sample size issue also affected the score for the structural validity of the FLLISS, which was  
 473 also ‘poor’ while all the rest of the scores were ‘good’ to ‘excellent’.

474 Even though the FLLISS is mainly concerned with assessing primary and secondary stressors, there  
 475 are still elements to the measure that fit well with the recovery framework. Within those domains are  
 476 items that assess the relationships between siblings, their family and friends, and topics like career  
 477 and employment. Also, the FLLISS has a section that looks at the mediators of stress which is more  
 478 relevant to the recovery framework as this assesses coping strategies and social support. The one  
 479 concern in considering this measure for use to assess recovery is that it was specifically designed and

480 validated for siblings of those with schizophrenia and as such it's unclear as to whether it could be  
481 used with other family carers.

### 482 **3.2.8 North-Sachar Family life Questionnaire (N-SFLQ) - (North et al., 1998)**

483 The N-SFLQ assesses the experience of caring for someone with schizophrenia and was not based on  
484 any sort of theoretical framework. It consists of 11 items set across five domains that cover: coping  
485 strategies, knowledge of the illness, communication, behaviour management, and employment. It is  
486 rated on a 5-point Likert scale. The N-SFLQ was designed for and piloted in a small pilot study (n =  
487 56) of a family intervention training program in the USA. No formal validation was carried out for  
488 this measure, which rendered it impossible to assess its psychometric properties using the COSMIN  
489 checklist.

490 This measure covers some of the aspects related to the recovery framework, such as coping  
491 strategies, communication and employment, however, it appears that there is also a large focus on the  
492 service user and their progress with items assessing number of hospital admissions and length of  
493 hospital stay. Additionally, this measure has no formal validation and because of these reasons, it is  
494 not recommended for use in assessing recovery in carers.

### 495 **3.2.9 Schizophrenia Caregiving Questionnaire (SCQ) - (Gater et al., 2015)**

496 The SCQ was specifically designed for carers of those with schizophrenia and assesses their  
497 experiences of caregiving. It was not based on any theoretical framework but was developed from a  
498 commonly used burden measure called the Zarit Burden Interview (ZBI) (Zarit et al., 1980). The  
499 SCQ has 30 items spread across 13 domains grouped into two main constructs of the 'humanistic  
500 impact' of caring, and 'aspects related to the caregiver role'. The response format is an 11-point  
501 numerical rating scale. The SCQ was validated in two parts. The first validation paper by Gater et  
502 al. (2015) assessed the content validity of the measure and outlined how the measure was devised.  
503 On the COSMIN checklist, the measure scored 'excellent' for content validity. The authors describe  
504 a high level of participant involvement in the development of the measure as they carried out in-  
505 depth qualitative interviews with 19 carers to discuss the measure using a cognitive debriefing  
506 technique to assess their understanding of the measure and whether it was relevant and  
507 comprehensive for carers. The authors claim the measure demonstrates strong face validity. The  
508 second validation for the SCQ (Rofail et al., 2016) assessed the psychometric properties of the  
509 measure. The SCQ scored 'excellent' for internal consistency with Cronbach alpha scores ranging  
510 between 0.80 and 0.96. Rofail et al. (2016) also assessed the test-retest reliability ( $r = .75 - .87$ )  
511 demonstrating 'good' reliability on the COSMIN checklist. The SCQ showed 'excellent' structural  
512 validity with a comprehensive factor analysis where 13 clear domains were identified. The SCQ  
513 scored 'fair' for hypothesis testing. Even though the authors report that the item domain validity was  
514 fully satisfactory and that it showed good item convergent and divergent validity, according the  
515 COSMIN checklist the SCQ scored 'fair' because it was not made apparent what the a priori  
516 hypotheses were regarding the correlations or mean differences were.

517 In terms of the recovery framework, the SCQ seems to have a good fit. Even though it is based on a  
518 burden interview (ZBI) the domains assessed seem directly relevant to aspects of the recovery  
519 approach. For example, the SCQ assesses the 'humanistic impact' of caring relating to the social,  
520 emotional, physical impacts on the carer's daily life, while the 'aspects related to the caring role'  
521 investigates the carers perceptions of caregiving and the financial impact. It is a very well validated  
522 measure with excellent participant involvement throughout the development process and as such  
523 would be a strong measure to use to assess aspects of carer recovery.

### 524 3.2.10 Social Network Questionnaire (SNQ) - (Magliano et al., 1998)

525 The SNQ was designed to assess social networks and was developed for use with carers of those with  
 526 schizophrenia. The measure was not based on any kind of theoretical framework but was based on  
 527 the wider literature on social networks (personal correspondence with L. Magliano, 2016). The SNQ  
 528 contains 15 items with four domains assessing the quality and frequency of social contacts, practical  
 529 social support, emotional support, and the presence and quality of an intimate supportive relationship.  
 530 The validation of the SNQ was discussed within a paper that reports the results of a large European  
 531 research trial (Magliano et al., 1998) and as such there is limited detail about how the measure was  
 532 developed. The SNQ scored 'fair' for internal consistency on the COSMIN checklist primarily  
 533 because the authors did not describe how missing items were handled. The SNQ had moderate  
 534 Cronbach's alpha values ranging between 0.56 and 0.75 for each of the four factors. The test re-test  
 535 of the SNQ was carried out with 50 carers 10 days apart however the SNQ scored only 'fair' on the  
 536 COSMIN checklist for reliability because it was not explained how missing items were handled. The  
 537 SNQ scored 'fair' for content validity as the authors did not describe whether they assessed all items  
 538 as being relevant to the construct being measured and did not base the measure on a theoretical  
 539 framework. There did not appear to be much participant involvement in the development of the  
 540 measure apart from carers providing comments on the comprehensibility and relevance of the items  
 541 on a trial version of the SNQ. To assess the structural validity of the SNQ the authors carried out a  
 542 factor analysis and found four distinct factors that accounted for 56% of the variance, however, SNQ  
 543 scored 'fair' for structural validity as it was not clear how missing items were handled.

544 The SNQ is the only measure to provide a comprehensive assessment of social networks which fits  
 545 well with this aspect of the recovery framework; however, this is only a part of the recovery journey  
 546 that carers may travel. For example, it does not cover whether carers have developed a greater sense  
 547 of meaning and purpose through caring, or whether they feel more confident and empowered to  
 548 rebuild their lives. Because of this the SNQ should not be used in isolation to assess recovery but  
 549 could be used in conjunction with other measures to create a suite of questionnaires to  
 550 comprehensively assess recovery for carers.

### 551 3.3 Additional analysis

552 The overall findings from the COSMIN assessment of all 15 studies was synthesised into a levels of  
 553 evidence table (Table 4) following the approach outlined in De Vet et al. (2011). This provides a  
 554 good overall summary of the quality of each psychometric property for each of the 10 outcome  
 555 measures reviewed. The quality criteria for each psychometric property used for this assessment  
 556 were based on the recommendations by Terwee et al. (2007) and is outlined in Appendix C.

557 [table 4]

## 558 4 Discussion

### 559 4.1 Summary of Evidence

560 The aim of this review was to identify self-report measures created for carers of those who  
 561 experience psychosis that assess aspects related to the recovery approach. A total of 95 measures  
 562 were found, a large proportion of which were not targeted for carers of those with psychosis or  
 563 schizophrenia. Of the 10 measures considered relevant for this review, half were developed  
 564 specifically for use with carers of those with psychosis or schizophrenia, 30% were developed for

565 carers of those with a serious mental illness and 20% were developed for carers of those with a  
566 serious mental illness and either dementia or a physical impairment.

#### 567 **4.2 Recommendations for instrument selection**

568 Out of the 10 measures, the CarerQol was the most frequently evaluated with three studies assessing  
569 its validity. However, these studies only assessed content validity and hypothesis testing and  
570 therefore did not score highly on the COSMIN checklist. Instead, the three measures that scored  
571 highly on the COSMIN checklist and thus showed the strongest psychometric properties were the  
572 CWS, the ECI, and the SCQ. The CWS was found to have excellent internal consistency, content  
573 validity and structural validity, with good hypothesis testing and a fair level of reliability. The ECI  
574 showed excellent internal consistency, content validity and structural validity, and good hypothesis  
575 testing. The SCQ demonstrated excellent internal consistency, content validity, structural validity, a  
576 good level of reliability and fair hypothesis testing. It should be noted that the COSMIN results only  
577 provide limited guidelines on instrument selection. There are two other important factors when  
578 considering instrument selection for this review, public involvement in the questionnaire design, and  
579 how well it assesses elements of personal recovery for carers.

580 Public involvement in the development of a measure, directly relates to the relevance and content  
581 validity of the measure (Slevin et al., 1988; Testart et al., 2013; Zendjidjian & Boyer, 2014). It is  
582 seen as good practice and crucial to current measure development processes (Sklar et al., 2013), as it  
583 adds to the robustness of the research and is recommended by policy and funding directives (Shippee  
584 et al., 2015). Public involvement in the development of the 10 measures was mixed: five showed  
585 ‘good’ to ‘excellent’ public involvement with only three demonstrating ‘excellent’ public  
586 involvement by involving carers at every stage of the development process. The latter aligns with the  
587 recommendations made by Rat et al. (2007) who argue that it provides the most valid set of items for  
588 respondents. The remaining five measures showed either poor or no public involvement at any stage  
589 of the measure development. A similar comprehensive review of outcome measures for carers by  
590 Harvey et al. (2008) also found that a relatively low proportion of measures (8 out of 25) were  
591 developed with public involvement. Harvey et al. (2008) did note a greater level of public  
592 involvement in the more recently developed measures and it is clearly seen as good practice in  
593 measure development (Streiner et al., 2015). However, this was not echoed in the present review as  
594 some of the most recent measures like the Family Mental Health Recovery Tool developed in 2016  
595 showed a limited amount of public involvement in the development process, and the measure that  
596 demonstrated one of the best levels of public involvement, the ECI, was developed in 1996.

597 The second important factor when considering instrument selection for this review is how well each  
598 measure fits within the recovery framework. The Family Mental Health Recovery Tool is the only  
599 measure that has a good fit with the recovery framework, however, it is not currently available for  
600 use outside of the ‘Families Healing Together’ intervention (Rue et al., 2016). The CareQol, ECI and  
601 FLLISS all have a substantial focus on the burden and stress of caregiving and are therefore not  
602 considered useful in assessing recovery. Even though the ECI is one of the most comprehensively  
603 validated measures and scores highly on the COSMIN checklist, it only partially fits the recovery  
604 framework assessing only two positive aspects of caring; rewarding personal experiences, and good  
605 aspects of the relationship with the person being cared for. The CWS incorporates several aspects  
606 related to personal recovery in the carer wellbeing subscale such as: day to day coping, interpersonal  
607 relationships, physical and emotional wellbeing, and feelings of personal safety. The SCQ also  
608 provides a comprehensive set of items that assesses aspects relating to recovery such as: the  
609 ‘humanistic impact’ on the social, emotional, and daily life of life of the carer, and the aspects and

610 perceptions related to the caregiver role. Our recommendation of the best measures to use to assess  
 611 personal recovery would be either the CWS or SCQ or a combination of the two as they show strong  
 612 psychometric properties, cover a range of relevant aspects related to personal recovery, and  
 613 demonstrated a good level of public involvement in the development of the questionnaires.  
 614 However, using multiple measures to assess personal recovery still does not assess the multi-  
 615 dimensional nature of the recovery concept, and it could become burdensome for carers to complete.  
 616 A solution to this would be the development of a new outcome measure with a specific focus on  
 617 recovery for carers that could be used in future research studies as a more appropriate way to assess  
 618 this construct.

### 619 **4.3 Strengths and limitations**

620 The COSMIN has several strengths as a robust and rigorous assessment tool that was developed by  
 621 an international team of experts (Mokkink et al., 2010). It is becoming recognised as the ‘gold  
 622 standard’ and is a popular tool for many health-related systematic reviews (Rosenkoetter & Tate,  
 623 2018). Thus, this review has used the strongest quality appraisal possible. This review is also  
 624 strengthened by the fact that it goes beyond reporting on the COSMIN findings, by assessing another  
 625 important aspect of good practice in questionnaire design, public involvement in research.

626 This review presented a challenge in trying to apply the concept of personal recovery to a carer  
 627 population, which has been both a strength and limitation. Because of the complex nature of how to  
 628 define personal recovery, the research team devised a way to operationalise the concept by reviewing  
 629 the definitions of recovery as outlined by the key authors in this area: Anthony’s (1993), Resnick et  
 630 al. (2005), Slade (2009) the CHIME framework outlined by Leamy et al. (2011). The key concepts  
 631 and linguistic terms were then incorporated into a checklist (see supplementary material) and formed  
 632 the basis of the search terms of this review. This can be seen as a strength as it provides a transparent  
 633 overview of our understanding of the key features of recovery for carers.

634  
 635 However, by focusing on elements of recovery we may have been overly inclusive in terms of papers  
 636 identified as being potentially relevant. Note that 95 measures were identified initially, but only ten  
 637 of these could be related directly to recovery in some way. This may raise questions about the focus  
 638 of our search strategy. In the searches, the terms used to describe the target population brought back  
 639 results for carers from different clinical populations (physical and mental health). Two searches were  
 640 used with the Boolean operator ‘AND’, however, this still brought back irrelevant studies for this  
 641 review. On a positive note, this means that it is unlikely that any relevant studies were missed.  
 642

643 A limitation of this review is a potential selection bias due to the choice to only include English  
 644 language measures due to lack of funding to employ translators. This review also excluded translated  
 645 versions of measures originally developed in English, and measures that were developed in a foreign  
 646 language, as there appeared to be many non-English language measures that this would warrant a  
 647 separate review. However, there were two potentially relevant measures that were excluded because  
 648 they were developed and validated in a non-English language sample. The Scale for Positive Aspects  
 649 of Caregiving Experience (SPACE) (Kate et al., 2012) was validated in Hindi, and the Schizophrenia  
 650 Caregiver Quality of Life Questionnaire (S-CGQoL) (Richieri et al., 2011) was validated in French.  
 651 This review did not include short form measures either as it was felt that the reduced number of items  
 652 would affect the content validity of the measure and considering that measures only partly assess  
 653 aspects of recovery this would prove to be problematic. A further limitation of this review was that it  
 654 was not possible for the second reviewer to carry out the full COSMIN assessment on all papers due

655 to time constraints, however, the second reviewer carried out a 20% check of the work with a good  
656 level of agreement to the first author.

## 657 **5 Conclusion**

658 This review set out to identify all self-report measures that have been developed for use with carers  
659 of those with psychosis or schizophrenia and that assess aspects of personal recovery. It seems that  
660 in fact, there may be no measure targeting carers' recovery per se, despite its potential importance.  
661 The authors therefore set out to examine carer measures that to some extent measure specified  
662 aspects of 'carer recovery' and attempt to encapsulate this issue across available instruments. A  
663 small number of measures are available that combined, could be used to assess personal recovery for  
664 carers. The only measure specifically developed to assess recovery, the Family Mental Health  
665 Recovery Evaluation Tool is not currently available to clinicians or researchers. To get the most  
666 comprehensive assessment of recovery using the measures that are currently available would mean  
667 that a selection of measures would need to be used together which would be time consuming and  
668 burdensome for respondents to complete. For example, if the CWS, the ECI, SCQ, and the SNQ  
669 were to be used as a set of questionnaires to assess recovery, this would involve the participants  
670 completing an approximate total of 160 items. One solution would be to combine selected subscales  
671 from each of the various measures to form a new measure, however, this would still need to be  
672 validated as a separate measure and would still not cover all the aspects related to the concept of  
673 personal recovery. This review highlights the need for further research in this area, and the potential  
674 development of a new measure that is specifically focused on assessing personal recovery for carers  
675 especially considering the recent call for more support for carers on their 'parallel' recovery journey  
676 (Lovelock, 2016; Poon et al., 2017; Wyder & Bland, 2014). The COSMIN checklist provided a  
677 useful quality assessment for this review despite some failings. It enabled an overall quality  
678 assessment of the psychometric properties of each outcome measure to be assessed. It is also clear  
679 that public involvement is important at every stage in the development of a measure if this is to  
680 provide a tool that is valid and relevant for the target population.

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934 **7 Appendices**

935 **7.1 Appendix A – Inclusion and exclusion criteria for title and abstract screening**

936 [See tables at the end of this document]

937 **7.2 Appendix B – Example search strategy**

938 Search strategy: PsychINFO (EBSCOHost)

- 939 1. [POPULATION] (Using thesaurus subject terms) DE "Caregivers" OR DE "Family" OR DE  
 940 "Extended Family" OR DE "Family Members" OR DE "Adult Offspring" OR DE "Biological  
 941 Family" OR DE "Daughters" OR DE "Sons" OR DE "Parents" OR DE "Fathers" OR DE  
 942 "Mothers" OR DE "Siblings" OR DE "Brothers" OR DE "Sisters" OR DE "Spouses" OR DE  
 943 "Husbands" OR DE "Wives" OR DE "Significant Others"
- 944 2. [POPULATION] (Using key words) carer\* OR relative\* OR families OR 'family caregiver\*'
- 945 3. Thesaurus subject terms OR key words

- 946 4. [POPULATION] (Using thesaurus subject terms) DE "Psychosis" OR DE "Acute Psychosis"  
 947 OR DE "Affective Psychosis" OR DE "Chronic Psychosis" OR DE "Postpartum Psychosis"  
 948 OR DE "Reactive Psychosis" OR DE "Schizophrenia" OR DE "Acute Schizophrenia" OR DE  
 949 "Paranoid Schizophrenia" OR DE "Mental Disorders" OR DE "Bipolar Disorder" OR DE  
 950 "Schizoaffective Disorder" OR DE "Chronic Mental Illness" OR DE "Personality Disorders"  
 951 5. [POPULATION] (Using key words) psychosis OR psychoses OR psychotic OR 'psychotic  
 952 disorder' OR schizophren\*  
 953 6. Thesaurus subject terms OR key words  
 954 7. [TYPE OF INSTRUMENT] (using thesaurus subject terms) DE "Measurement" OR DE  
 955 "Psychological Assessment" OR DE "Behavioral Assessment" OR DE "Cognitive  
 956 Assessment" OR DE "Emotional Assessment" OR DE "Motivation Measures" OR DE "Stress  
 957 and Coping Measures" OR DE "Questionnaires" OR DE "Surveys" OR DE "Data Collection"  
 958 8. [TYPE OF INSTRUMENT] (using key words) "outcome measure\*" OR "instrument\* and  
 959 assessment\*" OR "measurement scale\*" OR "rating scale\*" OR "survey\*" OR  
 960 "questionnaire\*" OR "patient reported outcome measure" OR "patient reported outcome" OR  
 961 "self-report measure"  
 962 9. Thesaurus subject terms OR key words  
 963 10. [CONSTRUCT] (key words only) recovery OR "recovery in mental health" OR "recovery  
 964 model mental health" OR "mental health recovery" OR hope OR optimism OR meaning OR  
 965 purpose OR empowerment OR "life satisfaction" OR "positive thinking" OR "valuing  
 966 success" OR aspirations OR "positive sense of identity" OR "quality of life" OR "meaningful  
 967 life" OR "rebuilding life" OR self-efficacy OR coping OR adaptability OR adjustment  
 968 11. Final Search using searches 3 AND 6 AND 9 AND 10  
 969 12. Limit to Age 18+ (Adulthood), English Language, Human Participants

970 **7.3 Appendix C – Quality criteria for good measurement properties**

971 [See tables at the end of this document]

972 **8 Conflict of Interest**

973 The authors declare that the research was conducted in the absence of any commercial or financial  
 974 relationships that could be construed as a potential conflict of interest.

975 **9 Author Contributions**

976 Ms Claire Hilton designed the study, wrote the protocol, carried out the literature searches, screened  
 977 the articles, carried out the data extraction, completed the COSMIN checklist analysis, wrote the  
 978 manuscript. Professor Bill Sellwood and Professor Steven Jones provided input into the study design  
 979 and protocol, contributed to and approved the final manuscript. Miss Nadia Akers screened articles,  
 980 contributed to the analysis, contributed to and approved the final manuscript. Miss Katerina  
 981 Panagaki contributed to and approved the final manuscript.

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991 **12 Supplementary Material**

992 [See separate file]



993 Table 1 Characteristics of included measures

Instrument	Authors	Target population	Country of origin	Year of development	Constructs assessed	Domains	Number of subscales (number of items)	Response options	Full copy of instrument available
Carer Coping Style Questionnaire (CCSQ)	Budd et al.	Carers of those with schizophrenia	UK	1998	Coping styles	Coping style subscales - collusion; reassurance; emotional over-involvement; constructive; resignation; passive; warmth; criticism/coercion; over-protectiveness	9 (89)	5-point Likert scale	Yes
Carer Well-being and Support Questionnaire (CWS)	Quirk et al.	Carers of those with serious mental illness and dementia	UK	2009 & 2012	Well-being and support	Subscale 1 - Carer well-being scale (10 domains): your day-to-day life; your relationship with the person you care for; your relationships with family and friends; your financial situation; your physical health; your emotional well-being; stigma and discrimination; your own safety;	2 (49)	4 and 5-point Likert scales	Yes

						the safety of the person you care for; your role as a carer. Subscale 2 - Carer support (5 domains): information and advice for carers; your involvement in treatment and care planning; support from medical and/or care staff; support from other carers; and taking a break (respite).			
Care-related Quality of Life (CarerQol)	Brouwer et al.	Carers of those with serious mental and physical illness	Netherlands	2006	Quality of life	7 dimensions exploring burden: fulfilment, relational, mental health, social, financial, support, physical, and 1 dimension exploring happiness	2 (8)	Mixed format: single choice answers and a VAS	Yes
Carers' and users' expectations of services – carer version (CUES-C)	Lelliott et al.	Carers of those with serious mental illness	UK	2003	Experiences of caregiving	13 dimensions: help and advice, information about care workers, information about mental illness, involvement and planning of care, support for carers, own life,	13 (26)	Normative statements with a 3-point rating scale, free-text response section	Carer Well-being and Support Questionnaire (CWS) replaced this.

						relationships, family and friends, money, wellbeing, stigma and discrimination, risk and safety, choice to care.			
Experience of Caregiving Inventory (ECI)	Szmukler et al.	Carers of those with serious mental illness	UK and Australia	1996	Experience of caregiving	8 negative (difficult behaviours; negative symptoms; stigma; problems with services; effects on family; the need to provide backup; dependency; loss), 2 positive (rewarding personal experiences; good aspects of the relationship with the patient)	10 (66)	5-point Likert scale	Yes
Family Mental Health Recovery Evaluation Tool	Rue et al.	Families of those with serious mental illness.	USA	2016	Positive aspects of caregiving, family recovery	Capacity to Support Family Member, Hopefulness toward Recovery, Mental Health Coping Skills, Boundaries and Role Clarification, Communication, Self-Efficacy toward Recovery	6 (46)	Mixture of 3 and 5-point Likert scales	No

<p>Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIISS)</p>	<p>Friedrich et al.</p>	<p>Siblings of those with schizophrenia</p>	<p>USA</p>	<p>2002</p>	<p>Stress and caregiving</p>	<p>Primary stressors (caregiving roles, reactions to caregiving, disturbing behaviours, homelessness, alcohol, drugs, relationship with ill sibling). Secondary stressors (relationships with parents and family, relationship with other siblings, concerns about own children, relationship with spouse, relationship with friends, school performance, work performance and career). Mediators of stress: coping strategies (emotional/spiritual, relationships, cognitive and action) and social support (from friends, relatives, professionals and organized groups). Outcomes (effect on health, view of self)</p>	<p>5 (256)</p>	<p>Mixture of Likert scales, multiple choice answers and specific answers</p>	<p>Yes</p>
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North-Sachar Family Life Questionnaire (N-SFLQ)	North et al.	Carers of those with schizophrenia	USA	1998	Experience of caregiving	Coping strategies, knowledge of illness, communication, behaviour management, employment	5 (11)	5-point Likert scale	Yes
Schizophrenia Caregiver Questionnaire (SCQ)	Gater et al.	Carers of those with schizophrenia	USA, and with an international validation	2015 & 2016	Experiences of caregiving	Two distinct constructs: 'Humanistic impact' – social, emotional, daily life and physical impact; 'Aspects related to caregiver role' – perceptions of caregiving, financial impact.	13 (30)	11-point numerical rating scale (NRS)	Yes
Social Network Questionnaire (SNQ)	Magliano et al.	Carers of those with schizophrenia	Across Europe	1998	Social networks	Quality and frequency of social contacts, practical social support, emotional support, the presence and quality of an intimate supportive relationship.	4 (15)	Not reported	Yes

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996 Table 2 Characteristics of included studies

Study	Population	Sample size	Age, mean (SD or range)	Female (%)	Country
<i>CCSQ</i>					
Budd et al., 1998	Carers of those with schizophrenia	91	59 (20 - 85)	71	UK
<i>CWS</i>					
Quirk et al., 2012	Carers for those with mental health problems and dementia	361	65.5 (13.1)	65.3	UK
<i>CarerQol</i>					
Brouwer et al., 2006	Carers of those with physical and mental health problems	175	60.8 (13.1)	75	Netherlands
Hoefman et al., 2011	Carers of those with physical and mental health problems	275	58.74 (12.74)	74.3	Netherlands
Hoefman et al., 2013	Carers of those with physical and mental health problems	1244	<47.1 – 47.1%	58.3	Netherlands
<i>CUES-C</i>					
Lelliott et al., 2003	Carers of those with mental health problems	243	60 (24 – 87)	Approx. 75	UK
<i>ECI</i>					

Joyce et al., 2000	Cares for those with psychosis	69	Not reported	Not reported	UK
Szmukler et al., 1996	Carers of those with mental health problems	626	1 <sup>st</sup> sample - 53 (+-30 years), 2 <sup>nd</sup> sample - 46 (+-15 years)	66 (1 <sup>st</sup> and 2 <sup>nd</sup> samples combined)	UK and Australia
<i>Family Mental Health Recovery Evaluation Tool</i>					
Rue et al, 2016	Carers of those with mental health problems	108	<40 – 86%	89.9	USA
<i>FLIISS</i>					
Friedrich et al. 2002 (Part 1 paper)	Siblings of those with schizophrenia	N/A*	N/A*	N/A*	USA
Rubenstein et al. 2002 (Part 2 paper)	Siblings of those with schizophrenia	761	39.7 (10.6)	73.7	USA
<i>N-SFLQ</i>					
North et al., 1998	Carers of those with schizophrenia	56	Not reported	53	USA
<i>SCQ</i>					
Gater et al., 2015	Carers of those with schizophrenia	19	51.63 (28 - 69)	79	USA

Rofail et al., 2016	Carers of those with schizophrenia	358	Not reported	Not reported	Argentina, Brazil, Canada, Germany, Spain, France, UK, Italy
<i>SNQ</i>					
Magliano et al, 1998	Carers of those with schizophrenia	236	Not reported	Not reported	UK, Greece, Italy, Portugal and Germany

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998 Table 3 COSMIN results showing the methodological quality of each study per measurement property

Name of measure and study	Internal consistency	Reliability	Content validity	Structural validity	Hypothesis testing
<i>CCSQ</i>					
Budd et al., 1998	Poor	-	Poor	Poor	Fair
<i>CWS</i>					
Quirk et al., 2012	Excellent	Fair	Excellent	Excellent	Good
<i>CarerQol</i>					
Brouwer et al., 2006	-	-	Excellent	-	Fair
Hoefman et al., 2011	-	-	Fair	-	Fair
Hoefman et al., 2013	-	-	Excellent	-	Fair



*CUES-C*

Lelliott et al., 2003	-	Fair	Good	Fair	-
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*ECI*

Szmukler et al., 1996	Excellent	-	Excellent	Excellent	Good
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Joyce et al., 2000	-	-	-	-	Fair
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*Family Mental Health Recovery Evaluation Tool*

Rue et al., 2016	Poor	-	Fair	Poor	-
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*FLIISS*

Friedrich et al., 2002 (Part 1 paper)	-	-	Excellent	-	-
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Rubenstein et al., 2002 (Part 2 paper)	Poor	-	-	Poor	Good
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*N-SFLQ*

North et al., 1998	-	-	-	-	-
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*SCQ*

Gater et al., 2015	-	-	Excellent	-	-
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Rofail et al., 2016	Excellent	Good	-	Excellent	Fair
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1001 **Appendix tables**

1002 **Appendix A – Inclusion and exclusion criteria for title and abstract screening**

Criteria	Inclusion	Exclusion
Duplicate	Not a duplicate	A duplicate
Abstract/ Language	Abstract and paper title provided in the English Language.  Paper appears to have been published in English language, in an English language journal.	Abstract or title either not in English, or non-existent.  Paper appears to be published in a language other than English.
Publication type	Primary research studies, measure validation papers, measure development papers, systematic review, meta-analysis, conference proceedings, grey literature, peer reviewed papers.  Papers using a quantitative approach or mixed methods as their primary methodology.	Opinion/discussion piece, book review, a noting of a correction to a study, study protocol, unpublished dissertations and theses.  Papers using a qualitative approach as their primary research methodology.
Date of publication	Any	None

Population

Adult carers/relatives/friends – may include: parents, spouses, partners, grandparents, siblings, extended family, close friends in a caring role.

Paid carers, in-patient care staff, young carers, relatives under the age of 18 years old. Young carers (below age 18) were excluded as they have a different and more complex care experience to adult carers that may include more input from external agencies.

Clinical group (service user)

The service user of the relative/carer must have a diagnosis of a psychosis related serious mental health problem and must be an adult over the age of 16 years.

All forms of dementia. Any form of learning disability. Any form of developmental disorder such as: language disorders, learning disorders, motor disorders, autistic spectrum disorders and ADHD. Any physical health problems such as cancer, stroke, head injury etc.

Includes:

Schizophrenia (all types), acute and chronic psychosis, first episode psychosis, psychotic episodes.

Those under the age of 16 years.

Psychotic features of other serious mental illness, such as bipolar disorder and personality disorder, where this is the main focus of the paper.

Outcome measures

Any formal set of questions that have been designed and tested for use with relatives and carers.

Measures designed for populations other than relatives, even if those measures are commonly used in research studies with relatives, for example: The General Health Questionnaire (GHQ).

Includes self-report measures such as: questionnaires, surveys, outcome assessments, instruments and rating scales.

Any measures assessing the service user.

Also includes measures completed by a health professional through verbal questioning of the relative, such as in a structured interview.

Measures that include a section with open ended questions or semi-structured interviews.

Measures developed or translated into another language. It will be assumed that measures that have been used in foreign language research studies will have been translated into a foreign language, unless it is stipulated in the methods sections that English language measures were used.

Concepts being assessed in the outcome measures

Relatives' own personal recovery as relates to the 'recovery approach' and 'mental health recovery'.

Physical health, general health, carer burden, family burden, negative aspects of caregiving, caregiving hassles, stress scales, strain scales, caregiver distress, depression, anxiety, personality inventories, medical outcomes.

Aspects of recovery such as:

Hope, optimism, goals, relationships, identity, meaning, personal responsibility, ‘full engagement with life’, empowerment, knowledge, ‘life satisfaction’, self-direction, ‘full potential’, person-driven, ‘peer support’, ‘support groups’, community, strengths, respect, ‘motivation to change’, ‘positive thinking’, ‘valuing success’, aspirations, ‘positive sense of identity’, ‘quality of life’, ‘meaningful life’, ‘meaningful social roles’, ‘rebuilding life’, employment, self-efficacy, coping, adaptability

Other aspects relating to the positive aspects of caregiving: social support, interpersonal support, family satisfaction, family adaptability and cohesion, spirituality and personal growth.

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1004 **12.1 Appendix C**

1005 Table 5 Quality criteria for good measurement properties modified from Terwee et al. (2007) and DeVet et al. (2011)

Measurement property	Rating*	Criteria <sup>a</sup>
Content validity	+	All items refer to relevant aspects of the construct to be measured AND are relevant for the target

(including face validity)		population AND are relevant for the purpose of the measurement instrument AND together comprehensively reflect the construct to be measured
	?	Not all information for '+' reported
	-	Criteria for '+' not met
Structural validity	+	<i>Factors should explain at least 50% of the variance or adequate or good fit by goodness-of-fit criteria for a confirmatory factor analysis (CFA) or exploratory factor analysis (EFA).</i>
	?	Not all information for '+' reported
	-	Criteria for '+' not met
Internal consistency	+	At least limited evidence for unidimensionality or positive structural validity AND Cronbach's alpha(s) $\geq 0.70$ and $\leq 0.95$
	?	Not all information for '+' reported OR conflicting evidence for unidimensionality or structural validity

		OR evidence for lack of unidimensionality or negative structural validity
	-	Criteria for '+' not met
Reliability	+	ICC or weighted Kappa $\geq 0.70$
	?	ICC or weighted Kappa not reported
	-	Criteria for '+' not met
Construct validity (Hypothesis testing)	+	<i>Convergent or divergent validity tested AND good correlations reported</i>
	?	No correlations with instrument(s) measuring related construct(s) AND no differences between relevant groups reported
	-	Criteria for '+' not met

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