**Who wants more social contacts? A cross-sectional study of people with psychotic disorders in England**

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**Abstract**

Many people with psychosis have few social contacts which can significantly reduce their quality of life. While the symptoms of psychosis are thought to contribute to social isolation, they could also lead to the perception that patients are uninterested in increasing their social contacts or in socialisation interventions. Hence, those who most need support to reduce their isolation may be less likely to receive it. Despite this, studies have yet to identify the characteristics of patients who do and do not want to increase their social contacts. A cross-sectional study was conducted with 548 participants with psychosis in community mental health teams across England, covering urban and rural areas. Logistic regression analysis was used to determine predictors of wanting to vs. not wanting to increase social contacts. Content analysis was used to explore reasons given. The majority (68%) of participants reported a desire for more social contacts, which in turn was significantly associated with lower quality of life. While people with lower quality of life were more likely to express a desire for more social contacts, they were less likely to feel confident in increasing them. Reasons for not wanting to increase contacts were related either to perceived barriers or to feeling content with current circumstances. It may be concluded that people with psychosis who have a lower quality of life and little confidence in socialising have a greater desire for more social contacts. Hence, contrary to traditional beliefs, they are likely to be particularly motivated to engage with support to reduce social isolation if it is offered.

**Keywords**

Psychosis, Schizophrenia, Social contacts, Social isolation, Social network

**1. Introduction**

Many people with psychosis have few social contacts outside home or health services (Giacco et al., 2016; Harley et al., 2012; Palumbo et al., 2015). Having few social contacts has been increasingly recognised as an independent risk factor for poor mental and physical health (Pantell et al., 2013; Holt-Lunstad et al., 2010). Patients with fewer social contacts tend to have higher levels of symptoms (Giacco et al., 2012; Norman et al., 2005; Bengtsson-Tops and Hansson, 2001), more hospitalisations (Norman et al., 2005) and increased chance of relapse (Pinto, 2006).

The low number of social contacts associated with psychosis could be, at least in part, attributed to their illness. Their symptoms may lead to an “active social withdrawal”, for example because of paranoid ideation (Perivoliotis and Carther, 2009) or a “passive social withdrawal” due to negative symptoms (Blanchard et al., 1998; Giacco et al., 2012; Palumbo et al., 2015). This is accompanied by the perceived stigma and the actual discrimination that people with schizophrenia often encounter (Romm et al., 2012; Birchwood et al., 2006; Pallanti et al., 2004).

The notion of social withdrawal could lead to the assumption that those who have fewer contacts do so because they are uninterested or unwilling to engage in socialisation. Patients with worse clinical and social outcomes can be viewed as difficult to engage in psychosocial interventions in general (Dixon et al., 2016), and supported socialisation interventions in particular (Barbato et al., 2007; Harley et al., 2012). This may mean that those who are most in need of support to reduce their isolation are less likely to receive it. Despite this, little is known about the characteristics of those who do and do not want to increase their social contacts.

In this cross-sectional study we interviewed a sample of patients with psychosis across a number of urban, semi-urban and rural areas in England about their quality of life, current social contacts, interest in increasing their social contacts and thoughts about doing so. We sought to establish whether current quality of life and number of social contacts differed according to whether or not respondents wanted to increase their social contacts and whether they felt confident in doing so.

Our specific research questions were:

1. Are quality of life and number of current social contacts associated with willingness to increase social contacts?
2. What are the reasons people give for wanting to or not wanting to increase their social contacts?

**2. Methods**

The study was given approval after review by the West Midlands – Solihull Research Ethics Committee (17/WM/0191).

*2.1 Design*

This cross-sectional, mixed-methods study was conducted in community mental health teams across England, covering urban, semi-urban and rural areas.

*2.2 Participants*

Participants were recruited from six participating NHS trusts: Cornwall Partnership NHS Foundation Trust; Devon Partnership NHS Trust; East London NHS Foundation Trust (covering East London, Luton and Bedfordshire); Oxford Health NHS Foundation Trust (covering large areas of Oxfordshire and Buckinghamshire); Somerset Partnership NHS Foundation Trust; and Tees, Esk and Wear Valleys NHS Foundation Trust (covering county Durham, Darlington, Teeside, York and North Yorkshire).

In order to be eligible for the study participants had to: i) be 18-65 years old, ii) have a diagnosis of a psychosis-related condition (ICD-10 F20-29), iii) be receiving care from outpatient secondary mental health services, iv) have the capacity to provide informed consent and v) the ability to communicate in English.

*2.3 Procedures*

Eligible participants were identified from the caseloads of community mental health teams across the participating trusts. Researchers screened all patients attending an outpatient clinic on a given day throughout the recruitment period. Those meeting the criteria were invited to meet with a researcher who explained the study to them in more detail. Participants were asked to provide written informed consent prior to any assessments being undertaken.

*2.4 Measures*

The assessment was administered by a trained researcher and consisted of open and closed-ended questions as well as validated questionnaires.

Socio-demographic characteristics were collected; including age, sex, ethnicity, relationship status, living arrangements, accommodation, highest level of completed education, employment status and receipt of benefits. Clinical characteristics including diagnosis and years since first contact with mental health services were also collected.

Subjective quality of life (SQOL) was measured using the Manchester Short Assessment of Quality of Life (MANSA) (Priebe et al., 1999) which asked participants to rate on a scale from 1 (couldn’t be worse) to 7 (couldn’t be better) how satisfied they were with different aspects of their life. The mean score of the 12 items was calculated to determine SQOL.

This was followed by a measure of social contacts in the previous week using the Social Contacts Assessment (SCA) (Giacco et al., 2016). A social contact was defined as a named person that the participant had a conversation with that was more than just a greeting and not directly related to work, it did not include people the participant was living with or mental health professionals. Participants were asked to list the contacts and state the type of relationship they had with that contact, the method of communication (i.e. face to face, phone, messaging or email) and the number of days they had contact with them.

Willingness to expand social networks was explored using a series of closed and open-ended questions. Participants were asked, “Are you interested in having more social contacts (going out and meeting new people)?” The following options were provided; “Yes I wish to meet new people and am confident I can”, “Yes I wish to meet new people but I am not confident I can” or “No I do not think I will ever wish to meet new people”. They were then asked if anything had made it difficult for them to meet new people and what they believed could help them to meet new people. This was followed by a brief description of a trial that would test a new intervention to support people to increase their social contacts. Participants were asked if they would consider taking part in such a trial and to give a reason for their answer.

*2.5 Analysis*

Descriptive statistics were used to describe social contacts, participant characteristics and MANSA score. Desire to increase social contacts was expressed as an absolute number and percentage in response to the question “Are you interested in having more social contacts (going out and meeting new people)?”

In order to explore whether quality of life and current social contacts were associated with wanting to or not wanting to increase social contacts, binary logistic regression models were used. Firstly, interest in increasing social contacts was dichotomised into “wants to increase social contacts” and “does not want to increase social contacts”. Sociodemographic variables were dichotomised based on the outcome of the descriptive statistics i.e. the majority response. Ethnicity was dichotomized as “White British”; “not White British”, relationship status as “single”; “not single”, living situation as “living alone”; “not living alone”, accommodation as “independent accommodation”; “not independent accommodation”, education as “tertiary”; “not tertiary”, and employment as “unemployed”; “not unemployed”. Secondly, we tested socio-demographic variables as potential confounders if they were significant at p<.10 level in multivariable models. Finally, we entered all variables showing an association with the dependent variable (wanting to increase social contacts/not wanting to) in a multivariable logistic regression model.

Significant characteristics identified in the multiple regression model were further explored in relation to wanting more social contacts. ANOVA tests were used to determine whether there were differences in characteristics between those who said “Yes I wish to meet new people and am confident I can”, “Yes I wish to meet new people but I am not confident I can” or “No I do not think I will ever wish to meet new people”.

Open-ended questions were analysed using content analysis and the procedures outlined by Elo and Kyngäs (2007), with a view to establishing participants’ reasons for wanting to or not wanting to increase their social contacts. This allowed patterns in the data to be recognised through grouping together responses that conveyed similar meaning (Elo and Kyngäs, 2007). Responses to the following questions were analysed together: “Has anything made it difficult to meet new people so far?” “Do you have any ideas of what could help you with meeting new people?” “Would you consider participating in a trial <to increase social networks> and what are your reasons?” Authors H.T and D.G independently analysed the data and applied descriptive labels consisting of a single word or phrase to data items pertaining to the research question. Responses directly relating to taking part in a research project rather than increasing social contacts were not included. Similar labels were grouped together and given a title to reflect the content. These identified themes and subthemes were checked and agreed upon through discussion between HT and DG.

**3. RESULTS**

*3.1 Sample*

Between June 2017 and May 2018, 548 participants with psychosis were recruited. Data from 13 participants were excluded from the analysis due to insufficient completion of the measures leaving 535 participants with data to be analysed. Socio-demographic and clinical characteristics are summarised in Table 1.

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| **Table 1. Socio-demographic and clinical characteristics** (N=535) |
| Age, mean (SD) | 43.5 (10.9) |
| Sex, female, N (%) | 184 (34.4) |
| Ethnic group, N (%)* White British
* Black/Black British – African
* Black/Black British – Caribbean
* Asian/Asian British - Bangladeshi
* Asian/Asian British - Pakistani
* Asian/Asian British – Indian
* White Other
 | 340 (63.6)36 (6.7)33 (6.2)30 (5.6)16 (3)15 (2.8)15 (2.8) |
| Relationship status, N (%)* Single
* Married
* Divorced
* Co-habitating/Civil Partnership
* Widow/Widower
* Separated
 | 402 (75.1)65 (12.1)37 (6.9)13 (2.4)7 (1.3)6 (1.1) |
| Living situation, N (%)* Living alone
* Living with family
* Shared accommodation
* Living with friends
 | 246 (46)186 (34.8)90 (16.8)8 (1.5) |
| Accommodation, N (%)* Living in independent/unsupervised accommodation
* Living in supported accommodation
* Homeless
* Other
 | 392 (73.3)114 (21.3)6 (1.1)19 (3.6) |
| Highest level of education, N (%)* Tertiary/Further education
* Secondary education
* Primary education or less
 | 233 (43.6)223 (41.7)40 (7.5) |
| Employment status, N (%)* Unemployed
* Voluntary work
* Student
* Employed part-time
* Employed full-time
 | 375 (70.1)58 (10.9)19 (3.6)31 (5.8)20 (3.7) |
| Receiving state benefits, N (%) | 473 (88.4) |
| Diagnosis * Schizophrenia, N (%)
* Schizotypal disorder, N (%)
* Delusional disorder, N (%)
* Brief Psychotic Disorder, N (%)
* Schizoaffective disorder, N (%)
* Psychosis NOS, N (%)
 | 365 (68.2)3 (0.6)12 (2.2)14 (2.6)83 (15.5)34 (6.4) |
| Years since first contact with mental health services, mean (SD) | 17.6 (10.7) |
| MANSA score, mean (SD) | 4.5 (0.9) |
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*3.2 Who wants to increase their social contacts?*

Sixty-eight percent of participants indicated that they would be interested in increasing their social contacts (Table 2). Of those who expressed an interest in increasing their social contacts, 53.6% did not feel confident in doing so.

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| **Table 2. Social Contacts** (N=535) |
| Social contacts within previous weekMean (SD)MedianMode | 2.9 (2.6)21 |
| Wants to increase social contacts, N (%) * I wish to meet new people and am confident I can
* I wish to meet new people but I am not confident I can

Does not want to increase social contacts, N (%) | 364 (68)169 (31.6)195 (36.4)104 (19.4) |
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Univariate analysis showed an association between a worse quality of life and interest in increasing social contacts. A lower number of social contacts and willingness to increase them did not show a statistically significant association, but only a trend towards an association (Table 3).

Univariate analyses of potential confounders found significant associations for age, ethnicity, relationship status, level of education and years since first contact with mental health services. It was decided that age and years since first contact with mental health services were sufficiently similar that one variable should be removed to reduce the risk of co-linearity (r=.646, n=472, p<.001). As age showed the least significant association in the univariate analyses it was excluded from the final model.

In a multivariable logistic regression analysis, lower MANSA score was associated with wanting more social contacts (B=-.358, p=.010), while no significant associations were found for ethnicity, relationship status, level of education, years since first contact with mental health services or number of social contacts in the past week (Table 3). Multicollinearity statistics were used to demonstrate that the variance inflation factor (VIF) for all tested variables was <1.2, indicating no collinearity was present.

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| **Table 3. Univariate and multiple logistic regression models for wanting to vs. not wanting to increase social contacts** |
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| *Univariate logistic regression models* |
|  |  |  | CI for Odds ratio (95%) |
|  | B | p | Lower | Upper |
| Sex | -.239 | .316 | .493  | 1.257 |
| Benefits | -.576 | .150 | .257  | 1.231 |
| Relationship status | .482 | .048\*\* | 1.005 | 2.608 |
| Level of education | .514 | .027\*\* | 1.059 | 2.637 |
| Accommodation | -.142 | .579 | .527  | 1.431 |
| Living situation | .095 | .673 | .708  | 1.706 |
| Employment | .046 | .849 | .650  | 1.689 |
| Ethnicity | .404 | .074\*\* | .962  | 2.333 |
| Diagnosis | -.002 | .879 | .978  | 1.020 |
| Age | -.018 | .079\*\* | .963  | 1.002 |
| Years since first contact with mental health services | -.023 | .032\*\* | .957  | .998 |
| Number of social contacts in past week | .092 | .066\*\* | .994  | 1.210 |
| MANSA score | -.364 | .004\* | .543  | .888 |
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| *Multiple logistic regression models* |
|  |  |  | CI for Odds ratio (95%) |
|  | B | p | Lower | Upper |
| Relationship status | .504 | .060 | .979 | 2.797 |
| Level of education | .186 | .460 | .736 | 1.972 |
| Ethnicity | .377 | .149 | .874 | 2.431 |
| Years since first contact with mental health services | -.022 | .061 | .957 | 1.001 |
| Number of social contacts in past week | .081 | .126 | .977 | 1.203 |
| MANSA score | -.358 | .010\* | .533 | .917 |

*\* p <.05, \*\* p <.1*

A one-way between subjects ANOVA was used to compare the effect of wanting to increase contacts and feeling confident in doing so, wanting to increase contacts but not feeling confident in doing so and not wanting to increase contacts on MANSA score (Table 4). There was a significant effect of wanting more social contacts but not feeling confident on MANSA score (F(2, 465) = 19.65, p<.001). Bonferroni testing indicated that the mean MANSA score for those who expressed “I wish to meet new people but I am not confident I can” (M=4.22, SD=.88) was significantly lower than for those who said “I wish to meet new people and am confident I can” (M=4.74, SD=.97) and those who said “I do not think I will ever wish to meet new people” (M=4.76, SD=.84). There was no significant difference between those who said they wanted more contacts and felt confident that they could and those who did not wish to have more contacts.

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| **Table 4. MANSA score** (N=468) |
| MANSA, mean (SD)* I wish to meet new people and am confident I can
* I wish to meet new people but I am not confident I can
* I do not think I will ever wish to meet new people
 | 4.74 (.97)4.22 (.88)4.76 (.84) |
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*3.3 What are the reasons for wanting to or not wanting to increase social contacts*

Themes and sub-themes identified in the content analysis are summarised in Table 5. Reasons for wanting to increase social networks were related to i) taking part in activities or doing more things, ii) socialising with other people, and iii) wellbeing or growth.

Reasons for not wanting to increase social contacts were related to i) not feeling the need, and ii) perceived barriers.

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| **Table 5. Themes, sub-themes, and example quotes** |
| *Reasons for wanting more social contacts (177 reasons)* |
| Taking part in social activities or doing more things (46) | Engaging in social activities to overcome boredom (13) | “Get us out of the house a bit more”“Keep me busy”“To get out the house and have something different to do” |
| Developing social skills and learning new things (33) | “The chance to improve my sociability skills“Interesting to learn new things and have other things to think about”“Doing something new and it could be interesting” |
| Socialising with other people (92) | Increasing friendships (43) | “To meet new people, make new friends"“To increase my social network (mostly family at the moment, would like some friends)."“Just to make new friends” |
| Feeling lonely because of having become socially isolated (24) | “I used to do lots of things but now I'm very isolated.”“I want to find new friends because I don't have that many.”“Want to meet new people; I'm very lonely.” |
| Integrating into the community (3) | “About helping people integrate into the community.”“I want to feel part of the community.”“I’m interested in my condition and social inclusion.”  |
| Developing helpful contacts (22) | “Find people like myself who have also become quite isolated and have similar experiences to me (e.g. medication).” “Looking to work on healthy relationships.”“Maybe meeting other people like myself would get help to work things through together.” |
| Wellbeing or personal growth (39) | Building confidence (13) | “It would help to meet the public and to become confident.”“To increase confidence.”“Help me get to know other people and build my confidence up to try activities and explore the world and life more.” |
| Believing social activities will help their wellbeing (13) | “Get back to how I was before I became ill, used to be more confident/sociable.”“Would like to do things, would make life more interesting, would put me in a better mood and would contribute to mental welfare.”“To help me and my wellbeing.” |
| Wanting a change (13) | “To make changes in my life and in the practice of doing things; to break from routine.”“I'm starting to see that if I don't do these things then nothing will change, it can only help.”“I think it would be good to break my usual routine and do new things and make life worth living.” |
| *Reasons for not wanting more social contacts (121 reasons)* |
| Feeling content with current circumstances (73) | Not wanting more social contacts (9) | “I don’t really want any more social contacts.”“I’m not particularly bothered about meeting new people.”“Prefer not to.” |
| Happy as I am (17) | “I’m alright with what I’ve got.Family and my friend V are all I need; I don’t want to meet any new people.” “I’m happy with my life as it is; I don’t want to meet new people.” |
| Feeling they don’t need help with increasing their friendships/social contacts (32) | “Don’t really feel like I need more support meeting people; now creating my own social networks.”“I don’t feel like I need help as quite confident meeting people, I have a lot of friends and am very sociable.”“Quite confident and ready to make new friends, know myself now.” |
| Having other priorities (15) | “I tend to have quite a lot going on anyway.”“Too busy, family commitments.”“Not sure I have the time as I am mostly at work.” |
| Perceived barriers (48) | Not trusting people (9) | “Don’t really like going out if I don’t have a friend with me as I feel paranoid; I don’t trust other people.”“People are evil so I don’t want to spend time with people.”“I don’t like strangers.Don’t really want to meet people who I don’t trust.” |
| Having had bad experiences in the past (4) | "If things hadn’t happened I could form relationships with others; I’m not comfortable going to see people who haven’t suffered from serious mental health problems." “Does not want to make new friends through mental health services […] in the past has found other service-users only want something from me rather than genuine friendship.”“I end up meeting people with mental health issues but these friendships aren’t useful to me.” |
| Not feeling confident | “Would not feel comfortable in that situation.”“Don’t like meeting strangers, I feel scared.”“Not confident in meeting new people, likes to keep himself to himself.” |
| Feeling a lack of motivation (3) | “Because I didn’t have the motivation to do these things.” “Not active, seems a lot of effort.”“Problem with me is things are a lot of effort, putting more activities on top of that makes for more tiredness.” |
| Feeling too unwell because of physical or mental health problems (14) | “I don’t really want to meet new people as the voices do not want me to, and they affect my concentration.”“I have a lot of physical health problems so I find it difficult to go out independently.”“Paranoia is the biggest barrier.” |

**4. Discussion**

4.1 Main findings

The study findings suggest that people with psychosis who have a lower overall quality of life are more likely to show interest in increasing their social contacts. However, they are also less likely to feel confident in being able to do so. There is also a statistical trend for people who have fewer social contacts to be more willing to increase them.

The association between poorer quality of life and a greater wish to increase social contacts is, to our knowledge, a novel finding. On the other hand, the fact that most participants reported a lack of confidence in increasing their social contacts has been reported in the literature (Romm et al., 2012; Birchwood et al., 2006; Pallanti et al., 2004). It has been reported that people with psychosis and comorbid social anxiety have lower levels of self-esteem and social functioning (Romm et al., 2012), are more likely to internalise stigma (Birchwood et al., 2006), and use more avoidant safety behaviours (Romm et al., 2012; Pallanti et al., 2004). These two findings, taken together, suggest that it is not that people are unwilling, but rather that they may not feel able to increase their social contacts. Hence, assumptions that active or passive social withdrawal are indicative of a disinterest in socialising are not confirmed by our findings.

Our qualitative findings may provide new evidence to the longstanding debate on the causes of social withdrawal in psychosis, which has focused the role of symptoms (Pallanti et al., 2004). Whilst difficulty trusting people or lack of motivation may be related to the impact of positive and negative symptoms, participants also cited a number of other barriers, particularly not feeling confident or worrying about past negative experiences. These may be more easily targeted by psychosocial interventions. Participants also gave a number of reasons for their willingness to engage in a trial to increase social networks, such as a wish to develop confidence and social skills, increase friendships, integrate into the community, achieve positive change and increase their wellbeing. This suggests an appetite for supported socialisation interventions among people with psychotic disorders.

*4.2 Strengths and limitations*

The strengths of this study lay in its large sample size and efforts to include participants from a range of geographical locations (urban, semi-urban and rural). People living in more densely populated areas tend to have more social contacts (Latane, Liu and Nowak et al.,1995; Preciado, Snijders and Burk et al., 2012; Small and Adler, 2019), and more socially deprived areas tend to be associated with increased loneliness (Kearns, Whitley and Tannahill et al., 2015). These areas also have higher rates of psychosis (Kirkbride, Barker and Cowden et al., 2008; O’Donoghue, Roche and Lane, 2016) so the impact of the wider environment on levels of social isolation cannot be ignored. A further strength is the systematic screening of caseloads. Researchers regularly attended outpatient clinics throughout the recruitment period; on these days all attending patients were screened for eligibility to minimise selection bias.

There are several limitations. Firstly, with regards to the representativeness of the sample; all those who took part in the survey were under the care of secondary mental health services. They were therefore receiving some degree of support and engaging to a certain extent with healthcare services and contacts with professionals. People who are more difficult to engage in research and care may also be more socially isolated. However, a selection bias is more likely to have influenced the absolute numbers and percentages of people with psychosis wanting more social contacts (or not) rather than the associations of this with other variables. It is well established that associations between variables tend to be more robust towards selection bias than prevalence estimates (Etter and Perneger, 2000).

Secondly, measures of social contacts were based on self-report from patients and may be influenced by recall bias or differing views on what constitutes a social contact. A precise definition of ‘social contact’ was provided, which should have reduced biases but perhaps not completely eliminated them.

Furthermore, responses to the question asking about reasons for wanting to or not wanting to increase social contacts are potentially confounded by the wording. Participants were read a summary of a proposed intervention that would support people to increase social networks and were asked if they would consider participating in such a trial along with their reasons why. Reasons given that were directly pertaining to being involved in a research study (e.g. “I want to help with research”) were excluded during the analysis but it is still possible that some answers were influenced by discussing social contacts in the context of a research project. This also opens the possibility of social desirability bias which could have led to an over-estimation of the number of people who want to increase their social contacts.

*4.3 Implications*

This study has implications for both research and health and social care services working towards reducing social isolation in people with psychosis. Firstly, those who have lower overall quality of life should be given the opportunity to engage in interventions which help them to socialise. Such interventions should consider that people who may want to take part in them, likely also have dissatisfaction in other areas of their life. This may mean added complexity which could make attempts to socialise more difficult. An awareness of these complexities and strategies to overcome them may make efforts to support patients more successful. Secondly, lack of confidence and anxiety around socialising appear to emerge, both from our study and the previous evidence (Romm et al., 2012; Birchwood et al., 2006; Pallanti et al., 2004), as crucial factors in influencing the development of social isolation in people with psychosis. The priority in this area should be to develop the means to support those who wish to expand their networks but do not feel confident in doing so. Thirdly, the majority of participants did report wanting more contacts. The exact absolute numbers and percentages may have been influenced to some extent by a selection bias; however, a substantial proportion of people with psychosis with low quality life and little confidence to increase their social activities appear particularly motivated to engage in interventions that may help them to socialise more. This means that such interventions are likely to be taken up by those who need them most. These findings should encourage the development and testing of specific interventions to build the confidence of people with psychosis to socialise and help them to increase their social networks and activities.

**5. Conclusion**

People with psychosis who have a lower quality of life are more likely to want to increase their social contacts and less likely to feel confident in doing so. They may be open to engaging in interventions which help to build and maintain confidence with socialising as they are exposed to more social contacts.

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**Appendix A. CONSORT diagram**

Assessed for eligibility (n=4219)

Insufficient data, i.e. measures not completed (n=13)

Declined to take part (n= 1052)

Enrolled (n=548)

Consented to participate (n=570)

Did not meet inclusion criteria (n =1482)

Declined to be approached (n=1115)

Patients approached (n=1622)

Included in the analysis (n=535)

Did not meet inclusion criteria (n = 12)

Withdrew (n=1)

Previously completed survey (n= 9)

**Appendix B. Case Report Form**



Assessing social networks and social activities of people with psychosis

(SCENE WP1)

SCENE WP1 Survey CRF

Version 3 27/11/17

|  |  |  |
| --- | --- | --- |
| **Assessment Date** **(DD•MMM•YY)** | **Participant ID** | **Interviewer ID** |
| 🞎🞎•🞎🞎🞎•🞎🞎 | 🞎🞎🞎🞎🞎🞎🞎 | 🞎🞎🞎 |

This booklet is **not complete until all boxes are filled**.

1. ***SOCIODEMOGRAPHIC INFORMATION (to be taken from clinical records)***

1.1 Date of birth / /

 d d m m m y y y y

1.2 Gender 1 Female

2 Male

3 Transgender

4 Prefer not to say

1.3 Marital status 1 Single/unmarried

 *(from a legal perspective)* 2 Married

 3 Co-habiting / civil partnership

 4 Separated

 5 Divorced

 6 Widow/widower

 9 Not known

1.4 Country of birth Country \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1.5 Highest completed level of 1 Primary education or less

 education 2 Secondary education

 3 Tertiary / further education

 4 Other general education

 Please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1.6a What kind of accommodation do

 you live in? 1 Independent accommodation

 2 Supported accommodation

 3 Homeless / roofless

4 Other accommodation

please specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1.6b What type of supported

Accommodation (if applicable) ? 1 24-hour staffed

 2 Staffed (less than 24 hours)

 3 Unstaffed (but with support from staff)

1.7a What is your living situation? 1 Living alone

 2 Living with a partner or family

 3 Living with friend(s)

 4 Living in shared accommodation

1.7b Postal Code (partial) 🞎🞎🞎🞎

1.7c LSOA Code 🞎🞎🞎🞎🞎🞎🞎🞎🞎🞎

1.8What is your employment status? 1 Paid or self-employment (full time)

 2 Paid or self-employment (part time)

 3 Voluntary employment (unpaid)

 4 Sheltered employment

 5 Unemployed 6 Student

 7 Housewife/husband

 8 Retired

 9 Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1.9 Do you receive any state benefits? No = 0; Yes = 1

2.0 Main psychiatric diagnosis ICD-10 code \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Please specify if code not known \_\_\_\_\_\_\_\_\_\_\_\_\_

 \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

2.1 Other psychiatric diagnoses ICD-10 code \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 ICD-10 code \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 ICD-10 code \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 Please specify if code not known \_\_\_\_\_\_\_\_\_\_\_\_\_

2.2. Year of first contact with mental health services \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

2.3 Ethnic group 1 White British

 2 White Irish

 3 White Other

 4 Black/Black British – African

 5 Black/Black British – Caribbean

 6 Other Black/Black British background

7 Asian/Asian British – Indian

 8 Asian/Asian British – Bangladeshi

 9 Asian/Asian British – Pakistani

 10 Other Asian/Asian British background

 11 Mixed – White and Black African

 12 Mixed – White and Black Caribbean

 13 Mixed – White and Asian

 14 Other Mixed background

 15 Chinese

 16 Other ethnic group

Please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

2.4 Healthcare service 1 Primary care

 2 Secondary care

**SOCIAL CONTACTS’ ASSESSMENT (SCA) – List of contacts (to be completed during the interview)**

**Please name all the people you have been in contact with in the last seven days and answer the following questions for each of them. For “being in contact” we mean that you can name them and have had a chat (more than just greeting) in the last week. Please do not include people you are living with or mental health professionals. In relation to people you work with, please consider only contacts which take place outside your work and are not related to your work.**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **List of contacts****(initials)** | **Type of relationship**  (**1=parent, 2=sibling,****3=friend, 4=partner,****5=other, spec.)** | **On how many days, in the last week, have you been in face to face contact with him/her?** | **Was the meeting one to one or in a group?**1. one to one

(b) group(c) both | **If both, on how many days did you have one to one meeting(s)?** | **On how many days, in the last week, have you been in contact by voice or video call (using phone, skype or facetime, etc.)?** | **On how many days, in the last week, have you been in contact by social networking, e-mail or text message?** | **Can you talk to him/her about your personal feelings and worries?**1. Yes
2. No
 | **Did you do something for him/her in the last week?**1. Yes
2. No

**If yes, what?** | **Did he/she do something for you in the last week?**1. Yes
2. No

**If yes, what?** |
|  |  |  |  |  |  |  |  |  |  |
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**What did you do and who did you meet yesterday (take all 24 hours of the previous day)? (to be completed during the interview)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Time | Contact(s) (initials) | Relative (how many) | Friend (how many) | Professional (how many) | Fellow patient (how many)  | Other, specify (how many) |
| Before 8 |  |  |  |  |  |  |
| 8-9 |  |  |  |  |  |  |
| 9-10 |  |  |  |  |  |  |
| 10-11 |  |  |  |  |  |  |
| 11-12 |  |  |  |  |  |  |
| 12-13 |  |  |  |  |  |  |
| 13-14 |  |  |  |  |  |  |
| 14-15 |  |  |  |  |  |  |
| 15-16 |  |  |  |  |  |  |
| 16-17 |  |  |  |  |  |  |
| 17-18 |  |  |  |  |  |  |
| 18-19 |  |  |  |  |  |  |
| 19-20 |  |  |  |  |  |  |
| 20-21 |  |  |  |  |  |  |
| 21-22 |  |  |  |  |  |  |
| 22-23 |  |  |  |  |  |  |
| 23-24 |  |  |  |  |  |  |

**If you want to meet someone for a walk and a chat next week, who could you contact and ask?**

**Please make a list and specify whether these people are relatives, friends, mental health professionals or fellow patients.**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Contact (initials) | Relative (Y/N) | Friend (Y/N) | Professional (Y/N) | Fellow patient (Y/N) | Other, specify (Y/N) |
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**TIME USE SURVEY**

*I am now going to ask some questions about things that some people do in their spare time. This excludes time spent with your mental health care team. For each activity that I mention could you please tell me whether or not you have done this in the last WEEK, AND how often?*

|  |  |  |  |
| --- | --- | --- | --- |
| **Activity** | **Number of times** | **Amount of time (to the nearest 10 Minutes)** | **Did you do this with someone? If so who was it and what is their relationship to you?**  |
| Been to the cinema |  |  |  |
| Been to an event as a spectator (e.g., sports event, theatre, live music performance)? |  |  |  |
| Been to a museum, art gallery or heritage site? |  |  |  |
| Been to a library? |  |  |  |
| Been out to eat or drink at a café, restaurant, pub or bar? |  |  |  |
| Been to a shopping centre, or mall, apart from regular shopping for food and household items? |  |  |  |
| Been to some other place of entertainment (e.g., dance, club, bingo, casino) |  |  |  |
| Been on any other outdoor trips (including going to places of natural beauty, picnics, going for a drive or going to the beach)? |  |  |  |
| Been to a day centre or any support groups? |  |  |  |
| Been to a local community social group? |  |  |  |
| Attended a religious group/activity/service? |  |  |  |
| Visited friends |  |  |  |
| Been visited by friends |  |  |  |
| Other: (please specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |  |  |

*I am now going to ask you about sports activities. Could you please tell me whether or not you took part in any of these sports in the past WEEK and how often?*

|  |  |  |  |
| --- | --- | --- | --- |
| **Activity** | **Number of times** | **Amount of time (to the nearest 10 Minutes)** | **Did you do this with someone? If so who was it and what is their relationship to you?**  |
| Swimming |  |  |  |
| Cycling |  |  |  |
| Gym/weight training |  |  |  |
| Exercise classes (e.g., aerobics, martial arts) |  |  |  |
| Team sports (e.g., rugby, football, cricket, hockey, netball) |  |  |  |
| Racquet sports (e.g., tennis, badminton, squash) |  |  |  |
| Jogging, cross country, road running |  |  |  |
| Walking or hiking for 30 minutes or more (recreationally) |  |  |  |
| Pub games (e.g., snooker, pool, darts) |  |  |  |
| Other: (please specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |  |  |

|  |  |
| --- | --- |
| **Is this a typical week for you?** | **1 = Yes 0 = No** |

**Manchester Short Assessment of quality of life - MANSA**

Please estimate how satisfied are you with different aspects of your life that are listed below (accommodation, friendships, financial situation etc.) Use this scale below ranging form 1 to 7.

**1=Couldn’t be worse; 2=displeased; 3=mostly dissatisfied; 4=mixed; 5=mostly satisfied; 6=pleased; 7=couldn’t be better**

|  |  |  |
| --- | --- | --- |
| mansa01 | How satisfied are you with your life as a whole today?  |  |
| mansa02 | How satisfied are you with your job (or training/education as your main occupation)?***or if unemployed or retired***How satisfied are you with being unemployed / retired? |  |
| mansa03 | How satisfied are you with your financial situation?  |  |
| mansa04 | Do you have anyone who you would call a “close friend”? | 0=NO1=YES |
| mansa05 | In the last week have you seen a friend? (visited a friend, been visited by a friend, or met a friend outside both your home and work)  | 0=NO1=YES |
| mansa06 | How satisfied are you with the number and quality of your friendships? |  |
| mansa07 | How satisfied are you with your leisure activities? |  |
| mansa08 | How satisfied are you with your accommodation?  |  |
| mansa09 | In the past year have you been accused of a crime?  | 0=NO1=YES  |
| mansa10 | In the past year have you been a victim of physical violence? | 0=NO 1=YES |
| mansa11 | How satisfied are you with your personal safety?  |  |
| mansa12 | How satisfied are you with the people that you live with? ***or if you live alone***How satisfied are you with living alone?  |  |
| mansa13 | How satisfied are you with your sex life? |  |
| mansa14 | How satisfied are you with your relationship with your family |  |
| mansa15 | How satisfied are you with your physical health? |  |
| mansa16 | How satisfied are you with your mental health? |  |

**Willingness to expand social networks**

1. **Are you interested in having more social contacts (going out and meeting with new people)? Please pick only one answer.**

Yes, I wish to meet new people and am confident that I can do this

Yes, I wish to meet new people, but I am not confident I can do this

No, I do not think I will ever wish to meet with new people

Other

Please specify ………………………………………………………………………………..

1. **Would you be willing to discuss with someone what you could do to have more social contacts and take steps to achieve this?**

Yes, I would be willing to discuss options and take steps to achieve this

Yes, I would be willing to discuss, but am unsure I will take steps to achieve this

No, I do not think I will ever wish to do this

Other

Please specify ………………………………………………………………………………..

1. **What type of activity would you consider to meet new people (for example sports, leisure activities, voluntary work)?**

 *(Allow participants to reply in their own words and note their responses - please use quotation marks to indicate any verbatim notes)*

1. **Has anything made it difficult to meet new people so far?**

 *(Allow participants to reply in their own words and note their responses - please use quotation marks to indicate any verbatim notes)*

*First encourage a spontaneous answer. If there is no answer, you can prompt:*

*Prompts:*

*Lack of financial resources*

*Lack of confidence*

*Not knowing about ongoing activities*

1. **Do you have any ideas of what could help you on meeting new people?**

*(Allow participants to reply in their own words and note their responses - please use quotation marks to indicate any verbatim notes)*

*First encourage a spontaneous answer. If there is no answer, you can prompt:*

*Prompts:*

*Cheap social activities*

*Knowing about events/groups*

*Encouragement to feel more confident*

*Having someone to come along*

**Do you think the internet might help you to make contact with people?**

Yes

No

Maybe

I have never thought about this

Other

 Please specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **If yes, in what way?**

*(Allow participants to reply in their own words and note their responses - please use quotation marks to indicate any verbatim notes)*

1. **If yes, which tools do you think are the most helpful?**

Probe reasons for named tools.

(e.g. Skype, chat rooms, forums, social media, websites on local events and community groups)

**Future Trial**

***Please show participants the trial leaflet. Allow them time to read it and ask them if they have any questions about it. Also ask if they would prefer for you to explain about the trial to them verbally.***

**1. Would you consider participating in a trial like this?**

Yes

No

Maybe

Other

 Please specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **What are your reasons for your response to Ques 1?**

[Probe if reasons are to do with the intervention and concerns about it, or whether they are to do with trial procedures, including randomisation. Probe how the participant would feel about not being able to choose the treatment group - ask the participant if they really think that they would sign up for the trial].

*(Allow participants to reply in their own words and note their responses –*

*please use quotation marks to indicate any verbatim notes)*

***If the participants response to question 1 was “no” please complete question 3 only, however if it was “yes” please complete question 4 only. For participants who have answered ‘maybe’ to the previous question, both sections 3 and 4 should be completed.***

*Please ask the participant if they agree with any of the categories listed below:*

**3. Reasons for not wanting to take part** (tick all that apply)**:**

I do not want to expand my social networks

I am worried/anxious about expanding my social networks

I am concerned about not knowing which group I will be in

The inconvenience

I do not have time

I am concerned other people will get to know about my illness

Other

Please specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

N/A

*Please ask the participant if they agree with any of the categories listed below:*

**4. Reasons for wanting to take part** (tick all that apply)**:**

I want to help with research

I want to improve treatment for other people with similar problems

It will provide an opportunity to expand my social networks

Reimbursement as a research participant

It will provide an opportunity to receive more support

Other

Please specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

N/A

**5. If you are willing to take part, may we contact you later once such a trial is ready to start?**

Yes

No

N/A

**6. If you don’t think you would want to take part, or you are ‘not sure,’ is there anything that might encourage you to take part?** [Probe what sort of support people would like to see available to enable them to take part if relevant to the response]

1. **Any further comments?**