The Healthy Lives Project
Full report

Dorothy Gould 2016

Acknowledgements

Project participants without whose willingness to share their experiences and recommendations the Project could not have occurred.

The Healthy London Partnership for providing funding for the project under its Mental Health Programme.

Members of the Stolen Years' steering group for their suggestions about the work of the project, in particular Dr Mary Docherty, Mr Jay Nairn and M/s Nam Thaker.

The range of managers and staff who publicised the project within their organisations, helped to recruit participants and/or hosted visits connected with the project.

The note-takers for the workshop days: Dr Mary Docherty, M/s Nam Thaker and M/s Sarah Holloway.

The graphic recorder: M/s Debbie Roberts.

Dr Jayasree Kalathil, independent researcher, Survivor Research, for her advice during the project and during the collation of the report.

Table of Contents

Part One: Introduction **4**

1. Project aims 4
2. Background to the project 4
3. Methodology 6

Part Two: Findings **21**

1. Good physical healthcare 21
2. Positive developments 35
3. Barriers 38
4. Changes needed 53

Part Three: Discussion and conclusions **58**

Part Four: Recommendations **66**

References **69**

Appendix A: Background documents **73**

1. The Stolen Years' steering group's terms of reference 74
2. Information about the National Survivor User Network 77

Appendix B: Project surveys and topic guides **78**

1. The survey for people diagnosed with a serious mental illness 79
2. The survey for unpaid carers and family members 88
3. The topic guide for the first workshop day 97
4. The topic guide for the second workshop day 100

Appendix C: Graphic recordings **102**

1. For the first workshop day 103
2. For the second workshop day 104

Appendix D: Lived experience models **105**

1. Wellbeing 106
2. Holistic self-management 107

Appendix E: Survey results tables **108**

1. Table One 109
2. Table Two 110

Part One: Introduction

1. Aims of the Healthy Lives project

These were to understand better the physical health needs and physical healthcare experiences which Londoners diagnosed with serious (enduring) mental illnesses have and to identify improvements in commissioning and in services which are thought to be needed.

2. Background

People with lived experience of serious mental health problems/mental distress have been emphasising for many years that improvements need to be made to the physical healthcare which they receive and further action taken, too, to address physical side effects of psychiatric medication. In the report from Rethink Mental Illness (2012), *20 Years Too Soon,* for example, study participants highlighted the need for:

- Better integration of mental and physical healthcare
- Improved monitoring of the side effects of psychiatric drugs and opportunities to reduce medication, or come off it completely,
- An increase in reasonable adjustments for people with lived experience at GP surgeries
- More focus on physical health too in inpatient psychiatric settings
- More information about and access to local services and support groups, including those run by peers.

In the report entitled *Lethal Discrimination* (Rethink Mental Illness, 2013), it is emphasised that people diagnosed with serious mental illnesses are twice as likely to develop diabetes, two or three times more at risk of developing hypertension and three times more likely to die from coronary heart disease. Attention is also drawn to the fact that there has been a ten-fold increase in deaths from respiratory diseases amongst people diagnosed with schizophrenia and that people with serious mental illness diagnoses are over four times more likely to die prematurely. There is, therefore, a strong call in the report for improved physical health services.

At government and clinical levels, whilst there has been recognition for many years that attention needs to be paid to physical health issues for people with serious mental illness diagnoses, it is during the last five years that there has been a particular focus on this (Mental Health Foundation, 2013, and Working Group for Improving the Physical Health of People with SMI*,* 2016). Thus, in its 2014 report, the British Medical Association underlines the fact that people diagnosed with serious mental illnesses are more at risk of long term physical health problems, receive poorer healthcare and die 15-20 years earlier than members of the public in general. Further attention has been drawn to this in the King's Fund report on bringing physical and mental health together (Naylor *et al,* 2016). The latter highlights the fact that people diagnosed with serious mental illnesses are at much greater risk of a variety of physical health problems, not just those diagnosed with bipolar disorders, or schizophrenia, but also people who, in psychiatric terms, have eating problems, personality, or drug and alcohol disorders, or unresolved depression or anxiety and that, as a result, their life expectancy is seriously reduced. The authors of all four reports cited here also emphasise the importance of finding solutions and put forward related proposals.

Research in other countries, in particular the United States (US), underlines the fact that these problems are not limited to the United Kingdom (UK). There has been a series of research studies in the US both about the issues and about the availability of interventions, for example the systematic review by Nover and Jackson (2013). Nover and Jackson highlighted the increased risk of metabolic syndrome which people diagnosed with major psychotic and/or affective disorders face, searched for studies about primary care-based educational interventions designed to decrease metabolic syndrome risk factors and concluded that it was not possible to demonstrate that there are effective interventions.

This physical health disparity is a major point of concern in itself. It also runs contrary to the UK government's continuing emphasis on the need for parity of esteem between physical and mental health services (Department of Health, 2011), to the stipulation in the Mental Health Act's revised Code of Practice (Department of Health, 2015) that detained patients also receive improved physical healthcare and to a series of government mandates, most recently this year's mandate to NHS England (Department of Health, 2016). These underline the need to reduce premature deaths amongst people diagnosed with serious mental illnesses and to close the health gap between people with mental health problems and the population as a whole, in line with the report from the Mental Health Taskforce (2016). The discrepancy is inconsistent as well with the World Health Organisation's call for universal health coverage for people with mental health problems, regardless of factors such as age, sex, socio-economic status, race, ethnicity, or sexual orientation (WHO, 2013).

Because of these issues, the London Mental Health Programme Board of the Healthy London Partnership[1] endorsed a work programme to bring in improvements

---

[1] The Healthy London Partnership stems from an initiative by NHS England and London's 32 Clinical Commissioning Groups. It has the brief of making London the world's healthiest global city.

to physical health outcomes for Londoners diagnosed with serious mental illnesses. In line with this, a working and steering group, currently called the Stolen Years Group, was set up in London to develop improvement priorities and to implement an agreed work programme. (For the steering group's terms of reference, see Appendix A.) One member of the steering group, the report author, has lived experience.

Under the Healthy London Partnership's mental health programme, a co-production initiative was also launched; the Healthy London Partnership commissioned the National Survivor User Network (NSUN) to take the lead for the Healthy Lives project which is the focus of this report, in partnership with the Stolen Years steering group. NSUN is a user-led organisation which sets out to collect experiences and perspectives of people with lived experience from both dominant and marginalised communities and then to influence national and local policy and practice on the basis of these. (See Appendix A.) It was this ethos which NSUN was commissioned to bring to the Healthy Lives project, together with its experience in also working with unpaid carers and family members.

3. Methodology

3.1 Responsibility for the Healthy Lives project

The Stolen Years steering group members who worked particularly closely with the NSUN project team were Mary Docherty (MD), a consultant psychiatrist, and Jay Nairn (JN) who had a project management role within the steering group. Nam Thaker (NT) then took over JN's role during the course of the project. All members of the NSUN project team were people with lived experience of serious mental distress. The project manager was Sarah Yiannoullou (SY), NSUN's managing director. The lead facilitator and analyst was Dorothy Gould (DG), an independent service user consultant. There was administrative support from Zoe Kirby (ZK), NSUN's team administrator, and graphic recording by Debbie Roberts (DR) of Engage Visually.

The co-production emphasis for the study was unusual. As recently as four years ago, for instance, a worrying finding from Chadwick *et al* (2012) was that most recent research papers about physical health issues for people with serious mental illness diagnoses had been reported from professional perspectives with little focus on service users' opinions; their search related to papers which had been published in English during the last 10 years. Happell *et al* (2016) identified only four studies within peer-reviewed journals published in English for which people with lived experience acted as co-researchers. None of these studies stemmed from England; the studies were based in either the US, or Canada. Furthermore, in the case of one US study, the authors counted researchers who had professional roles in housing support services as equivalent to service user researchers on the basis that these services had a mediating role for service users, whereas the two roles are not the same. The paper by Thornicroft, Rose and Kassam (2007) about physical healthcare discrimination which people with lived experience may encounter is, however, an example of a paper co-authored by a researcher with lived experience.

One reason for the limited involvement of service user researchers may be the fact that studies in which people with lived experience have leading research roles are quite often viewed as less credible and legitimate than those by researchers without lived experience (Beresford, 2003). Russo and Beresford (2015), who are researchers with lived experience themselves, link this tendency with the concept of epistemic injustice which has been put forward by Fricker (2007). Fricker suggests that one type of epistemic injustice is testimonial injustice, members of disadvantaged groups' being given less credibility for what they say than other members of society, because of differences which there may be between their views and mainstream views. It is all the more important, therefore, that NSUN was funded to take a lead with the Healthy Lives project.

3.2 Project design

As has been set out in its paper on theory and methodology in qualitative research (NSUN 2016), NSUN has a 'reflexive' approach to research: questions the concept that it is possible to produce scientific forms of research which are without bias. In line with Byrne (2012), NSUN's position is that all researchers work within the context of particular social worlds and particular positions which, by definition, are likely to affect the methodology employed for a study, the questions used and the analytic conclusions reached. Thus NSUN's starting point is the lived experience ethos described in section 2 above. In common with Spicer (2012), NSUN would contend that quantitative research also rests on values and assumptions which researchers bring to the research design and to the interpretation of data; they, too, work within particular contexts.

Rose (2009:41) discusses what the ideas outlined above mean for user-led and collaborative research in mental health contexts, in particular in relation to presumptions that researchers with lived experience are liable to be 'subjective' because they are too close to the subject. She suggests that mainstream research:

'...comes from a particular standpoint. In psychiatry, that standpoint is the perspective of those who deliver services and treatment and who research them (usually the same people). If this is so, user-focused research is not biased and subjective but comes from a different standpoint – that of those who receive services and treatments'.

Given the presumption that all studies, including user-led, or co-produced studies, are affected by their contextual nature, steps were also taken, however, to promote trustworthiness and rigour in the Healthy Lives project, in terms of the methodology selected, the recruitment process employed, the data collection tools and the analysis; see further the material which follows in the rest of section 3.

An initial step was to draw on the advantages of a mixed methods approach for the project. This methodology has become much more usual in recent years, particularly with the recognition that the employment of more than one methodological strategy avoids privileging one particular approach. Consequently, provided it is designed and implemented competently, a mixed methodology generates a more diverse range of views, so enabling a greater variety of perspectives to be taken into account (Spicer, 2016). Quantitative data and some qualitative data was collected during May and June 2016 through a survey for people with a serious mental illness diagnosis and through another for unpaid carers/ family members of people with this diagnosis. There were also two workshop days, one in June and one in July 2016, during which a series of focus groups occurred. The employment of surveys made it possible to obtain a wider number of opinions than would have been possible to achieve through focus groups alone. The use of focus groups facilitated a more in-depth exploration of participants' views.

For its mixed methods approach, the project team drew on criteria put forward by Lincoln and Guba (1985, cited in Shenton, 2004): took into account issues of credibility, transferability, dependability and confirmability. They also made use of suggestions from Sale and Brazil (2004) about ways in which these criteria may be used as a basis for trustworthiness and rigour in a mixed methodology.

3.2.1 The surveys

Questions in the service user survey covered the following issues:

- Respondents' demography
- General physical health issues and/or long term conditions for respondents
- Ways in which they already looked after their physical health
- What physical health support they would like and where they would like it
- Their experiences of physical healthcare
- What involvement, choice and control they had in relation to physical healthcare.

Unpaid carers and family members were invited to supply information which covered the following points:

- Their demography

- General physical health issues and/or long term conditions for the person to whom they provided care/their relative

- Ways in which that individual already looked after his/her physical health

- What physical health support they thought that s/he would find most beneficial and where they thought that s/he would most like it

- The individual's experiences of physical healthcare

- What involvement and influence they had as unpaid carers/family members.

For both surveys, account was taken of a range of sources. One was a small consultation (Gould, 2016) on guidance for commissioners about physical health needs of people with serious mental illness diagnoses; the report author had sought the views of others who have lived experience, as part of her membership of the Stolen Years' steering group. Use was also made of recent reports on physical health issues for people diagnosed with serious mental illnesses, in particular those from Rethink Mental Illness (2012), the Mental Health Foundation (2013), the British Medical Association (BMA, 2014) and the Kings Fund (Naylor *et al,* 2016). Recent research articles on this subject were utilised as well. One was a literature review by Doherty and Gaughran (2014) about the interface of physical and mental health and about ways of improving care for people with two particular mental health diagnoses (depression and psychosis) and two particular physical health conditions (diabetes and cardiovascular disease). The second addressed 'co-morbid physical illness' experienced by people with psychosis and considered strategies for dealing with this (Docherty, Stubbs and Gaughran 2016).

The survey questions were compiled by NSUN's managing director and the lead facilitator and analyst. To promote trustworthiness and rigour, feedback about the questions was then invited from an independent survivor researcher and from members of the Stolen Years steering group and relevant points taken into account.

(For copies of each survey, see Appendix B.)

3.2.2 The workshop days

Two workshop days were held, the first while the surveys were still open and the second once the surveys were complete. Both were held in a community setting (a local hotel) so that the venue was as participant-friendly as possible. The topic guide for the first workshop day built further from the survey questions. The topic guide for the second workshop day took into account both initial findings from the surveys and data from the first workshop day. The process used to promote trustworthiness and rigour was similar to that adopted for the surveys: initial compilation of the topic guides by NSUN's managing director and the lead facilitator and analyst, followed by opportunities for feedback by others.

At the first workshop day, there was a series of focus groups. Participants were invited to say what they thought an ideal physical health service would be, what examples of good services they already had, what obstacles there were and what changes they would like to see in commissioning, service provision and the influence which they had at personal, service and commissioning levels.

Varied methods were employed to draw out responses, so that it was as easy as possible for participants to contribute. As well as seeking verbal responses to questions in the topic guide, the facilitators invited participants to:

- Put together written and pictorial descriptions of their ideas about ideal physical health services and then to discuss these
- Use a set of six cards to help them to think about commissioning changes which they most wanted and then to talk about these. One card was blank for participants' own ideas and five cards contained some key suggestions which have already been advocated by a number of people with lived experience; contributions from the latter to the values-based guidance produced by the Joint Commissioning Panel for Mental Health (2013) were one particular source. Suggestions on the five cards were:
    - More information about how commissioning works (what money there is for health services, who holds it and who makes the decisions about it)
    - More use of values-based commissioning (giving as much weight to service users' and carers' views as to professional views and research findings)
    - More funding decisions based on research about people's experiences (qualitative research) as well as on statistics (quantitative research)
    - More funding to improve health services for groups who may face particular disadvantages (for example people from black, Asian and other minority ethnic communities, homeless people and older people)
    - More funding for non-clinical resources as well (for instance local community groups and user-led groups)
- Prepare one-minute soap box presentations, in pairs, about changes which they thought were most needed in physical health services
- Watch a short video clip produced at NSUN about an increased influence over physical healthcare which people with lived experience of varied genders, ages and ethnicities would like and then to comment on this and to talk about any changes in influence which they themselves would value.

The second workshop day started with focus groups during which participants had the opportunity to add further comments about:

- Suiting services to people's genders, sexual orientations and ethnicities
- Services for people with long term physical health conditions.

Responses were again invited through general discussion and, in the case of long term physical health conditions, through participants' selecting one, or more pictures to convey the concepts and feelings which came to mind when they thought about service provision for long term physical health conditions.

Findings from the surveys and the first workshop day were then presented, so that workshop participants could take these into account as well in deciding what they thought were especially key issues in physical healthcare services. Participants were invited to use green dots (for 'very important') and orange dots (for 'important') to indicate which findings they thought were particularly critical. They then explained and discussed their choices.

(For copies of the workshop topic guides, see Appendix B.)

At both workshop days, participants had post-it notes, which they could put up, and separate paper where they could make comments and then pass them on to the workshop facilitator privately. This was so that they could make anonymous comments, if they preferred, or additional observations if time available for a particular topic had run out.

In addition to audio recordings and note-taking at each workshop, there was also graphic recording: capturing key points from participants through short phrases and pictures portrayed on large posters. This was a way of summarising participants' responses in a visible form and so provided a further way of thinking about these. (For copies of the graphic recordings, see Appendix C.)

3.3 Recruitment

The selection criteria for participation in the surveys were as follows:

- Having a diagnosis of serious mental illness, or being an unpaid carer/family member of someone with this diagnosis
- Being an adult (aged 18 and above)
- Living in the London area.

The workshop criteria were the same, other than the fact that London-based professionals in non-clinical roles who had experience with people diagnosed as seriously mentally ill were also eligible to attend.

Those who offered to take part in the project were self-selecting, which means that, as with any study, individuals who had a particular interest in the project theme were most likely to be the people who put themselves forward; in that sense, therefore, there was the possibility of some bias in responses (Rutterford, 2012). To reduce selection bias as much as possible, the project team approached a wide variety of organisations (voluntary, user-led, carer-focused and Trust-based), with varying stances, and did so throughout the London area. The project team put a particular emphasis, too, on the recruitment of people who were diverse in terms of factors such as age, ethnicity, socio-economic circumstances, gender, sexual orientation and disabilities. Recruitment included people who had experienced homelessness, people with dual diagnoses and people in contact with the criminal justice system.

Service users and unpaid carers/family members were recruited independently of each other and so respondents to the two surveys might have no inter-connection.

3.3.1 Survey recruitment and participation

Following initial publicity about the service user and carer surveys, both surveys were launched through SurveyMonkey. To facilitate informed consent, written information about the surveys was provided (their purpose, the uses to which responses would be put and their anonymity) and NSUN's managing director also made herself available to answer questions about the surveys. To help further with the range of participation, a NSUN volunteer was available to provide support if that was helpful. In addition, respondents had the opportunity to complete hard copies of the survey, if they were unused to online surveys; NSUN staff then uploaded these.

One hundred and thirteen people sent unspoilt responses to the service user survey. There was considerable diversity amongst service user respondents, except that rather fewer men than women completed the survey and there were smaller numbers of participants under 35 and over 65. Age ranges amongst respondents were as follows:

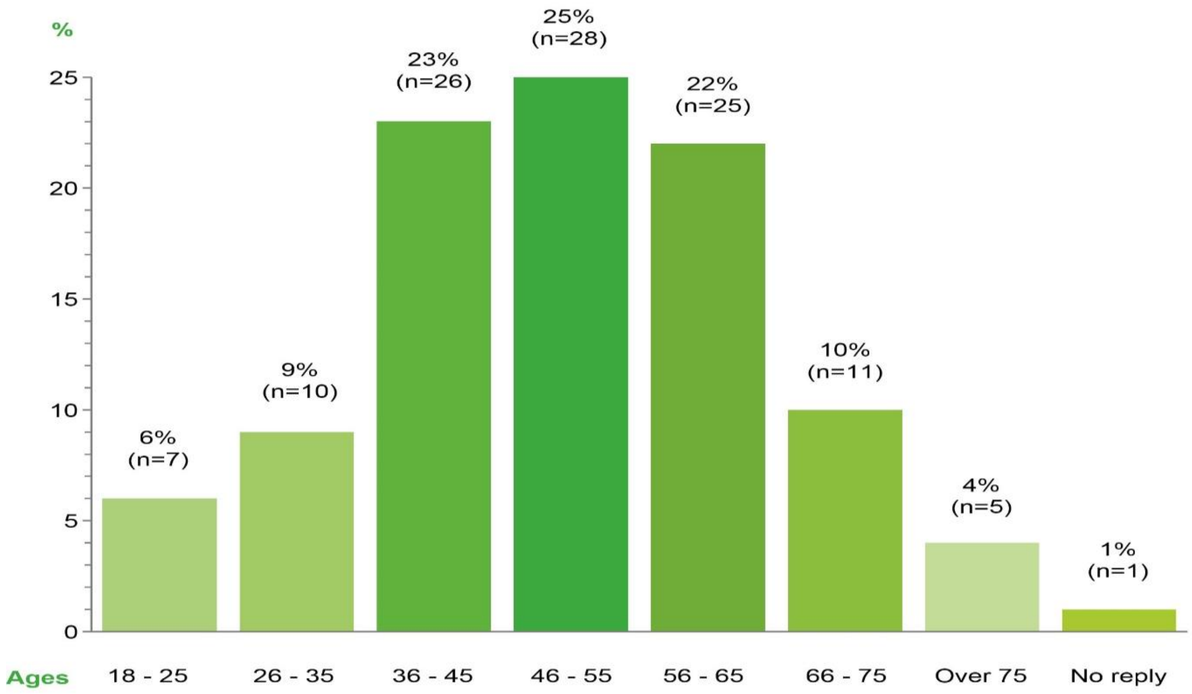


Figure 1 Age ranges of service user participants

The ethnicity of service user participants is set out in Figure Two below:

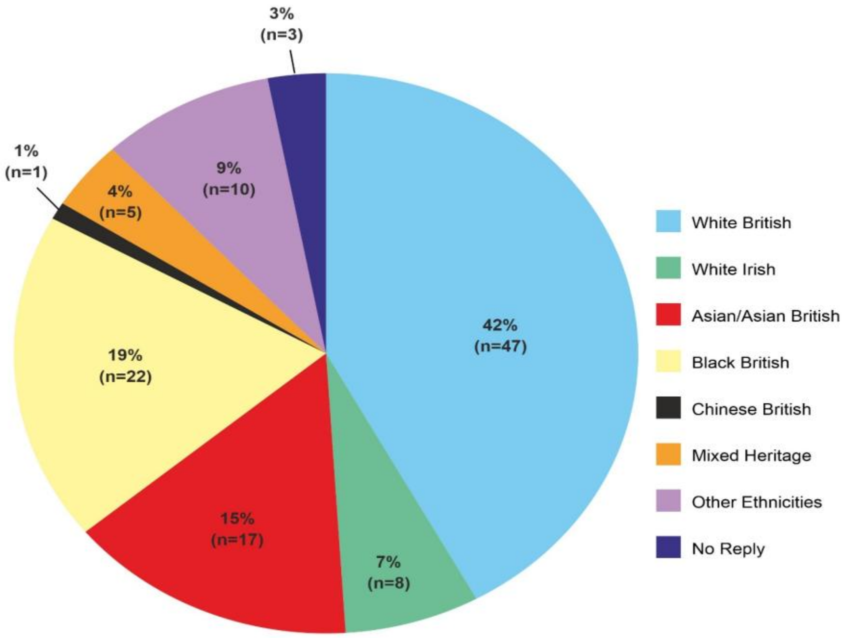


Figure 2 Ethnicity of service user participants

In terms of gender, 33% of service user participants (n=37) said that they were described as male at birth, 65% (n=73) that they were described as female and 3%

(n=3) did not reply to the question. Thirty percent (n=34) viewed themselves as male now, 58% (n=66) as female, 4% (n=5) thought of themselves in another way (as pangender, male/female, closet transgender and ‘human’) and 7% (n=8) made no reply.

In sexual orientation terms, 65% (n=73) of service user participants identified as heterosexual, 25% (n=28) as lesbian, gay, bisexual (LGB), or other and 11% (n=12) did not answer the question. Forty two per cent (n=48) spoke of having additional disabilities; in 50% of cases these were physical, or sensory disabilities, but a few mentioned other disabilities such as dyslexia, dyspraxia, or a learning disability.

Fifty nine people sent unspoilt responses to the survey for unpaid carers and family members. There was also considerable diversity amongst these participants, except that respondents under 36 were least well represented and there were again considerably fewer male than female participants. Age ranges amongst respondents were as follows:

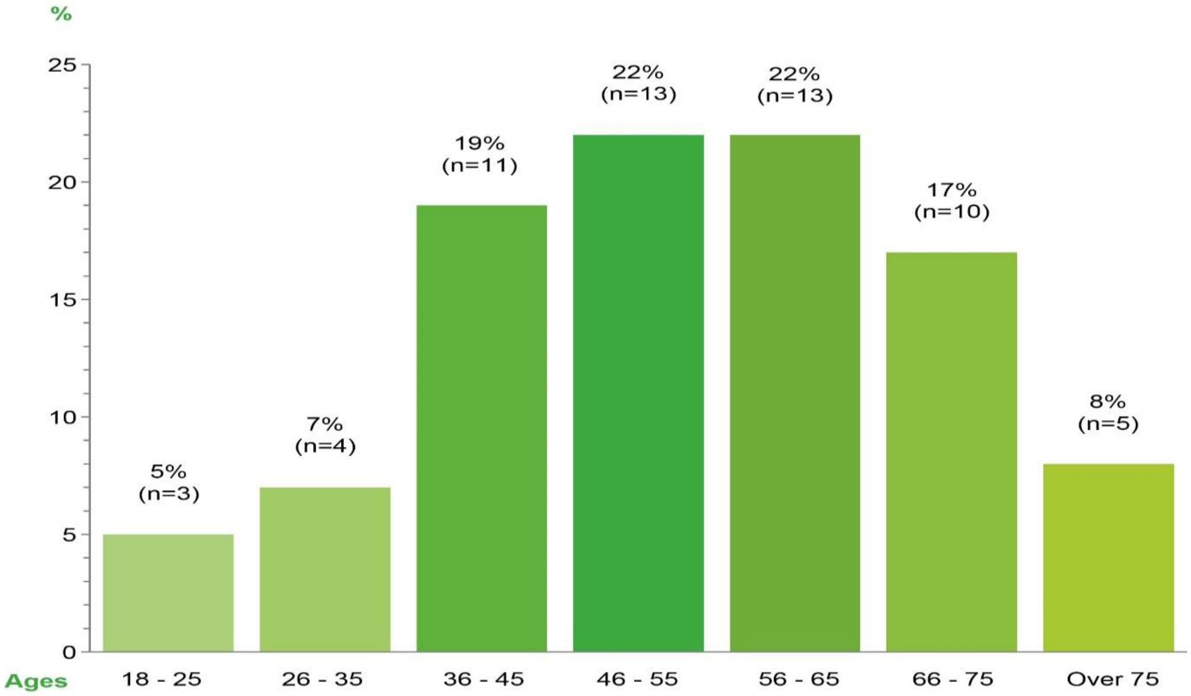


Figure 3 Age ranges of unpaid carers/family members

The ethnicity of unpaid carers/family members is set out in Figure Four below:

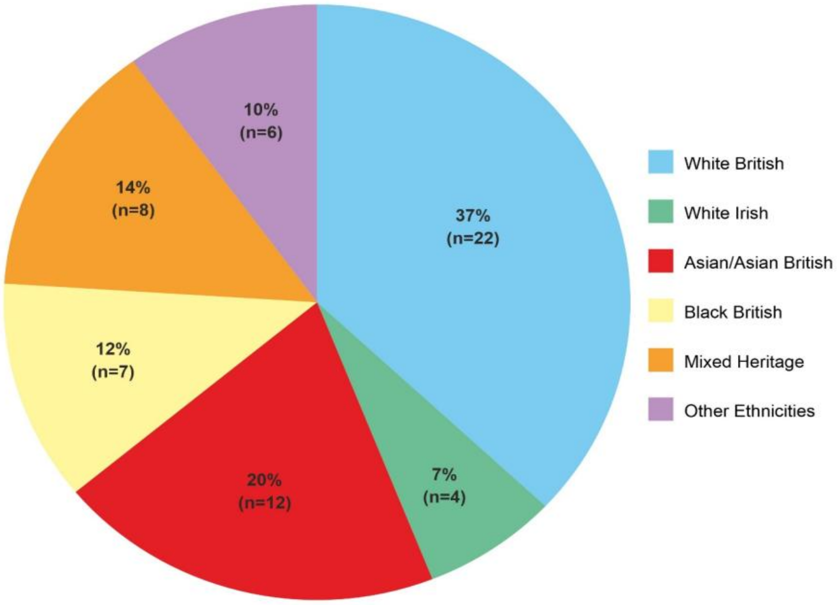


Figure 4 Ethnicity of unpaid carers/family members

In gender terms, 30% (n=18) of unpaid carers/family members said that they were described as male at birth and 69% (n=41) that they were described as female. 27% (n=16) viewed themselves as male now and 68% (n=40) as female. No unpaid carers/family members thought of themselves in another way. Five per cent (n=3) did not reply.

In terms of sexual orientation, 86% (n=51) of unpaid carers/family members identified as heterosexual, 10% (n=6) as lesbian, gay, or bisexual and 3% (n=2) did not answer the question. Thirty percent (n=18) spoke of having additional disabilities; in 83% (n=15) of cases these were physical, or sensory disabilities, but 17% (n=10) also had mental health diagnoses themselves.

The main differences between service user and unpaid carer/family member respondents were that there was a higher percentage of older respondents amongst the latter, none who identified as ‘other’ in gender, or sexuality terms and a somewhat increased percentage of participants from minority ethnic communities; within this there were more Asian/Asian British participants and participants of mixed ethnicities, but fewer African/African-Caribbean participants.

3.3.2 Workshop recruitment and participation

The workshops were again made known through initial publicity. People who were interested in a workshop place were sent a role description. They had the opportunity for further dialogue about the workshops with NSUN’s managing director, to help ensure that they were giving informed consent to participate, and were then asked to complete a brief application form and a consent form to confirm their interest and their understanding of the project. Following this, twelve people were invited to take part in the workshops. This number was set so that there were enough people present for a range of views to be possible, but, at the same time, not so many that dialogue would have been difficult, or the project budget exceeded. The allocation of workshop places was also based on having as wide a demographic mix as possible within the overall total of twelve participants, not on the holding of particular views, again with the intention of reducing selection bias so far as possible.

As has been mentioned, recruitment to the workshops was extended to professionals as well. The aim was to have approximately six people with lived experience, three unpaid carers/family members and three non-clinical professionals. It was thought important to give most weight to people with lived experience, as the direct recipients of mental health services, but also to recognise the importance of views from unpaid carers and family members. Involving some professionals, as well helped to extend the dialogue further. Recruiting non-clinical professionals meant that some non-clinical professional views were heard as well. Once the project report and its recommendations have been circulated, there will be a meeting between some workshop participants and some members of the Stolen Years steering group, who mostly have clinical backgrounds: to discuss recommendations from workshop participants and to see how these can be utilised in guidance which the steering group is compiling to influence the commissioning and provision of physical health services.

At the first workshop day, there were 11 participants. Five said that they had experienced a serious mental illness diagnosis, one person described herself as a family member, three spoke of having both service user and carer experiences, one was a researcher in a relevant field and one worked at a Jewish charity.

The age ranges amongst participants were as follows:

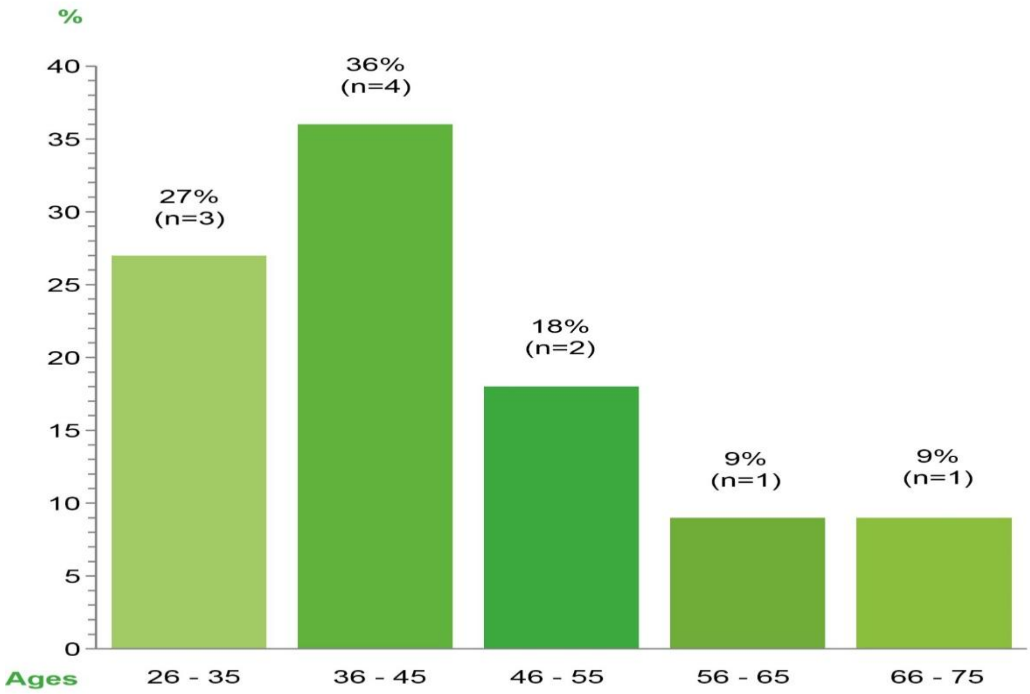


Figure 5 Ages of workshop one participants

The ethnicity of participants is shown in Figure Six below:

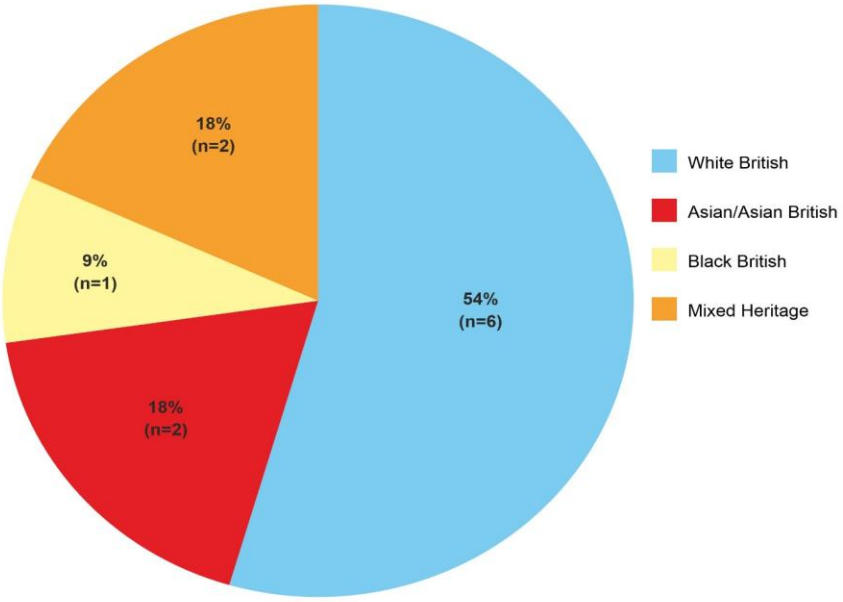


Figure 6 Ethnicity of workshop one participants

At the second workshop day, there was considerable continuity of participants and numbers of participants again amounted to 11. Two people with lived experience were unable to re-attend, however. One of these two places was taken by another person with lived experience. A non-clinical professional from NHS England also joined the second day. This meant that the makeup of participants was as follows: four people who said that they had experienced a serious mental illness diagnosis, one person who described herself as a family member, three who spoke of having both service user and carer experiences and three non-clinical professionals.

The age ranges amongst participants on the second day were as follows:

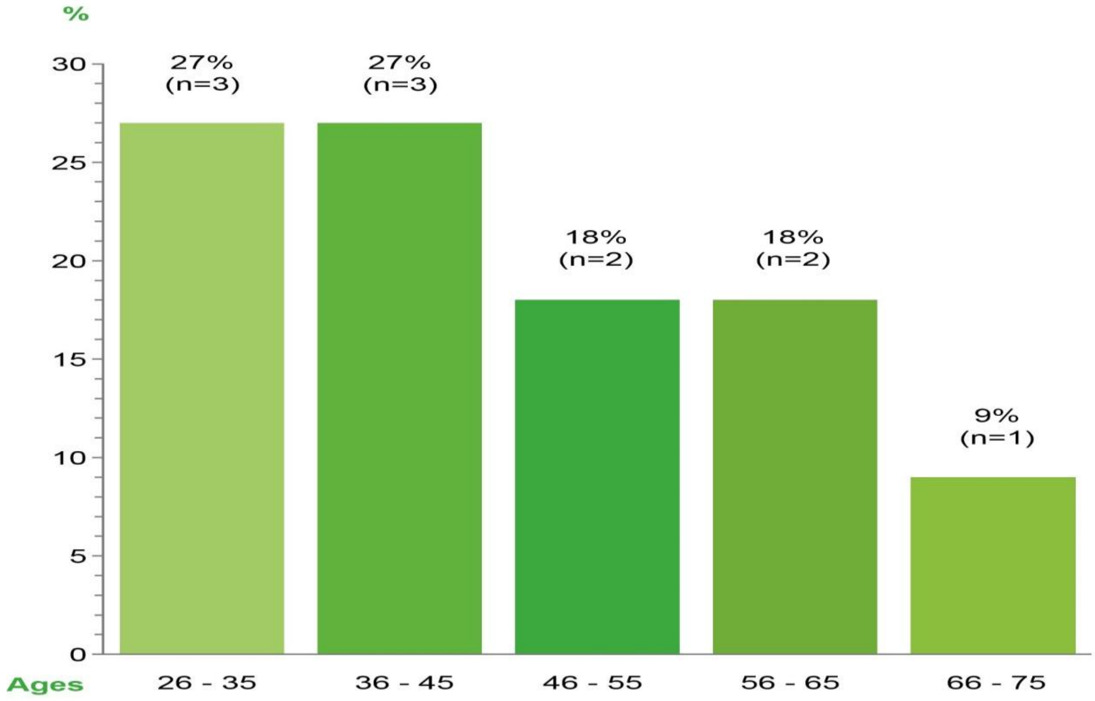


Figure 7 Ages of workshop two participants

The ethnicity of participants on the second day is shown in Figure Eight below

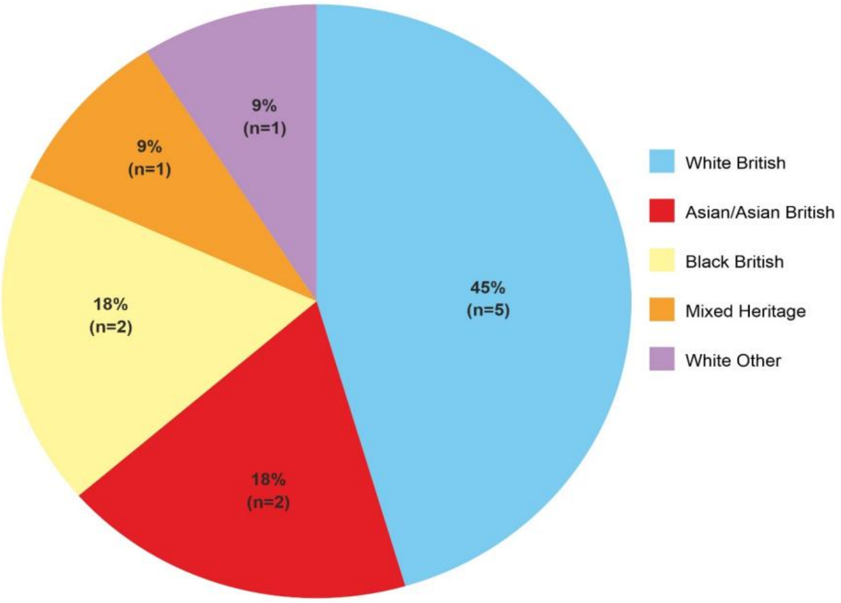


Figure 8 Ethnicity of workshop two participants

At both workshops, 36% (n=4) of participants described themselves as male, 64% (n=7) as female. No participants spoke of themselves in another way. People who identified as heterosexual varied between 73% (n=8) and 82% (n=9) across the two workshop days, with the remainder identifying as gay, bisexual, or other. Across the two workshops, 18% (n=2) of participants mentioned having additional disabilities: sensory disabilities, dyslexia and/or an attention deficit hyperactivity disorder (ADHD).

3.4 Analytic approach

Quantitative survey data was collated and analysed through SurveyMonkey, so that intelligent descriptive observations could be made from it. Responses in the surveys for service users and unpaid carers/family members were analysed independently of each other and the findings then compared, so that pertinent similarities and differences could be noted. Both sets of data were also cross-tabulated for demographic patterns. Where there were clear patterns and the resulting findings were relevant to the study aims, these are again included in the report.

Framework analysis (Ritchie and Spencer, 1994) was employed for analysing qualitative data. Framework analysis was utilised, because it has proved an effective tool for service evaluations (Srivastava and Thomson, 2009) and because this type of analysis can allow well for responses from people who belong to marginalised as well as more dominant communities. Given the comparatively small amount of data, it proved adequate to use spreadsheets for framework analysis purposes rather than a formal tool such as NVivo.

The focus group data was analysed separately from the survey data. Similarities and differences in views held by focus group members from diverse demographic groups and by service users, unpaid carers/family members and professionals were also noted. In a number of cases, views were shared. Where there were significant differences, these are again specified in the report. The findings were then compared with the survey data, so that connections could be made.

During the analysis, trustworthiness and rigour were promoted through the following measures. The project analyst had a lead role in the analysis, in liaison with the project manager, with each having independent access to the data for analytic and reflective purposes. Initial feedback about the draft report was then invited from two other researchers with lived experience, a NSUN staff member and an external consultant, neither of whom had been involved in the data collection. Subsequently, Stolen Years' steering group members had the opportunity to make observations and, as professionals who are mainly in clinical roles, to offer clinical perspectives also. The benefit of bringing in fresh perspectives was that those concerned could, as necessary, challenge any mistaken assumptions which the project analyst, or project manager might be making because of their closeness to the project. In addition, workshop participants (people with lived experience, unpaid carers/family members and non-clinical professionals) were invited to supply their views about the report, on behalf of themselves and other participants. This provided a further check of the accuracy of the material and the conclusions drawn. All relevant points were then taken into account in the final material produced.

3.5 Limitations of the project

Because the project needed to be implemented within the parameters of a somewhat limited budget, the amount of data collected was comparatively small and the statistical data is descriptive only. There are, too, some constraints on particular conclusions which can be drawn; for example, there is not sufficient data to establish whether differing care pathways for people with differing physical health conditions cause some variation in views held. In demographic terms, male project participants were in a minority, despite strong efforts to recruit similar numbers of men and women and the larger number of participants were aged between 36 and 65. By definition, too, the project was London-based. Further studies would be needed if the applicability of the findings to other parts of the UK, in particular to rural areas, were to be demonstrated.

Some noteworthy findings have nonetheless emerged from the project, not least because the study was unusual in having a user-led project team, as has been mentioned in 3.1 above, and because it had a particular focus on people from marginalised as well as dominant communities.

Part Two: Findings

Four main themes emerged from the survey and workshop data:

1. Good physical healthcare for people with serious mental illness diagnoses
2. Positive developments
3. Barriers to effective physical healthcare and physical wellbeing
4. Changes needed in commissioning, in services and in the influence which people with lived experience have over physical healthcare at personal, service and commissioning levels.

These are set out in the material which follows below:

1. Good physical healthcare

Participants had clear ideas about this. The following sub-themes emerged:

1.1 Involvement, influence and control

Participants emphasised that, if physical healthcare is to be good for people diagnosed with serious mental illnesses, then the latter need to have a clear role in this. The vast majority of respondents to the service user survey wanted a voice about physical healthcare services. Ninety five percent (n=101) of them saw it as relevant to have choice and control about their physical healthcare and 90% (n=90)[2] viewed it as relevant to have involvement in the commissioning of physical healthcare services.

In the focus groups, this point was developed further. There was general agreement that people with lived experience should have an influence over physical healthcare provision at personal, service and commissioning levels. Participants also explained their reasons for seeing this as important. Service user participants mentioned, for instance, that people with lived experience are experts in their own care:

> *I think it's putting recovery at the heart of things rather than it being a top down, doctor says this, doctor says that you must do that. I think recovery has a really big part to play in the fact that we have a say, we have a brain. We also have like, we have an idea how things are affecting us ...*

They thought, too, that they had a lot to offer at service provision and commissioning levels:

---

[2] Although there was a high level of response, not all survey participants replied to every question. For that reason, there is some variation in numbers of answers cited in the report.

> *Unless you have felt what it's like to have a mental health condition, you're not going to be as passionate to make change... That's why it's so important ... service users being brought into commissioning groups and being really involved in the big decisions and how services are moved on.*

These points were supported by other focus group members.

1.2 Support from family members, friends and peers

In their survey responses, service user participants stressed the important role that family members, friends and peers have in encouraging them to make use of options for looking after their physical health, for example 'support from a friend or partner if I feel nervous about going' (to see a health professional). Unpaid carers/family members also spoke of a role for themselves in providing such backing.

In the focus groups, there was a further emphasis on support from family, friends and peers. For instance, one participant explained that peer support can make you so much more comfortable:

> *I feel so self-conscious about the way I look now as a result of gaining weight from medication that it's hard to even get to the gym ... If only there was a group of people who had similar things* (to join there)*, that we're all in the same boat ...*

1.3 Professional assistance wanted

Participants thought that there was a place for professional support with physical health as well. Survey participants' views about support which helps people with lived experience to keep physically healthy are set out in Figure Nine below:

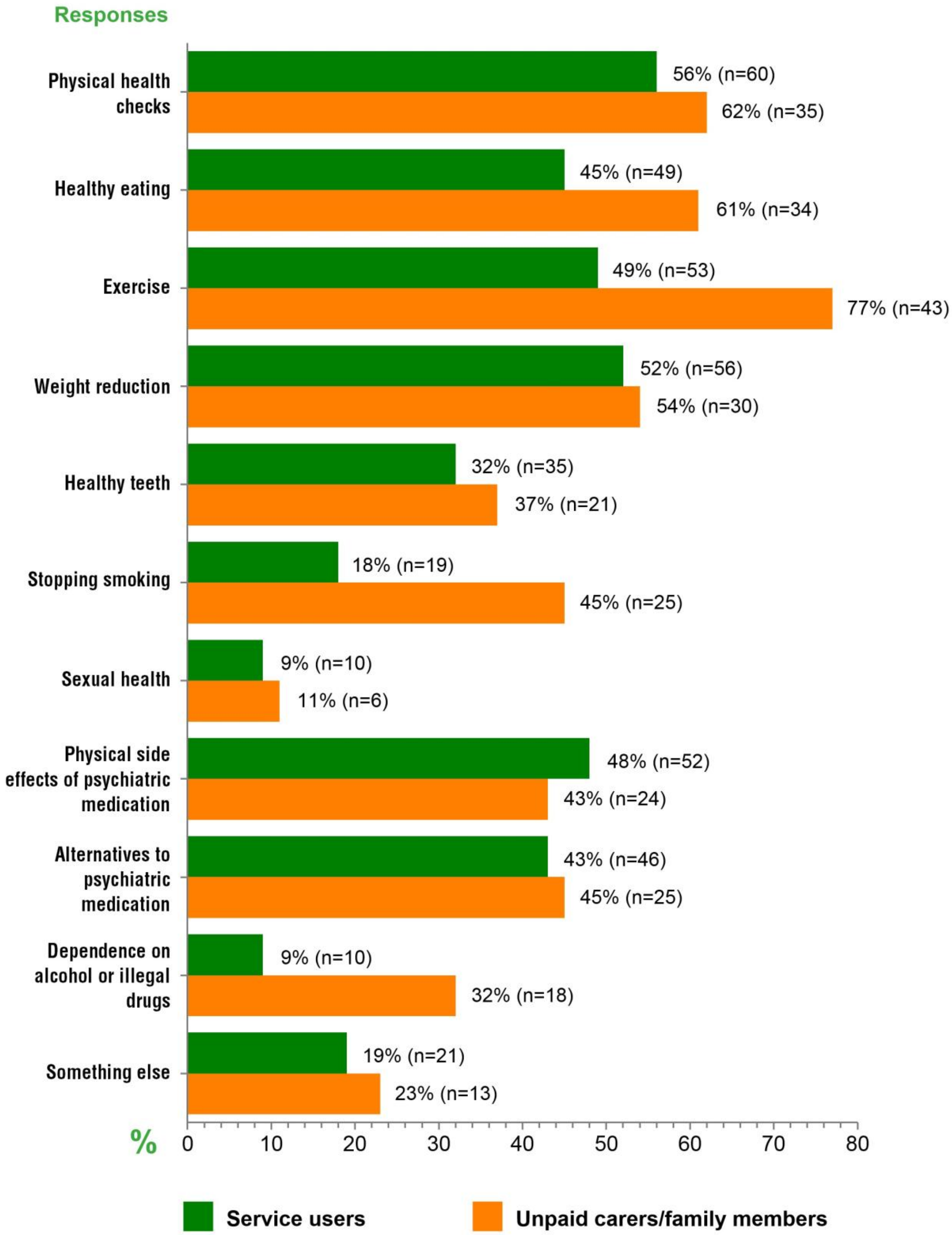


Figure 9 Physical healthcare support wanted by survey participants

As the figures demonstrate, both sets of respondents had some use for support in most of the above categories. In particular, just under, or just over 50% of service user participants put an emphasis on physical health checks, support with healthy eating, exercise and weight reduction and help with the physical side effects of psychiatric medication and alternatives to it. Amongst service users aged 66 and over, physical health checks were most important of all; 70% of them prioritised these. Carers had some very similar priorities, but put more emphasis on assistance for the person they cared for/their relative with physical health checks, healthy eating, exercise, stopping smoking and dependence on alcohol and illegal drugs. Their overall ratings tended to be higher too. There were no suggestions about other types of support where participants had the opportunity to name 'something else'[3]

There was also some emphasis on assistance with long term health conditions where people diagnosed with serious mental illnesses were experiencing these. Sixty two percent (n=70) of survey respondents with lived experience mentioned health conditions such as diabetes, hypertension, heart problems, osteoarthritis, asthma and bowel diseases and 75% (n=37) of unpaid carers/family members spoke of their relative/the person they care for having conditions such as these. The forms of support most frequently mentioned by service user respondents overall were help with healthy living, medication and medical input such as check-ups, advice, information and treatment. At this stage, however, men put more emphasis on clinical input, as did people who identified as LGB, or other. Unpaid carers and family members had very similar ideas overall about the support which would most benefit the person they cared for/their family member, but put gave less weight to medication and medical treatment than service user participants as a whole did.

In the focus groups, there was a further emphasis on professional support with healthy living, both in general and in relation to long term conditions, on the need for information about options and on the value of assistance with drawing up healthy living plans:

> *I'd like some package of what people can do when they've had a diagnosis. Mine was bipolar, can be schizophrenia. But it's all common that health foods, super foods, exercise, mindfulness, help everyone.*

In terms of technology, survey participants in general appreciated reminders by text about appointments and treatments due. Seventy two percent (n=65) of people with lived experience who replied to this question found these useful, though text messages were welcomed by only 27% of the11 service users aged 66 and above who answered the question. Eighty percent (n=43) of unpaid carers/family members thought that texts were beneficial for the person they cared for/their relative. Unpaid carers/family members also gave some weight to activity tracking devices; 41% (n=22) suggested that these were useful, in contrast to people with lived experience, amongst whom only 24% (n=22) were interested in them.

---

[3] In the report, responses in the category of 'something else' are included only if they add further information.

Apart from that, the use of technology was not particularly popular with respondents to the service user and unpaid carer/family member surveys. In addition, 20% (n=23) of service user participants did not select any items from the choices offered.

In the focus groups, there was some enthusiasm for the provision of website information about physical health conditions, available resources and self-management. One reason was that it might be possible to set this up more quickly than other resources:

> *Everything that we've discussed* (about a community centre) *... that's just not going to happen tomorrow. Now you could still do that virtually and put that in a website. That's the good, appropriate use of technology.*

Equally strong reservations were expressed about internet information, however. Participants holding this view considered that personal contact was more valuable, that it might be hard to focus on the internet at times, or difficult to use it and that seeing a GP for physical health diagnoses was better than self-diagnoses through the internet. They also thought that a focus on the internet may be an obstacle to being part of communities:

> *You know, you need to connect with people to feel part of a community and that's something that we have lost, feeling part of the community ... and I think that supersedes any kind of technology.*

1.4 Alternatives to medical model approaches

In the surveys, a thread running through responses was interest in a wide range of resources, rather than purely clinical resources, as is clear in the themes set out above and those which follow below. As has been evidenced in Figure Nine above, forty three percent (n=46) of service user respondents also wanted alternatives to psychiatric medication and 45% (n=25) of unpaid carers/family members thought that alternatives to it would be helpful to the person they cared for/their relative.

In the focus groups, participants developed this theme much further still. They strongly emphasised their wish for physical health provision which is no longer set within a medical model (a focus on diagnoses and medication, a risk orientation and links with the use of compulsory powers under the Mental Health Act 2007). They experienced this model as still very prevalent.

> *When you're drinking, the doctors never ask you: 'Why are you depressed?' (They say): 'Well this is what you can get medication-wise ...' They're always treating the symptoms in that kind of medical model*

> *Medication isn't the answer. It's always the other areas that have to be kind of balanced and healthy and medication can work alongside them, but that's not going to be working so hard*

> *Some of these places, if you get in a secure unit, it's a toss-up whether it's mental health, or a prison.*

1.5 Holistic approaches

For survey respondents and focus group members, it was important both that professionals recognise the link between physical and mental health and that they take a whole person approach in general. Thus a service user survey respondent spoke of the difference it made to her when physical health issues were taken into account as well:

> ... *When my hair began falling out, the GP blamed stress. After 18 months, a locum sent me for a blood test, which showed anaemia. Iron supplements helped my hair grow back and also improved my depression ...*

A respondent to the survey for unpaid carers/family members remarked:

> *Physical health and mental health are inter-connected, yet they are treated as separate entities. The two should be worked on together.*

In the surveys, 96% (n=99) of service user respondents and 98% (n= 52) of unpaid carers regarded a whole life approach to people with lived experience as relevant.

Focus group members put a considerable further emphasis on this. For instance, when explaining a picture (a whole life circle) which he had selected during a discussion about long term physical health conditions, one focus group member explained:

> *There're four big aspects where mostly just the mental health is looked at in the medical model and they almost ignore the spiritual, physical, or emotional health and it's treated with drugs, or whatever that mental health side is. It's that aspect, if you were meditating in Tibet 15 hours a day and chanting, you're seen as a guru. If you do that on the streets of Hackney, you're sectioned.*

Focus group members also proposed that a much wider range of whole life options is made available, including options which suit people from minority ethnic communities. They cited drumming sessions, music and story-telling, for example, and courses which help people to re-build their lives. There was also mention of holistic, lived experience models which are being produced[4]. (Examples of these may be found in Appendix D.)

---

[4] https://wellbeingwhatworks.org/

1.6 Professional qualities and environments

Survey respondents mentioned the importance of understanding, respect, non-judgemental approaches, compassion, support and encouragement from professionals in helping them to look after their physical health:

> *... Take all the CMHT locations and mental health hospitals and run a proper, compassionate, non-punitive system ...*

In the focus groups, this point was developed further. There was an emphasis on welcoming settings, respect, empathy, listening, flexibility, fun approaches, creativity, strengths-based models and an ethos of moving towards a positive future rather than purely avoiding physical health problems. Thus participants made the following sorts of comments:

> *A friendly environment, rather than really serious, sitting in the waiting room fearful, quite fearful environments. The doctor then comes out and he's all serious and: 'Oh my God, what's going to happen here?'. It's all kind of,* (be) *more light hearted is the word*

> *When I've had a good experience with a doctor, yes they're under time constraints, but she's conversed with me in a way that I feel she's listening and I feel like she cares about what's going on*

> (In terms of motivation) *I wish that they could make things a bit more fun. I just had some wacky ideas, but like for stress a cat-stroking cafe*

> *But your doctors are using an 'away from' strategy, which is always trying to prevent something. Whereas, if we have a towards strategy, where you're going to something good, rather than waiting for something bad. Like, when I go into the doctor's office, all I see is stroke, dementia, cancer, death.*

1.7 Meeting diverse needs

Both survey and focus group participants spoke about the importance of physical healthcare services being accessible for people in general, not just for people from dominant communities. They mentioned issues such as appropriate environments for people of all ages, physical health services available to people on low incomes, women-only facilities, provision for people who identify as lesbian, gay, bisexual, or transgender and culturally appropriate resources.

Some suggestions from service user survey respondents were:

> *Environments are important. GP surgeries cater for toddlers, but not for older people's/mental health patients' comfort (water available)*

> (Have) *a community-based drop-in women's sexual and menstrual health centre, run by women for women*

> *Financial support for slimming world should be provided.*

Focus group members mentioned that:

> *... The sexual health clinic has like a men's only and a gay men's drop-in session ... which I always found quite helpful, because ... you don't have that awkward, waiting room kind of experience, because it's specialist doctors and the same kind of group*

> *Quite a lot of women, they've got particular things in their past which would make it difficult to be around men*

> *You cannot hide away from the fact that race is a very big part of many people in their lives in this country ... My sister, she's a Rastafarian. She has sought counselling through a Rastafarian counsellor and was able to open up to her and alternative holistic therapy. Well we need more of these alternatives and we're not given that option if we're black, especially if you're a black man.*

Whilst the focus of the Healthy Lives project is physical health services for people with lived experience, attention was also drawn to the fact that unpaid carers/family members can feel marginalised and that this needs addressing. It was thought, too, that unpaid carers themselves need support if they are to be able to offer support to people with lived experience. Thus in the survey for unpaid carers/family members, one participant commented:

> *We receive very little help in the time of a crisis.*

In the focus groups, a comment was:

> *We haven't talked about carers much, but I think that family support can be critical to recovery. So .. I think more support for carers.*

1.8 Service venues

The location of physical health services also mattered to survey respondents and focus group members. Figure 10 below shows the venues where respondents to the surveys thought that support with physical health would be most beneficial:

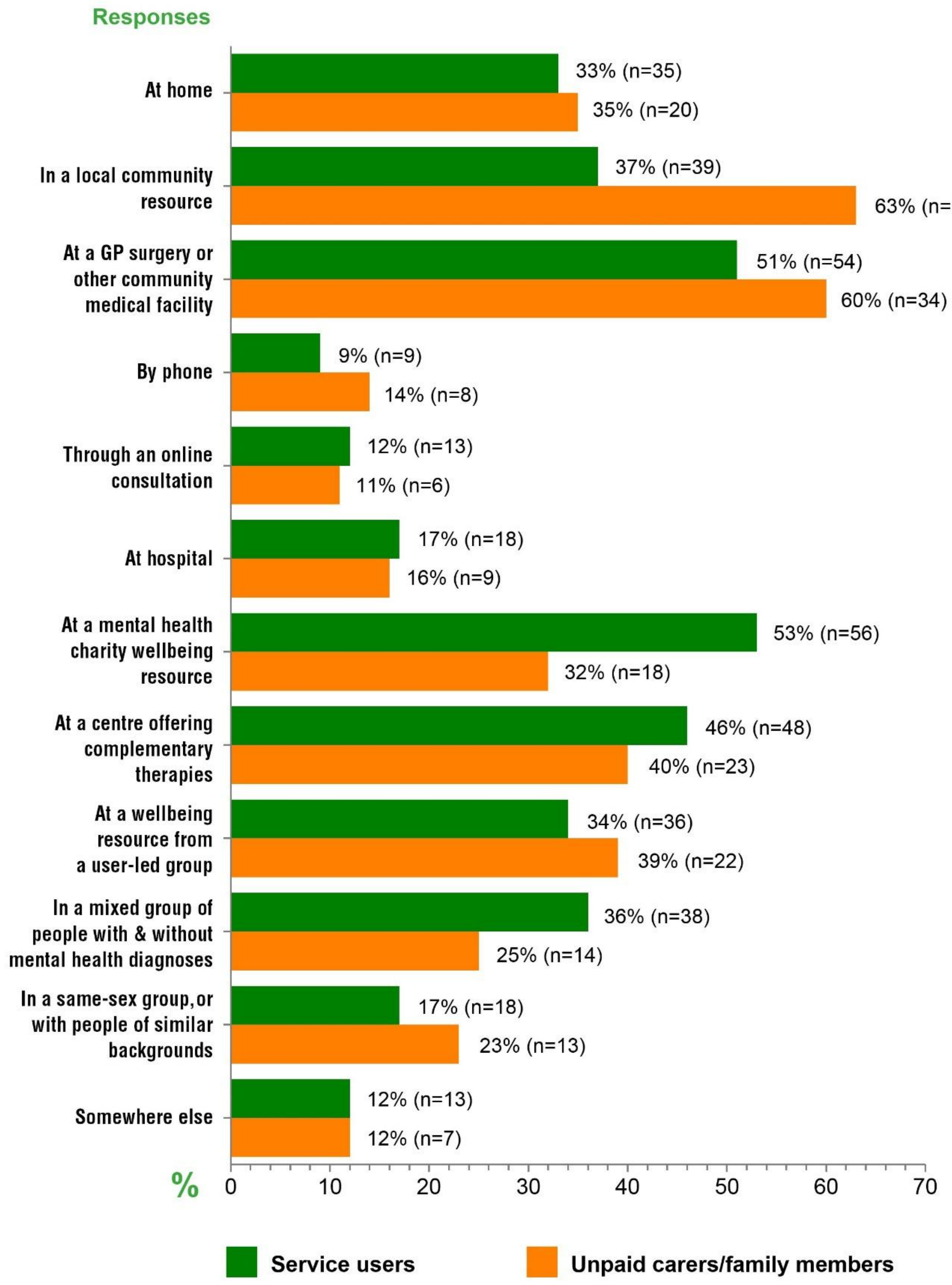


Figure 10 Survey respondents' preferred venues for general physical healthcare support

As can be seen from the data, community-based facilities were preferred by both sets of survey respondents and there was an emphasis on non-medical community facilities, not just medical resources. Service users overall especially emphasised their GP surgery, or another community-based medical facility, a wellbeing resource provided by a mental health charity and a centre offering complementary therapies. Unpaid carers/family members put a particular focus on a local community resource, and a GP surgery, or another community-based medical facility. Some survey participants also thought that individual help in such settings would help to increase service user involvement with their physical healthcare; they spoke of the value of support from a personal trainer, or mentor, for instance. Service user participants from black, Asian and minority ethnic (BAME) communities put a GP surgery/another community-based medical resource considerably lower than white British service users, however; 45% did so in contrast to 60% of white British service users. Amongst service users of 66 upwards, it was also noticeable that none favoured online consultations.

Survey respondents' views about helpful venues for support with long term physical health conditions are set out in Figure 11 below:

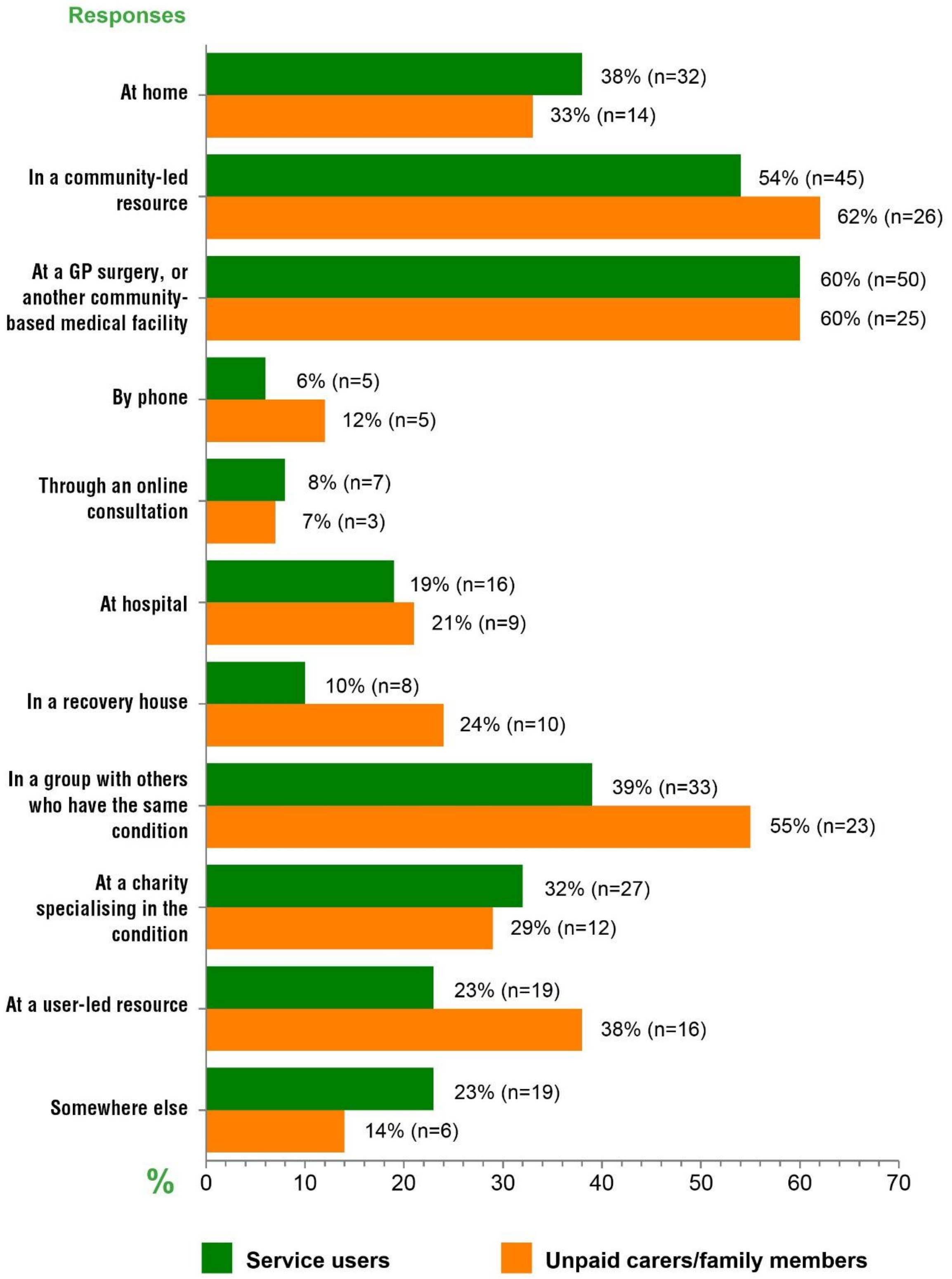


Figure 11 Survey respondents’ preferred venues for support with long term conditions

For long term physical health conditions as well, service user survey participants were particularly interested in community-based care. They rated their GP's surgery/ another community-based medical resource and a community-led resource most highly. Male participants prioritised their GP's surgery, or another community-based medical facility for assistance at this stage; 67% did so, in contrast to 55% of women. Service user participants who identified as LGB, or other also prioritised their GP's surgery/another community-based medical resource: 71% of them over against 56% of heterosexuals. These findings would correspond to the fact that both groups had put most emphasis on medical input for long term physical health conditions. Service user participants from BAME communities again gave a lower rating than white British service users to a GP surgery/another community-based medical resource; 48% described it as useful in comparison with 78% of white British service users. Fifty four percent of them valued a community-led resource most, in other words there was some difference of emphasis amongst BAME respondents.

The next choices for service user participants overall were being in a group with others who had the same condition, help at home and support from a charity specialising in the condition. Male service users saw these as a lower priority, however, as did people who described themselves as LGB, or other. BAME participants gave as their next choices their GP surgery (48%), or another community-based medical facility, input at home (42%) and being in a group with others who had the same condition (40%).

Although ratings for phone calls and online consultations were very low amongst service users generally and ratings for hospital admissions somewhat low, this trend was particularly noticeable amongst service users of 66 upwards; no older service users favoured phone calls, or online consultations for long term physical conditions and only one opted for care in hospital.

As can be seen from Figure 11, unpaid carers /family members had related, but slightly different opinions about venues which the person they cared for/their relative would find helpful. They considered that a community-led-resource, a GP surgery/another community-based medical resource, or being in a group with others who had the same condition would be most beneficial to the person they cared for/their relative. Their next choices were help at home, or a user-led resource.

In the focus groups, where there was opportunity for more detailed discussion, there was also an enthusiasm for community-based resources. Focus group members added further points about community-based groups and about the forms which these might take in supporting both the general physical health of people with lived experience and long term conditions which they might have. Because focus group members thought that it might be difficult for people with lived experience to know about and access the full range of resources which can be available, several expressed interest in a community centre where the various whole life services which people with lived experience value could all be provided in one place. One comment, for instance, was:

> *What I believe is needed ... is a re-introduction of community centres specifically for people with mental health problems ... a centre there that has advice, that has activities, that provides a place for everyone to go to feel comfortable, that's non-judgemental, that is providing useful exercise, art, advice on jobs, training ... and to integrate all the holistic ideas that we've said today.*

Focus group members as a whole had mixed views, however, about community groups which were for other members of the public as well. Some focus group members felt strongly that separate physical health services for people with lived experience were important if people with lived experience are to feel relaxed and to have their needs met. One service user participant commented, for example:

> *I think the GP is a good place to start. There could be like a specialist day centre, or a day at the GP's that was devoted to that kind of thing for people with mental health problems to come and get their physical health checked.*

For others, separate resources felt unhelpful, because they experienced these as keeping people with lived experience apart from their local community.

Focus group members also thought that, over time, recovery colleges might be another useful venue for the promotion of holistic approaches. At the moment, however, perceptions were that availability of courses is limited, resulting in long waits for them, and that courses may not cover as wide a range of issues as people with lived experience want.

1.9 Information

For both survey respondents and focus group members, the need for information was another theme. 87% (n=84) of service user respondents thought it relevant to have information about public health resources which could support their physical health and 96% (n=51) of unpaid carers/family members who replied saw such information as helpful to the person they cared for/their relative. The vast majority of service users who replied, 96% (n=101), viewed it as pertinent to have information about ways of managing their physical health and 98% (n=46) of unpaid carers/family members who replied considered that this would be useful for the person they cared for/their relative. A wish for information was also a sub-theme in the survey data, in responses about tools for self-management, for example.

Focus group members added further points. A key issue for them was the need for information about side effects of psychiatric medication so that people with lived experience could make informed choices. One focus group member explained, for instance:

> *When I’ve had medication in the past, I’ve had these crazy side effects. I felt like it wasn’t working and I was going crazy. And I went back to my doctor at my three-month psychiatrist check and I’ll be like: ‘I think I’m mad. It’s like I don’t know what’s going on’. And then he’s like: ‘Oh yeah, that medication I gave you, it doesn’t work’. I was like: ‘You could have told me that’.*

For focus group members, information about available resources was important as well. As has been mentioned in 1.8 above, they thought that a community centre would be useful for this purpose. In addition, there was the suggestion in 1.3 above of setting up a website with details about all the facilities in a particular area.

1.10 Training

A further theme for focus group members was the need for healthcare professionals to have additional training in the provision of physical healthcare for people with serious mental illness diagnoses. Survey participants were not asked directly about training for healthcare professionals. Ninety six percent (n=100) of service user respondents and all unpaid carer/family member respondents saw it as relevant for healthcare professionals to have an understanding of physical health issues for people with lived experience and the ability to provide relevant treatment for them, however, whilst only 18% (n=19) of service user respondents and 9% (n=5) of unpaid carers/family members thought that this happened ‘a lot’.

Focus group members stressed that, if physical health services are to be effective for people with lived experience, physical health clinicians need training about mental health and physical health issues faced by people with serious mental health diagnoses and, in turn, mental health professionals need more training about physical health issues. There were also proposals that healthcare professionals have more diversity training and additional training in interpersonal skills such as counselling, empathy and compassion. Comments related to GPs, for example, were:

> *I did want to say that I think GPs do need more training about, like, awareness of diversity and stuff, because I still get people saying stupid things to me and making me feel uncomfortable*
>
> *... It would be really interesting and better for everybody if all GPs had a sort of level of counselling skills built into their training, so that they know how to converse with people.*

A suggestion was that people with lived experience provide the training:

> *Training should be by experts by experience, training the mental health and physical health professionals about both sides of things.*

There were mixed opinions amongst focus group members as to whether additional interpersonal skills training would make a difference to healthcare professionals, however. A contrary view was that, if a professional does not already have qualities such as empathy and compassion, these cannot be acquired through training.

2. Positive developments

Both survey participants and focus group members mentioned progress with physical healthcare for people diagnosed with serious mental illnesses. These related both to steps taken by people with such diagnoses and to productive services.

2.1 Self-management

Whilst the views of people with lived experience were more positive than those of unpaid carers/family members, survey responses from both nonetheless suggest that considerable numbers of people with a serious mental illness diagnosis are taking steps to keep themselves physically healthy. Ninety three percent of service users gave at least one example of doing so and 68% of unpaid carers/family members thought that the person they cared for/their relative took at least one piece of action. (See Table One below.)

Number of examples provided	**Service users**	**Unpaid carers/family members**
One	93% (n=105)	68% (n=40)
Two	69% (n=78)	37% (n=22)
Three	42% (n=47)	25% (n=15)

Table 1 Self-management of general physical health

The majority of comments in both surveys related to taking exercise and to eating healthily. Examples of exercise included walking, running, cycling, yoga, pilates, attendance at gyms, martial arts, dancing, swimming, sport, gardening and housework. In terms of healthy eating, respondents referred to eating at least one good meal a day, following a balanced diet, being aware of ‘five a day’, avoiding sugar, going to weight watchers, drinking plenty of water, limiting alcoholic intake, or cutting out alcohol, and fasting.

There was also evidence from service user respondents that they are taking steps themselves to manage long term physical conditions which they have and, in this case, a larger number of unpaid carers/family members agreed. The findings here were particularly positive, therefore. Ninety four per cent of service users supplied at least one example of self-management and 86% of unpaid carers/family members cited at least one piece of action which the person they cared for/their relative was taking. (See Table Two below.)

Number of examples provided	Service users	Unpaid carers/family members
One	94% (n=66)	86% (n=32)
Two	61% (n=43)	51% (n=19)
Three	33% (n=23)	16% (n=6)

Table 2 Self-management of long term physical health conditions

Respondents again particularly mentioned dietary measures and exercise, providing similar examples to those set out above. Acquiring more information about their condition, pacing themselves, avoiding harmful situations and monitoring their health through mechanisms such as glucose level checks were also cited. Taking relevant medication was a theme, too, though a less major one, and there were some allusions to keeping in touch with doctors. In addition, service user respondents spoke of the role played in the management of their physical health by personal qualities of theirs such as determination and emotional strength.

During the focus groups, there was a continuing strong emphasis on the part which self-management can play and on its importance, particularly as an alternative to psychiatric medication:

> *They were treating the* (psychiatric) *symptoms almost like a dripping tap, by putting a bucket underneath ... and keeping emptying it ... rather than going to the top and turning the tap off ... By me treating these causes, eating healthily, coming off alcohol, mindfulness, I started treating the causes ... For the last seven years, I've been off medication, managing bipolar with a really helpful lifestyle and diet ... so, in a sense, I treated those causes, so the causes are not there anymore.*

2.2 Effective services

Respondents to both surveys had some favourable comments about physical health support available to people with lived experience. Fifty nine per cent of service users and 64% of unpaid carers/family members provided at least one example.

(See Table Three below.)

Number of examples provided	Service users	Unpaid carers/family members
One	59% (n=67)	64% (n=38)
Two	33% (n=37)	36% (n=21)
Three	13% (n=15)	12% (n=7)

Table 3 Positive comments about physical health support

Examples which survey respondents mentioned included help from GPs and some allied professionals, medical aids, exercise resources, family support and contacts with friends and peers. Unpaid carers and family members spoke mostly about assistance from primary and secondary healthcare professionals, but made some mention, too, of exercise resources.

In the focus groups, participants put forward the following as good examples of physical healthcare provision which they had experienced:

- Crisis recovery houses in the participant’s area, though these are limited in number
- A Jewish mental health organisation, where the approach taken is holistic and external resources are highlighted as well
- Improved access to psychological therapies in the area where the participant lives
- The transformative effect of music therapy for older people with dementia
- Sound therapy
- Laughter yoga
- A cafe for people of widely different backgrounds and educational attainments which offers ‘out of the box’ activities at no cost
- A sexual health clinic with a men only and a gay men drop-in facility
- A positive change to a new GP who not only spotted immediately why the participant was in major physical pain, but drew up a care plan with her and was helpful about her daughter’s physical health needs as well

- A psychiatrist who wrote to a participant’s GP at regular intervals requesting checks of the participant’s blood pressure, cholesterol levels, diabetes and weight
- Family support
- A health and wellbeing network which is being commissioned in the participant’s area and which is bridging gaps between secondary and primary care
- Extensive health checks, available at regular interviews, in a mental health arts centre
- A sports-based recovery centre
- Evidence from the Council for Evidence-based Psychiatry about harmful effects of psychiatric drugs which may be portrayed as safe and effective
- The use of Open Dialogue as an alternative approach.

Whilst at least as many of these examples were drawn from outside as inside the NHS, it was clear that there are some existing resources which participants think directly help to promote the physical wellbeing of people with lived experience and do so from a holistic stance. The view was also expressed that, whilst there is considerable room for further change, the involvement of people with lived experience in services was making some difference to service provision.

3. Barriers

Although Healthy Lives project participants had positive comments to make, as is clear from Section Two, they also thought that a considerable number of factors act as obstacles to effective physical health for people with serious mental illness diagnoses.

3.1 Personal experiences of mental health problems/mental distress

For service user respondents to the survey and even more so for unpaid carers/family members, mental health problems/mental distress were what made it most difficult for people with lived experience to look after their physical health. When respondents were asked to say how much of a difficulty mental health problems/mental distress were, over 50% of service users in general and almost 70% of unpaid carers/family members saw these as a major factor. These two sets of figures in combination were the highest ratings given by survey participants. (See Table Four below.)

How much of a difficulty	A lot		Sometimes		Never		Not relevant	
	SU	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ Family**
Mental health problems/mental distress experienced	53% (n=54)	68% (n=39)	39% (n=40)	26% (n=15)	5% (n=5)	0% (n=0)	3% (n=3)	5% (n=3)

Table 4 Survey respondents on the impact of mental health problems

Mental health problems were a particular issue for service users over 65 in general and for white British service users of all ages. 78% of respondents over 65 described mental health problems as a difficulty ‘a lot’. 61% of white British service users rated them as a major difficulty, which was higher than the 44% of service users from BAME communities who did so.

The sheer impact of mental health problems/mental distress was also a theme in the focus groups. Participants talked about times when they were too low to lift themselves up and access physical health resources. As one participant explained:

> *There’s a certain level of mental health where you can’t motivate yourself to look after your physical health, because you’re down there [*gesturing towards the floor with her hand].

3.2. Difficulties arising from personal life circumstances, including social exclusion

Service user respondents and unpaid carers/family members saw these as considerable barriers to physical health, with the strongest views again being expressed by the latter, as is clear from the figures in Table Five below:

How much of a difficulty	A lot		Sometimes		Never		Not relevant	
	SU	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ family**
Personal circumstances (e.g. a low income, or housing problems/ homelessness)	37% (n=36)	46% (n=24)	36% (n=34)	42% (n=22)	10% (n=10)	6% (n=3)	18% (n=17)	6% (n=23)

Social exclusion	38% (n=33)	52% (n=26)	38% (n=33)	38% (n=19)	14% (n=12)	6% (n=3)	10% (n=9)	4% (n=2)

Table 5 Survey respondents on the impact of personal circumstances and exclusion

Personal circumstances were an issue ‘a lot’ for 43% of BAME service users compared with 31% of white British service users, 40% of women compared with 33% of men and 43% of service users who defined themselves as LGB, or other compared with 34% of heterosexual service users. In other words, these were a particular concern for service users from marginalised communities. In addition, 42% of women saw social exclusion as a problem ‘a lot’ compared with 29% of men. However, 46% of white British service users thought that this was a difficulty for them ‘a lot’ compared with 31% of BAME service users. A similar pattern of opinions emerged amongst BAME unpaid carers/family members.

Both survey and focus group participants added further comments about problems arising from personal circumstances and social exclusion, drawing attention, for example to problems related to a low income, rough sleeping, isolation and direct discrimination

> *To access activities costs a lot of money. Assistance from the state would be a welcome help and incentive*
>
> *But you see some people who are just mentally not well just walking the streets, sleeping on the streets, because they’ve just closed all the day centres. Care in the community! What care in the community? Who ... is by my side, who is holding my hand? There isn’t anyone*
>
> *Loneliness and social/financial exclusion, together with not feeling part of a gang, contribute massively to a lack of physical health*
>
> *The gyms in my area are all very trendy*
>
> *The rise in racist talk is unhelpful.*

3.3 Shortfalls related to community resources

Survey participants valued community-based physical health resources, as the responses cited under theme one above make clear. They thought, however, that service users were not receiving adequate information about these, nor sufficient access to them and that there were not enough of them, particularly in the case of community-led groups, charities, advocacy services and user-run agencies. Thus,when they were asked how much the shortfalls were making it difficult for service users to look after their physical health, the ratings given indicate some serious concerns. (See Table Six below.)

How much of a difficulty	A lot		Sometimes		Never		Not relevant	
	SU	Carer/ family	SU	Carer/ family	SU	Carer/ family	SU	Carer/ Family
A lack of information about public health resources which can support physical health	36% (n=35)	28% (n=15)	33% (n=32)	62% (n=33)	18% (n=17)	6% (n=3)	13% (n=13)	4% (n=2)
A lack of access to such resources	44% (n=40)	43% (n=23)	28% (n=25)	45% (n=24)	18% (n=16)	8% (n=4)	10% (n=9)	4% (n=2)
A shortage of community-led groups, charities and advocates	48% (n=43)	54% (n=29)	32% (n=29)	39% (n=21)	12% (n=11)	2% (n=1)	8% (n=7)	6% (n=3)
A shortage of user-led groups	49% (n=43)	50% (n=25)	30% (n=26)	42% (n=21)	14% (n=12)	6% (n=3)	8% (n=7)	4% (n=2)

Table 6 Survey respondents on the impact of shortfalls in information and access

Shortfalls in community-based resources might again more often be seen as an increased problem amongst service user respondents from marginalised communities. Somewhat more BAME service users than white British service users considered that there were difficulties ‘a lot’ with access to public health resources (48% versus 40%) and a shortage of community-led groups, charities and advocates (49% versus 44%). Considerably more thought that a shortage of user-run agencies was an issue ‘a lot’ (55% versus 41%). Unpaid carers/family members from BAME communities had similar concerns.

Somewhat more female than male service users thought that there were problems ‘a lot’ with a lack of information about public health resources (39% versus 32%) and considerably more that a lack of access to such resources (48% versus 38%) was a major difficulty. However, many more male service users than female service users rated a shortage of user-led groups as an obstacle ‘a lot’ (60% versus 48%). More service users who identified as LGB, or other than heterosexuals experienced problems ‘a lot’ with a shortage of community-led groups, charities and advocates (58% versus 46%) and a shortage of user-run agencies (55% versus 47%).

Focus group members in general expressed concerns about shortfalls in information provided and access to an adequate range of resources:

> *But it's all common that health foods, super foods, exercise, mindfulness help everyone. It's not kind of given to people to access and to find out what's on offer*
>
> *There's a lot of emphasis on treating the symptom, or going to see the doctor and little about sharing good self-management, or looking after your health, how to eat better*
>
> *All the support groups* (in my area) *have been underfunded, or run down.*

3.4 Difficulties with healthcare interventions and approaches

These were a major factor for participants:

3.4.1 Problems with psychiatric medication

When survey respondents were asked to what extent side effects of psychiatric medication made it difficult for people with lived experience to look after their physical health, this was clearly thought to be a considerable issue, by service user respondents and still more so by unpaid carers/family members.(See the data in Table Seven below.)

How much of a difficulty	**A lot**		**Sometimes**		**Never**		**Not relevant**	
	SU	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ Family**
Physical side effects of psychiatric medication	31% (n=20)	57% (n=29)	38% (n=36)	18% (n=9)	11% (n=10)	4% (n=2)	21% (n=20)	22% (n=11)
The impact of psychiatric medication on a physical condition	32% (n=30)	41% (n=21)	29% (n=28)	31% (n=16)	13% (n=12)	2% (n=1)	26% (n=25)	25% (n=13)

Table 7 Survey respondents on the impact of psychiatric drugs

There was some variety in responses from different demographic groups. Male service user respondents were especially concerned about physical side effects of psychiatric medication (38% of them in comparison with 28% of women), as were service user respondents who identified as LGB, or other (34% in comparison with 21% of heterosexual respondents). Respondents identifying as LGB or other were also particularly concerned about the impact of psychiatric medication on a physical condition of theirs (33% in comparison with 25% of heterosexual respondents).

Within the focus groups, expressions of disquiet about psychiatric drugs were extensive amongst most participants. It was thought, for instance, that psychiatric medication has very negative effects on physical health and that inadequate information is provided about it:

> *... after I was given the medication, no-one actually said to me: 'As a result of these meds, this is what could happen ...'. So, as a result of the medication I was taking, I put on weight which is quite common with a mood stabiliser. As a result of putting on weight, I developed sleep apnoea and diabetes type two. Nobody told me that when I was taking my medication ...*
>
> *I feel so self-conscious about the way I look now, as a result of gaining weight from medication, that it's hard to even get to the gym.*

The view was also expressed that people were left on psychiatric medication for far too long:

> *... to be 48, or 49* (and) *still pumped full of anti-psychotic drugs and depot injections really is a lack of care, or duty of care.*

There was some disappointment, too, that there are not yet courses at recovery colleges which help people to come off psychiatric medication.

One strongly held, though minority, professional view, however, was that there is no option in the case of older people with dementia other than to drug them heavily, if they are not to be locked up in mental health units and if residents and staff are to be kept safe. Other group members emphasised that there are valid and preferable alternatives, but that adequately funding for these is not yet available and they are not yet widely practised.

Scepticism was also expressed about the effectiveness of psychiatric medication and disquiet about the lack of other options on offer:

> *There's no such thing as an anti-psychotic. It doesn't do what it says on the tin. There's no such thing as an anti-depressant ... The second thing is there's an alternative, there are so many alternatives, well used, St John's Wort for example. CBD* (cannabidiol) *... has been tested. It's the other part of cannabis. It's been tested as an anti-psychotic and the trials that have been done show it compares favourably, if not just as well ...*[5]

---

[5] According to Leweke *et al* (2016), there is some preliminary evidence that cannabidiol may be more effective in alleviating psychotic symptoms without the side effects of established anti-psychotics, although evidence about its long term effects is not yet available.

It was suggested that one main reason for a dominant usage of psychiatric drugs was the power which pharmaceutical companies exert:

> *Pharmaceuticals are really very powerful. They have all the money and they produce all the drugs.*

There were strong concerns in the group that people diagnosed with serious mental illnesses die earlier than other people because of psychiatric drugs. Thus one participant said:

> *I feel like an old woman because of the medication I'm on ... I don't feel right, I just feel like they're killing me slowly.*

There was also mention of a hospital programme in which the fact that men and women with schizophrenia die prematurely had been highlighted. A concern, however, was that these deaths had been attributed to lifestyles amongst people with this diagnosis without any consideration of the impact which psychiatric medication has:

> *They said that this was because of poor quality of life - that they didn't exercise, they smoked, obesity ... – but they didn't mention medication.*

Particularly high numbers of early deaths amongst service users from BAME communities were also noted.

It was suggested, too, that male service users hold back from physical health checks because they fear that these will show up serious health conditions caused by psychiatric drugs. Thus one service user participant explained why his male colleagues were not making use of physical health checks available at a local arts-based resource:

> *There's a big fear about physical health in some of the members, because they're so full of medication that they fear if something found is kind of extensive, so I don't know how you lessen that fear around getting a health check.*

3.4.2 Undue use of a medical model

Participants experienced physical healthcare services as still very much tied to a medical model in ways which they found difficult. For instance, one respondent to the service user survey raised as an issue the fact that:

> *If you have both a mental and a physical disability, the practice still today is of the medical model of disability.*

For both survey respondents and focus group members, their concerns were linked with unease which they felt about psychiatric medication. (See 3.4.1 above). Focus group members also spoke in detail about other misgivings which they had. One factor was doubt about the scientific basis for diagnoses:

> *It takes two psychiatrists to say you're off your head ... on the basis of some chemical imbalance that's never been proved. There's no evidence at all to support any chemical imbalance ...*

A second factor for focus group members was that they thought that there is too much emphasis on symptoms and not enough on options which promote physical health and wellbeing:

> *They just seem to treat the symptoms which can go on for years and years rather than you learning how to get healthy foods, super foods, exercise, meditation ...*

> *I think there are a lot of things going on that can, you know, be much better than a doctor. I'm not in any doubt about this sound therapy for me.*

A third factor was that a medical model was considered unhelpful, not just in holistic terms generally, but because it is experienced as culturally inappropriate:

> *I speak for Indian myself, Indian, Chinese, Asian and I would say also ... African-Caribbean. I would say they had a different mindset on mental health from the outset, so, when they come across the medical model, it's this alien thing and you don't get hope until it's too late. But, if they had a properly holistic service ... exercises, natural herbal remedies, breathing techniques, meditating practices ... reflexology ... Even if you were just told about them, I think that would be a good start.*

It was also thought that a medical model is too bound up with a focus on risk and the use of compulsory powers under the Mental Health Act 2007. It was suggested that one reason for a failure to use multi-cultural options is because:

> *All they're focused on is the risk of what that person might do ...*

Psychologically damaging effects of being sectioned were underlined as well:

> *The fact that you're being locked up and being forcibly restrained kind of imputes that you're some kind of criminal.*

There were concerns, too, that experiences of sectioning are detrimental to service users' overall wellbeing and to their ability to exercise whole life skills.

3.4.3 Interpersonal issues

An emphasis from both survey participants and focus group members was that breakdowns in relationships between healthcare professionals and people with lived experience can occur and that these have a negative impact on the use which the latter make of physical health services. One survey participant spoke of feeling ‘betrayed by psychiatry’, for example; he had taken psychiatric drugs because he trusted his psychiatrist, but then came to the conclusion that he had not needed the drugs at all. This had led him to distrust doctors and so to hold back from an operation suggested by his GP.

Focus group members developed this type of point further:

> *Fundamentally, consistency, trust, being knowledgeable and kindness are important for both physical and mental healthcare, but particularly for people with mental health problems accessing physical healthcare. One unpleasant encounter, even with a receptionist, and I may not come back as the psychological effort and stress to return will be considerable*
>
> *My son’s had really nice doctors come up to him for various physical things, but he now hates doctors so much ... Even if he was dying, I don’t think he’d go to a doctor, because they’ve intruded on him, they’ve dragged him away in handcuffs, they’ve locked him up, injected him against his will ...*

3.4.4 Shortfalls in whole life and integrated care approaches

When they were asked for their views about the amount of professional help which service users receive with holistic and integrated care approaches, survey respondents thought that there are considerable shortcomings in physical healthcare in these regards. (See Table Eight below.) For both service users and unpaid carers/family members, this was true of all the spheres listed in Table Eight and especially in relation to a whole person approach and integrated care, with the highest unease of all concerning partnership working.

How much of a difficulty	**A lot**		**Sometimes**		**Never**		**Not relevant**	
	SU	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ Family**
A whole person approach (account taken of personal, social and spiritual needs too)	19% (n=20)	4% (n=2)	30% (n=31)	34% (n=18)	47% (n=48)	60% (n=32)	4% (n=4)	2% (n=1)
Understanding of physical health needs and relevant treatment for them	18% (n=19)	9% (n=5)	55% (n=57)	57% (n=31)	23% (n=24)	33% (n=18)	4% (n=4)	0% (n=0)

Professionals sharing information where this has been agreed	12% (n=12)	4% (n=12)	48% (n=48)	58% (n=29)	34% (n=34)	36% (n=18)	5% (n=5)	2% (n=1)
Provision of integrated care by physical and mental healthcare professionals and other professions (e.g. social services and housing)	10% (n=10)	4% (n=2)	22% (n=22)	40% (n=21)	55% (n=54)	48% (n=25)	13% (n=13)	8% (n=4)
Partnership working between healthcare professionals and community-led groups, charities and user-led groups	10% (n=10)	2% (n=1)	23% (n=23)	35% (n=17)	58% (n=54)	59% (n=29)	8% (n=8)	4% (n=2)

Table 8 Survey respondents' views about whole life and integrated care provision

Survey data again indicated that service users from marginalised communities might experience particular difficulties. (See Table One in Appendix E.) Those from BAME communities had higher ratings than white British respondents for 'never' receiving help from healthcare professionals in almost all the areas set out in Table Eight above, though the differences were only marked in relation to the third and fifth areas (the sharing of information and partnership working). However, there were similar ratings for 'never' from all ethnic groups in relation to the first area, the whole life approach taken by healthcare professionals. Service users who identified as LGB, or other had markedly higher ratings than heterosexual service users for 'never' receiving healthcare assistance with a whole person approach, for the provision of integrated care and for partnership working between healthcare professionals and community-led groups, charities and user-run agencies. Heterosexual service users more often thought that healthcare professionals 'never' understood their physical health needs/provided relevant treatment for these and 'never' shared information about them with each other, however. (See Table Two in Appendix E.) 70% of service users aged 66 and upwards considered that there was 'never' partnership working between healthcare professionals and others.

In the focus groups, participants supplied further explanation about the need for physical healthcare to be better based in whole life approaches and integrated support. One participant, for instance, emphasised the importance of looking at someone’s environment, not just treating the person:

> *If you have a flower that’s dying and withering away, you tend to look at the environment the flower’s in ... and a lot of the time the environment that people are in is so chaotic and traumatic ...*

It was thought, however, that:

> *You’ve got no choice, limited choice, even with an advocate.*

Other comments centred on difficulties in obtaining physical health checks and adequate physical healthcare:

> *I do think my physical health, not just by me, is neglected more by health care professionals ... Nobody actually looks at it and says: ‘Well, actually your cholesterol‘s high and actually did you go for your smear test, or whatever?’. They don’t look at that because they just see mental health ... So therefore I’m thinking: ‘They’re not looking after it. Why should I?’*
>
> *At one time, I had pain in my abdomen for 5 months ... I was in so much pain, so I said: ‘Can you send me for a scan’. 8 weeks passed. I went back and he’d forgotten to send the letter and then it took 22 days to actually get the scan to go to the hospital appointment. When I went to the hospital appointment, she said he’d written it on the wrong letter. I was in so much pain I burst into tears.*

Focus group members also mentioned thinking that input from physical health consultants was less than satisfactory.

Another issue for focus group members was that, when people with lived experience left a mental health unit, integrated care might be a problem:

> *If you have someone who’s in crisis, moves to a hospital and is then released ... unless you’ve got a section 117, what support is there?*

It was clear, therefore, that focus group members had some serious concerns about the provision of a whole life and integrated care approach for people with serious mental illness diagnoses. There was recognition, too, however, of the real difficulties which healthcare professionals may be facing, that their training may have been inadequate, that they have to work to very tight time constraints and that the pressures on them can be very high.

One focus group member remarked, for instance:

> *I did nurse training and you very quickly realise there is no time to do what it says is best practice.*

Another recognised that :

> *The doctors haven't got the time and it's much easier to prescribe a pill.*

3.4.5 Information issues

In the surveys, both service user respondents and unpaid carers/family members indicated that information from healthcare professionals about ways in which service users can manage their physical health falls short of the help needed. (See the data in Table Nine below.)

How much of a difficulty	**A lot**		**Sometimes**		**Never**		**Not relevant**	
	SU	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ Family**
Information about ways of managing physical health	12% (n=19)	9% (n=19)	54% (n=53)	60% (n=28)	30% (n=29)	30% (n=14)	4% (n=4)	2% (n=1)

Table 9 Survey respondents' views about physical health management information

There was again some evidence that service users from marginalised communities were faring worse than those from majority communities. BAME service user respondents had considerably higher ratings for 'never' receiving information than white British respondents; 35% of them gave this rating in comparison with 22% of white British service users. In gender terms, female respondents were still more concerned than male respondents about shortfalls in information; 34% of them thought that they never received information about ways of managing their physical health compared with 22% of male respondents.

Shortcomings in information about self-management were a theme in the focus groups as well. One participant commented, for instance:

> *We don't get much help with learning to self-manage when we have a* (psychiatric) *diagnosis.*

It was also thought that self-management courses might lack substance.

3.4.6 Problems related to equal opportunities

When they were asked about the extent to which professionals provide physical health services which are respectful and relevant in equal opportunities terms, data from survey respondents indicated that there are considerable shortfalls. This was apparent in responses from service user participants and still more so in responses from unpaid carers/family members. (See Table 10 below.)

How much of a difficulty	**A lot**		**Sometimes**		**Never**		**Not relevant**	
	SU	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ family**	**SU**	**Carer/ Family**
Physical health services which are respectful of mental health difficulties/mental distress	18% (n=18)	4% (n=2)	33% (n=34)	53% (n=28)	44% (n=46)	40% (n=21)	5% (n=5)	2% (n=1)
Physical health services which are respectful and relevant in other ways (e.g. take account of ethnicity, gender, sexual orientation, age, or learning disability)	15% (n=14)	4% (n=2)	30% (n=28)	52% (n=27)	38% (n=35)	40% (n=21)	17% (n=16)	4% (n=2)

Table 10 Survey respondents' views about equal opportunities in physical healthcare services

Particularly pessimistic views were again expressed by survey respondents from some marginalised groups. More service users from BAME communities than white British service users thought that physical healthcare provision was 'never' respectful and relevant to them in terms of factors such as their ethnicity; 41% of them gave this rating in comparison with 32% of white British participants. There was a similar difference between the ratings from BAME unpaid carers/family members and white British unpaid carers/family members. Service user respondents who defined themselves as LGB, or other had more concerns than heterosexual service users about physical healthcare provision on a dual front. Fifty per cent of them considered that they 'never' received physical healthcare which was respectful of their mental health difficulties/mental distress in comparison with 44% of heterosexual service users. Forty eight percent of them spoke of 'never' receiving physical health care which was respectful and relevant to them in other ways, in comparison with 35% of heterosexual service users.

Survey respondents added some comments about equal opportunities obstacles experienced by people with serious mental illness diagnoses. A family member who mentioned having a son with both physical and mental disabilities expressed very strong concerns about the treatment which he had received, as someone with dual disabilities. She had found it both uncaring and discriminatory.

Others spoke of a lack of physical healthcare support for people with lived experience from BAME communities and a lack of sensitivity to people who defined themselves as LGB, or other:

> *... Distribution of healthcare should be divided appropriately. Black Afro-Caribbean patients are not being supported at all* (in the local area)*...*

> *I've had bad experiences with nurses and GPs assuming I'm heterosexual and asking what I felt to be intrusive questions about contraception and not believing me, or showing visible disbelief that I've never had sexual intercourse with a man.*

Focus group members developed the dialogue still further. They spoke about difficulties in accessing physical healthcare, if one has a mental health diagnosis:

> *As soon as they class us as un-compos mentis, all the person-centred care and everything has gone out of the window, because we're 'nuts', you know.*

In the experience of focus group members, there might, too, be a failure to provide services which took gender into account. For example, it was thought that there needed to be more recognition of fears which may hold men back from physical health checks and difficulties for some women if they do not have access to female doctors:

> *Particularly men fear ... being checked over and something found, like a MOT, a car, if the exhaust is a bit flat or something ... Men are very scared to go and get health checks and stuff. There needs to be more emphasis on that and empathy*

> *I kind of won't go to my GP, even if it's an emergency, if I'm going to go and see a male ... and to get an appointment with my GP, with a female, it's like 3 weeks. It's you know, for me personally, it puts me off because I'm diabetic as well, so I suffer because I can't go and see them.*

Another concern was that disability issues might not be recognised adequately:

> *You know, my care co-ordinator told me to go on the internet. Well, if you'd read my notes, you'd know I can't see properly.*

For some BAME participants, insufficient account was taken of their ethnicity; one mentioned, for instance, that, although he hates ‘playing the race card’, he may only be heard if he does. There were also concerns that holistic resources for black people were scarce and were not promoted well within the NHS.

3.5 Difficulties in having involvement and influence

Survey respondents with lived experience thought that their involvement in and influence over physical healthcare were limited. In the survey for unpaid carers/family members, participants who wanted a voice about the physical healthcare received by the person they care for/their relative expressed still more pessimistic views about the impact which they were able to have. (See Figure 12 below.)

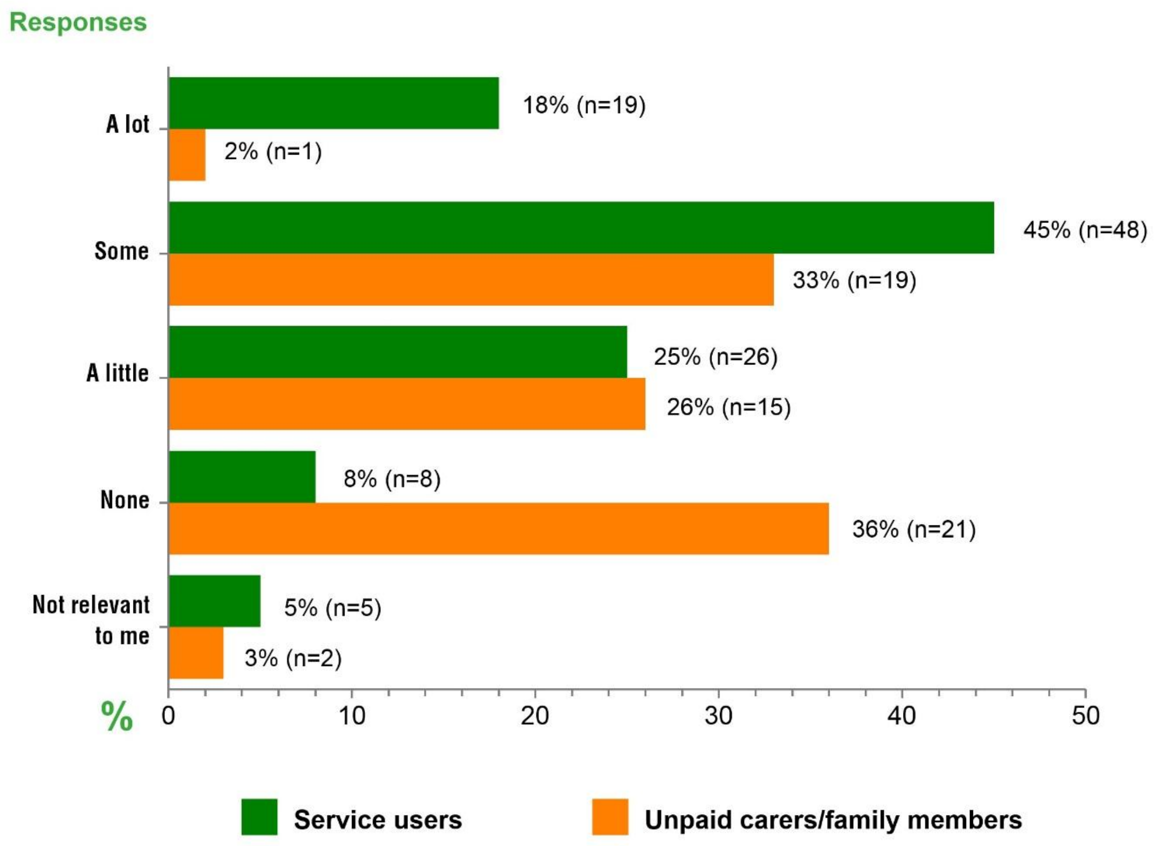


Figure 12 Survey respondents’ views about their involvement and influence

A lack of involvement and influence was also a theme in the focus groups and was developed further in these. For instance, focus group members highlighted the fact that, if people with lived experience had been subject to compulsory detention, it was hard for them to feel that they could have any real powers within the healthcare system generally:

> *The mental health system, what they really do is take away, rob you of your personal autonomy.*

The survey data indicates that service users and unpaid carers/family members thought that they had even less part in the commissioning of physical health services - and that unpaid carers/family members again had a still more pessimistic view about this. (See Figure 13 below.)

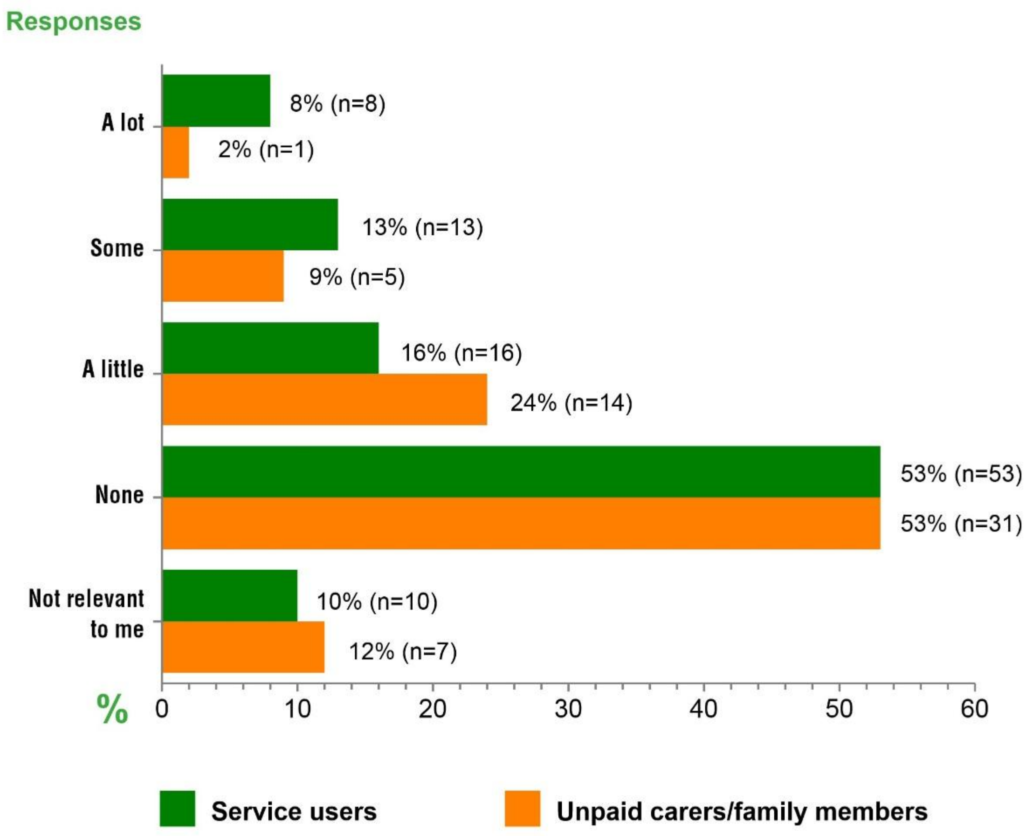


Figure 13 Survey respondents' views about their involvement in commissioning

4. Changes needed

Focus group members built forward from the points made about obstacles by survey respondents and themselves by also suggesting changes which they thought would be helpful in the commissioning of physical healthcare services, in service provision and in the influence which people with lived experience have over physical healthcare.

4.1 The commissioning of physical health services

In line with the emphasis on alternatives to clinical resources and on a use of community settings that ran through data from survey and focus group respondents, focus group members put considerable emphasis on their being more funding for holistic provision. They were concerned that, so far from this being the case, voluntary, local community and user-led resources were closing because of a lack of funding and that there were difficulties in new initiatives of this sort being funded:

> *There was one in South London and that was going for many years, 21 years, and they've run out of money, or at least are very underfunded – and people really depend on that.*

Focus group members recognised limits in available funding, but suggested that, if less money was spent on expensive medical model provision, funds would then be available for alternative resources and that the latter are often more effective:

> *... Why don't they spend money helping you talk through like it might be a housing issue, or a combination of things ...? That is obviously a cheaper option and it makes more sense and affects more people.*

Focus group members thought that more use of values-based commissioning (Whitelock and Perry, 2014) was important as well; under this type of commissioning, as much weight is given to service users' and unpaid carers'/family members' views as to professional opinions and research findings. Focus group members saw this approach as a way of 'challenging top down' commissioning processes. It was suggested, too, that changes in commissioning need to include research funding for physical health resources which people with lived experience find helpful, but which lack an evidence base:

> *... We can't promote our way of doing things as evidence, because it's so hard to get those through clinical trials with this sort of technique.*

Increased funding for other service user involvement measures was also given some weight, in particular monies for self-management courses and peer supported Open Dialogue. Self- management was considered important because people with lived experience can use it to break away from purely medical resources. It was commented that increased self-management would again result in considerable savings as well:

> *You know, when I was a younger guy, I had so many people in my network helping me to manage, whereas now I manage my condition over years of learning that skill. I don't have many people around, so that kind of social workers, CPNs, family members are no longer employed in managing me* (and) *resources are no longer employed in managing me.*

There was some emphasis, too, on adequate pay for people with lived experience who provide input to organisations on self-management and other issues, because this would also change a top-down hierarchy in which higher pay for professionals gives the latter more status.

There was recognition that more funding is needed to make sure that people from disadvantaged groups do not face poorer healthcare, though a feeling that, if services were functioning adequately, this would not be the issue that it is at the moment. There was an awareness again that resources are finite and so suggestions were made about cost-effective healthcare provision for people from marginalised groups; for example, if women-only groups ran in a community hall, this might prove an inexpensive option.

There was an interest in increased funding for qualitative research studies on the basis that these represent service users' experiences and needs in more depth than quantitative research and, in that sense, more adequately. It was suggested that this type of research also helps to alleviate a top-down approach:

> *My number one choice was more funding decisions based on research about people's experiences as well as on statistics. I kind of felt that this was a little bit similar* (to the ethos behind values-based commissioning).

It was understood that quantitative research may be more manageable in commissioning terms. It was thought, however, that the quality of questions in this type of research is key and that questions need to stem from issues that are important to people with lived experience.

There was little interest in the provision of more information about commissioning processes. The level of dialogue from focus group members also suggested that participants already had some sense of these.

4.2 Physical healthcare provision

Some improvements in services compared with those provided twenty years ago were acknowledged. A number of suggestions were also made, again related particularly to less clinical and/or more holistic provision:

- Move away from the use of psychiatric medication and damaging physical effects which it can have
- Provide services which demonstrate the interconnection between eating, food and mood
- Have advertised checklists in GP surgeries which let people know how they can ask their GP about weight issues and keeping fit and explain why it is important to ask about these

- Set up a joint referral point for entry into mental health services whereby people with lived experience see someone for a physical healthcare check at the same time as they see a psychiatrist

- Draw on a sports-based recovery project which is already available

- Have mental health community centres at which physical healthcare and mental wellbeing resources are intertwined

- Set up central community services which people with lived experience can use when they are in crisis, or have just been discharged, with inexpensive, or free activities. Have facilitators in each borough to encourage people to attend

- Provide a free website with regular updates about different physical health conditions, what people can do about these and what community resources are available. Help people to access this through the provision of peer support

- Set up a co-produced self-management programme available over the internet, with narrative contributions, and show people how to use it.

4.3 The influence of people with lived experience over physical healthcare

Focus group members made various suggestions about an increased involvement and an increased influence for people with lived experience at individual, service provision and service commissioning levels, with a view to physical health services being less medically- and more community-based and better meeting the needs of people diagnosed with serious mental illnesses better.

At an individual level, one suggestion was having a ‘mental health PALS’ to address issues for people with lived experience and, at an organisational level, participants wanted more people with lived experience on commissioning and provider boards.

Focus group members with lived experience thought that training for themselves would help them to have more influence in organisations, together with ‘qualifying’ their own views and obtaining professional backing for these from sympathetic experts who had relevant evidence:

> *What I’ve noticed is like, trying to affect change, we have to be trained in a way that people who make decisions will respect our opinion, which is kind of anti people just being themselves, but, in a sense, if we have to break into, you know, being and working with commissioners and working with councils and things like that, we need to be able to participate in a way that is acceptable to them*

> *The problem is this* (non-medical) *approach goes against the grain of psychiatry. This is where the problem lies. So, firstly, I'm trying to do something myself. It's about qualifying yourself. You have less weight, in fact you're weightless, so, if you said to someone 'go and do some yoga, go for a run', you've got no professional credibility. If you're a doctor, and you hand them anti-depressants, you've got all the professional credibility.*

Another suggestion was that the 4Pi National Involvement Standards (Faulkner, 2015) might be used to increase the influence of people with lived experience over physical healthcare; these were collated by a National Involvement Partnership, under NSUN's leadership and with funding from the Department of Health. A further idea was that promoting a change in language used to refer to people with lived experience would be useful, because language is influential and may quickly change from being 'neutral' to being stigmatising and so disempowering:

> *I think language is so important, so subtle, and it's so subliminal, you know, nobody realises... It's like a bacteria and you have to keep changing it, because language is changing over time. This thing with mental health, when it was invented, it probably was with the best of intentions, but now it's become like a pejorative thing.*

It was suggested, too, that more intergenerational work might be useful; if younger and older people drew jointly on each other, this might help things to progress.

Service user and carer participants were not altogether confident, however, that changes in commissioning and services could be achieved through the NHS and thought that they might need to initiate action themselves. They also discussed collecting enough electronic signatures to ensure that key issues are debated in parliament.

Part Three: Discussion and conclusions

The findings will be discussed in relation to three particular areas: what participants regarded as good resources for people with serious mental illness diagnoses, what positive examples they cited and what changes they thought were needed.

1. Good physical health resources for people diagnosed with serious mental illnesses

It is apparent from the findings that participants very much wanted good physical health services for people with lived experience. A clear and well-justified picture has also emerged in the findings about the sorts of physical health and physical wellbeing resources which were thought to be helpful to people diagnosed with serious mental illnesses. What participants advocated were wide-ranging services with a focus on community settings:

1.1 As part of this, they advocated a move away from a dominant medical model in mental health services; they currently experienced mental health provision, as focusing on diagnoses and psychiatric medication, as having a risk orientation and as being too closely linked with compulsory powers under the Mental Health Act 2007. This is not an emphasis that has been apparent in other, professionally-led consultations about physical health. Participants' views were very similar, however, to those expressed in the user-led study by Gould (2012); in this, people with lived experience also stressed the need for changes from this type of approach if the Care Programme Approach was to be effective in promoting recovery as they understood it, including physical health components of recovery. As Beresford (2013) has highlighted, a value of service-user led studies is that research themes and research design employed in these draw out findings which do not necessarily emerge from other studies, but which are important to people with lived experience. Because of the weight which participants in the current study gave to moving away from a dominant medical model, it would seem key that this is taken into account in future commissioning of physical healthcare and in future physical healthcare provision.

1.2 Participants emphasised the benefits of taking a holistic approach to the commissioning and provision of services for people with serious mental illness diagnoses in both mental health and physical health provision. To them, this meant an equal focus on addressing mental wellbeing, physical health, personal circumstances, socio- economic issues and demographic factors for people with these diagnoses. Within this, participants thought that the maintenance of physical wellbeing and support with long term physical health conditions were important, including information about psychiatric medication and strong measures to deal with its side effects and the impact of these on quality of life and on life expectancy. They did not regard 'holistic' as limited to mental wellbeing and physical health, however, and, in this sense, took a more comprehensive view of 'holistic' than may be employed in government and professional documentation; the report from the All Party Parliamentary Group (2015) on progress with parity of esteem, for example, equates ‘holistic’ with physical and emotional health. In line with their concepts of ‘holistic’, participants also considered it valuable for there to be a variety of resources for achieving the model which they wanted: local community centres, charities and user-led resources in addition to clinical services. They stressed that, if a holistic approach is to be successful, then information about the full range of resources and access to a wide number of them is vital, together with partnership working, not just between health and other statutory professionals, but between the latter and community-led groups, charities, advocates and user-run agencies.

1.3 Participants also spoke of the key part which good interpersonal skills and flexible, creative approaches from professionals have within a holistic model and of the need to recognise that people with lived experience often appreciate personal contact with professionals more than online consultations and websites, though some value was placed on websites as well. They put an emphasis, too, on the meeting of diverse needs. Participants suggested training for professionals in the overall approaches which they considered helpful for people diagnosed with serious mental illnesses and in the qualities mentioned above, but were not altogether sure that training in the latter is effective. They also proposed training for people with lived experience, to help their voices to be taken seriously.

In other consultations involving service users and carers, some similar points have been made. For example, in the report *20 Years Too Soon* from Rethink Mental Illness (2012), there is an emphasis on integrated care, on dealing with issues related to psychiatric medication and on ensuring information about and access to local community services reasonable adjustments by GPs, and training for GPs. The Mental Health Foundation’s report about integrated care (2013) puts a focus on holistic services and integrated approaches, particularly in relation to statutory services, and on the key role which staff qualities need to play within these. In the current consultation, however, the model put forward is considerably wider, including the note of catering for demographic differences, and so merits careful further consideration.

1.4 In addition to the points made above, participants stressed the importance of people with lived experience having involvement and influence at personal, organisational and commissioning levels if physical health services are to run in the sorts of ways described above and, too, the valuable roles which family members, friends and peers can play in this sort of model. These are not new concepts at government, or service levels, but might helpfully be extended further in some current physical healthcare documentation. For example, in the report from the All Party Parliamentary Group (2015) on progress with parity of esteem, it would be valuable to see an emphasis on user involvement in the recommendations put forward and on the role of family and peer support. Similarly, in the report from the

Mental Health Foundation (2013), it would seem important to add service user involvement and influence to the factors for good integrated care which are listed in the document and to allow in these for the roles which family members and friends can take.

In the King's Fund report (Naylor *et al,* 2016), whilst there had again been consultation with service users and carers, there is recognition that the integrated service models put forward in the report may not be at quite the same level as the whole person perspective emphasised by service users and carers, but an assumption that these models could nonetheless play a role in bringing about the kind of change required by the latter. Evidence for this assumption is not provided, however.

2. Positive examples

It is clear from the findings that participants had some favourable views about the current situation. They spoke of the extent to which people diagnosed with serious mental illnesses manage to look after their physical health, for instance. As has been highlighted in section 2.2 of the findings, respondents to the surveys for people with lived experience were mostly able to name at least one step which they took to keep healthy and/or to look after a long term physical health condition which they might have. In addition, the larger number of unpaid carers/family members named at least one way in which the person they cared for/their relative was doing so. Successful self-management was also a note which ran through other data from participants.

This finding may be worth contrasting with the somewhat problem-focused picture which can be evident in other reports. In the British Medical Association report (BMA, 2014) about achieving parity of esteem, 'health behaviour' of people with serious mental illness diagnoses, in particular the use of alcohol and substances, smoking, poor diet and a lack of physical activity, is cited as a major cause of physical health problems and detailed in the report. In contrast, self-help measures which people with lived experience adopt receive little focus and ways in which further health promotion could be built from these are not discussed.

It is also evident from the findings in section 2 of Part Two that there are physical health and physical wellbeing services which participants consider helpful in promoting the physical health of people with lived experience in ways which fit the approaches put forward by them. Participants provided a number of examples. Although as many as half of these were drawn from outside the NHS, they included a number of instances with a whole life focus from within the NHS. In addition, the value of support from family members, peers and friends was mentioned, together with some differences which participants thought that people with lived experience had been able to make to physical health provision themselves. Given that the majority of these examples came from people with lived experience and unpaid carers/family members, it would seem particularly useful to take note of them and to see what could be done to identify further, similar examples and build from them.

3. Changes needed

It is also clear that the approaches proposed by participants imply radical change in the commissioning and provision of physical healthcare services for people with serious mental illness diagnoses and that considerable obstacles need overcoming if participants' proposals are to become a reality:

3.1 As has been mentioned above, people diagnosed with serious mental illnesses are taking steps to look after their physical health and may, in fact, strongly emphasise self-management. It is evident from the study findings that the sheer scale of mental health difficulties which they face needs stressing, too, however. Participant feedback from the two surveys in combination demonstrated that the mental health problems/mental distress factors which people with serious mental illness diagnoses experience are a bigger obstacle to their looking after their physical health than personal, environmental or social factors and shortfalls in the support received from healthcare professionals, though the ratings about the difficulty presented by healthcare professionals' failure to work in adequate partnership with community-led groups, charities and user-run agencies came very close.

This finding would seem to make it all the more vital to address major difficulties highlighted by participants which people with lived experience encounter in existing mental health services: the fact that they find these dominated by a medical model which to them is unhelpful and disempowering. In this sense, the findings may be something of a challenge to elements of the Mental Health Taskforce report (2016), given that mental distress is defined here in diagnostic terms belonging to a white western model rather than alternative models being included too. Whilst clinical terms are employed in the Mental Health Foundation's report on integrated care (2013) as well, there is also recognition in the report of a tendency for clinical approaches to dominate.

3.2 The project findings underline the urgency of providing more information for service users about psychiatric medication, adequately addressing the impact which physical side effects of this has on service users' quality of life and on their life expectancy and making more alternatives available; participants have stressed how major these issues are for them and they are not new findings, as the literature cited in Part One makes clear.

3.3 It is apparent, too, from the survey ratings and focus group data in section 3 of Part Two that social deprivation and social exclusion, together with shortfalls on the part of healthcare professionals in listening respectfully and empathetically, addressing these factors adequately and taking the whole of people's circumstances and needs into account, constitute further obstacles to the physical health of people with serious mental illness diagnoses and to physical healthcare approaches which they want. At least some of these factors have again been highlighted elsewhere, for example in the report from the British Medical Association (2014). The issue is that there has not yet been sufficient change in structures and approaches to address the problems for people with lived experience adequately.

In addition, it is evident that there will be continuing obstacles to the sorts of holistic and community-based healthcare provision advocated by participants while there are the shortcomings amongst healthcare professionals which participants have highlighted in relation to:

- Input about self-management techniques
- Information about and access to the range of physical health resources provided by public health services, community-led resources, charities and user-run groups
- Adequate funding of these
- Integrated care and still more so partnership working with non-health workers

3.4 Study findings raise significant equal opportunities issues:

3.4.1 It is concerning that only 18% (n=18) of survey respondents with lived experience and 4% (n=2) of unpaid carers/family members thought that physical health services are respectful of mental health difficulties/mental distress ‘a lot’ (3.4.6 in Part Two). In addition, a particular finding of this study has been the greater physical health obstacles which people with lived experience may face when they belong to marginalised communities. The survey ratings from service users who belonged to BAME communities and from people who identified as LGB, or other were quite frequently still lower than those from majority communities. This was apparent, for instance, in data about their personal circumstances, their wish for more information about and access to community-led groups, charities, advocates and user-run agencies and their concerns for more respectful and relevant physical health provision. In addition, female service users rated difficulties stemming from their personal circumstances and from social exclusion as more of an obstacle than male service users did. Similar findings were apparent in the focus group data.

By definition, the numbers contributing to the project were quite small. The findings about ethnicity, sexual orientation and gender very much reflect those in larger studies, however. For example, the recent report from the Equality and Human Rights Commission (2016) on race equality illustrates the racial inequities that continue to exist within mental and physical health services and, too, in wider spheres such as education, employment, housing, living standards, the justice system and participation within society. Similarly, Stonewall reports identify major inequities for people who identify as LGB, or T both within society and its structures generally (YouGov, 2013) and within healthcare specifically (Somerville, 2015); within healthcare, difficulties may range from sexual orientation being seen as irrelevant to direct discrimination.

It would seem important, therefore, both to address shortfalls in professional respect towards people with lived experience in general and to take specific holistic action and anti-discriminatory measures to address physical health issues for people from BAME communities, LGB or other communities and women, so that they do not become further marginalised. An emphasis on these groups too appears still more necessary because additional problems for them do not receive any real focus in major recent reports about physical healthcare, such as those from the All Party Parliamentary Group (2015), the Mental Health Foundation (2013), the Kings Fund (Naylor *et al,* 2016) and Working Group for Improving the Physical Health of People with SMI (2016). Obstacles arise as well when other diversity issues are not taken into account, for example the fact that men may hold back more than women from physical health checks, or may then give more weighting to input from their GP/another medical resource than non-clinical community facilities for long term conditions. These, too need attention.

3.4.2 Service users aged 66 or over also emerged as having some different healthcare needs from younger participants. They emphasised physical health checks more strongly than younger people did and indicated that, for them, a lack of partnership between healthcare professionals and non-clinical community services was still more of a concern; that seems unsurprising, given that physical health tends to decrease with age and that the maintenance of links with the local community can become correspondingly more important. Older participants experienced their mental distress as even more of a problem than younger participants; it may be that this was because their physical health was worse as well. The fact that older participants had very limited interest in technology and a total lack of interest in online consultations fits findings in the recent factsheet from Age UK (2016); it is clear from the factsheet that, whilst internet usage amongst older people is increasing, it is still less extensive than that of younger people. Because formal complaints about the care of older people in hospital amount to an average of 28 per 100 beds, as is again evidenced in the Age UK factsheet, it is understandable, too, that older participants were not enthusiastic about hospital care. Issues such as these are, therefore, ones which would also seem to need addressing.

3.5 It is concerning that only 18% (n=19) of service user survey respondents thought that they had ‘a lot’ of involvement in and influence over physical healthcare, that fewer than half considered that they had ‘some’ influence and control and that 53% (n=53) described themselves as having no involvement in the commissioning of healthcare services. Focus group members expressed similar views. This is a situation which urgently needs remedying, if people diagnosed with serious mental illnesses are to receive the physical healthcare approaches, services and resources which they find valuable.

3.6 Responses from unpaid carers/family members which differ from those of people with lived experience also merit a focus:

3.6.1 In the surveys particularly, the views of unpaid carers/family members about support which they thought the person they cared for/their relative needed were quite frequently still stronger than those of service user participants. Higher percentages of unpaid carers/family members favoured more help for the person they cared for/their relative with physical health and more use of technology than service users did (see 1.3 in Part Two above). This may perhaps have been because they regarded service users' mental health problems/mental distress as even more of a barrier to self-management than service user respondents did and were not quite so confident as service user respondents that the latter were taking steps to look after their physical health.

In their survey responses, unpaid carers/family members also rated the following as still more of a barrier to service users' physical health than the latter did: personal circumstances, social exclusion, problems with psychiatric medication and professional shortcomings with whole life approaches and with an understanding of physical health needs/provision of relevant treatment for these. There can, of course, be differences of viewpoint depending on whether one is viewing mental distress from the position of an unpaid carer/family member, or from lived experience of it. It may be the case, too, that, when one is immersed in an experience, such as serious mental health problems/mental distress, one is less aware of its full impact than others are. It should be borne in mind as well that there were fewer unpaid carer/family member than service user participants and that there was no necessary connection between the two groups; unpaid carers/family members and service users were recruited independently of each other. What is useful, however, is that the outlooks of unpaid carers/family members bring yet other perspectives.

3.6.2 The fact that respondents to the unpaid carer/family member survey thought that their voices were heard particularly inadequately is not a new finding; as recently as this year, written evidence from Carers UK (2016) calls for more recognition of the expertise which carers have and more support for them. Whilst service users' right to confidentiality must always be respected, the valuable role which unpaid carers/family members can play in decisions made about physical healthcare would also seem to need a further focus.

Conclusions

Given the scale of changes which participants are recommending, the need to establish evidence bases for different types of services which participants have identified as helpful and the fact that both participants with lived experience and unpaid carers/family members have experienced a limited influence over physical healthcare provision to date, it is not surprising that they were unsure whether these changes can really be achieved within the NHS. What has emerged from the study, however, is a very explicit portrayal of the changes in London-based physical health services that participants think would make a major difference to the physical health and physical wellbeing of people with serious mental illness diagnoses and their reasons for promoting this. It is a portrayal which merits serious consideration by commissioners and service providers in London – and a study of the relevance which it may have to other parts of the UK. It is the change of culture, change of funding processes/funding allocations and change of structures and approaches that will be the challenge, however, if participants' views are to be taken into account.

Part Four: Recommendations for the commissioning and provision of services in London

1. Medical model usage

Move away from a dominant medical model approach in mental health and physical health services

2. A fully holistic approach

2.1 Take full account of the impact which lived experience of serious mental health problems/mental distress can have on people's ability to look after their physical health, whilst also acknowledging steps which people with a serious mental illness diagnosis take to self-manage

2. 2 Provide more information for service users about the impact of psychiatric medication, address its physical side effects more fully and make sure that a wider range of alternatives is available

2.3 Give increased priority to whole life approaches in physical health services which cover mental wellbeing, physical health, personal life circumstances, socio-economic environments, social status and spiritual beliefs and do so through a range of resources, not just clinical provision

2.4 Build on the sorts of whole life examples which project participants have identified as helpful to people with lived experience

2.5 Put a particular emphasis on the commissioning and provision of community settings and community-based resources for physical healthcare: community centres, community-led groups, charities and user-run agencies as well as public health facilities, GP surgeries and other community-based medical facilities

3. Information and access

3.1 Make sure that information about holistic resources for physical healthcare and support with accessing them are available in a variety of settings for people with lived experience, including those who are on low incomes

3.2 Be aware of the value which people with lived experience put on personal contact, but also use internet resources and information technology such as text messages to update people with lived experience where they find the latter helpful

4. Integrated support and partnership working

4.1 Ensure better information-sharing between healthcare professionals where people with lived experience have agreed to the passing on of personal information

4.2 Significantly improve the co-ordination of care between physical and mental healthcare professionals and between them and other professionals, for example those working in social services and in housing

4.3 In the provision of physical health services, promote much stronger partnerships between healthcare professionals and workers in community-led resources, charities, advocacy services and user-run groups

5. Equal opportunities

5.1 Make sure that physical health services are respectful of and tailored to people's lived experience and to factors such as age, ethnicity, gender, sexual orientation and/or additional disabilities

5.2 Specifically address physical health issues for those who may face additional disadvantages, including members of BAME communities, women, people who identify as LGB, or other and older people, for example their experiences of and models for mental health problems, their life circumstances and their access to physical health resources which are relevant to them

6. Settings and approaches

6.1 Make physical healthcare settings welcoming and inviting

6.2 Recognise the extent to which people subjected to detention under the Mental Health Act 2007 can feel disempowered and distrustful of professionals and work hard to establish empowering and positive relationships with them

6.3 Put a greater focus on listening skills, empathy, fun and creative approaches, strengths-based models and a note of moving towards good things rather than avoiding physical health risks

7. Training

7.1 Provide more input for health professionals about mental and physical health services which people with lived experience find meet their needs

7.2 Offer people with lived experience opportunities to supply training for healthcare professionals in the physical and mental healthcare models, approaches and interventions which they find valuable

8. Research

8.1 Promote research funding for physical health and physical wellbeing options which are important to people with lived experience

8.2 Give weight to qualitative as well as quantitative research when reaching decisions about which physical health services to commission and provide

9. Influence and involvement

9.1 Make sure that people with lived experience can have a real and increased influence at personal, service provision and commissioning levels, for example through further self-management opportunities, organisational uptake of the 4Pi National Involvement Standards and the use of values-based commissioning

9.2 Provide for training which equips people with lived experience to have the voices they want about helpful physical healthcare commissioning and provision

9.3 Pay increased regard as well to the valuable roles which family members, friends and peers can play in supporting people with lived experience to address their physical health needs and to have an influence in the commissioning and provision of services

9.4 Act on changes in the commissioning and provision of physical health services which people with lived experience want.

References

Age UK (2016) *Later Life in the United Kingdom August 2016,* http://www.ageuk.org.uk/Documents/ENGB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true

All Party Parliamentary Group on Mental Health (2015) *Parity in Progress?* http://www.mind.org.uk/media/1939983/appg-parity-in-progress-final.pdf

Beresford, P. (2003) *It's Our Lives: a Short Theory of Knowledge, Distance and Experience,* London: Citizen Press in association with Shaping Our Lives

Beresford, P. and Baxall, K. (2013) 'Where do service users' knowledges sit in relation to professional and academic understandings of knowledge?' in Staddon, P. (ed.) *Mental Health Service Users in Research. Critical Sociological Perspectives,* Bristol: Policy Press

British Medical Association (2014) *Recognising the Importance of Physical Health in Mental Health and Intellectual Disability. Achieving Parity of Outcomes,* London: BMA

Bryman, A. (2016) *Social Research Methods* (5th edn), Oxford: Oxford University Press

Byrne, B. (2012) 'Qualitative Interviewing', in Seale, C. (ed.) *Researching Society and Culture,* (4th edn), London: Sage

Carers UK (2016) *Evidence for the Carers' Strategy. Written Submission from Carers UK,* http://www.carersuk.org/for-professionals/policy/policy-library/submission-to-the-carers-strategy

Chadwick, A, Street, C, McAndrew, S. and Deacon, M. (2012) 'Minding our own bodies: reviewing the literature regarding the perceptions of service users diagnosed with serious mental illness on barriers to accessing physical health care', *International Journal of Mental Health Nursing,* 21: 211-2019

Department of Health (2011) *No Health Without Mental Health. Delivering Better Mental Health Outcomes to People of All Ages,* London: DH

Department of Health (2015) *Mental Health Act 1983: Code of Practice,* Norwich: The Stationery Office

Department of Health (2016) *The Government's Mandate to NHS England for 2016-2017,* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/494485/NHSE_mandate_16-17_22_Jan.pdf

Docherty, M, Stubbs, B. and Gaughran, F. (2016) ‘Strategies to deal with co-morbid physical illness in psychosis’, *Epidemiology and Psychiatric Sciences,* 1017 (10): 1-8

Doherty, A. M. and Gaughran, F. (2014) ‘The interface of physical and mental health’, *Society of Psychiatry and Psychiatric Epidemiology,* 49: 673-682

Equality and Human Rights Commission (2016) *Healing a Divided Britain: The Need for a Comprehensive Race Equality Strategy,* https://www.equalityhumanrights.com/sites/default/files/healing_a_divided_britain_-_the_need_for_a_comprehensive_race_equality_strategy-final.pdf

Faulkner, A. (2015) *The 4Pi National Involvement Standards. Executive Summary,* http://www.nsun.org.uk/assets/downloadableFiles/4PiNationalInvolvementStandardsExecutiveSummary20152.pdf

Fricker, M. (2007) *Epistemic Injustice. Power and the Ethics of Knowing.* Reprint. Oxford: Oxford University Press, 2010

Gould, D. (2012) *Service Users’ Experiences of Recovery under the 2008 Care Programme Approach.* Reprint. London: NSUN and MHF, 2015

Gould, D. (2016) *A Consultation with People Who Have Lived Experience About the Draft Commissioning Guidance: Stolen Years Group.* Unpublished report. NSUN

Happell, B, Ewart, S.B, Platania-Phung, C. and Stanton, R. (2016) ‘Participative mental health consumer research for improving physical health care: an integrative review’, *International Journal of Mental Health Nursing,* doi:10.1111/inm.12226

Joint Commissioning Panel for Mental Health (2013) *Guidance for Implementing Values-Based Commissioning in Mental Health,* http://www.jcpmh.info/wp-content/uploads/jcpmh-vbc-guide.pdf

Leweke, F.M, Mueller, J.K, Lange, B. and Rohleder, C. (2016) ‘Therapeutic potential of cannabinoids in psychosis’, *Biological Psychiatry* 79(7): 604-612

Mental Health Foundation (2013) *Crossing Boundaries. Improving Integrated Care for People with Mental Health Problems. Final Inquiry Report,* *https://www.mentalhealth.org.uk/sites/default/files/crossing-boundaries.pdf*

Mental Health Taskforce (2016) *The Five Year Forward View for Mental Health,* https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf

National Survivor User Network (2016) *Theoretical Framework and Methodology for Qualitative Research,* http://www.nsun.org.uk/assets/downloadableFiles/NSUNtheoryandmethodpaper20162.pdf

Naylor, C, Das, P, Ross, S, Honeyman, M, Thompson, J. and Gilburt, H. (2016) *Bringing Together Physical and Mental Health,* London: The King's Fund

Nover, C. and Jackson, S.S. (2013) 'Primary care-based educational interventions to decrease risk factors for metabolic syndrome for adults with major psychotic and/or affective disorders: a systematic review', *Systematic Reviews* 2013 (2): 116

Rethink Mental Illness (2012) *20 Years Too Soon. Physical Health: The Experiences of People Affected by Mental Illness,* www.rethink.org/media/511826/20_Years_Too_Soon_FINAL.pdf

Rethink Mental Illness (2013) *Lethal Discrimination,* www.nhsconfed.org/~/media/Confederation/Files/public access/2013-10-04 Rethink Mental Illness-Lethal Discrimination.pdf

Ritchie, J. and Spencer, L. (1994) 'Qualitative data analysis for applied policy research', in Bryman, A. & Burgess, R.G. (eds) *Analysing Qualitative Data,* Oxon: Routledge

Rose, D. (2009) 'Survivor-produced knowledge', in Sweeney, A, Beresford, B, Faulkner, A, Nettle, M. and Rose, D. (eds) *This is Survivor Research,* Ross-on-Wye: PCCS Books

Russo, J. and Beresford, P. (2015) 'Between exclusion and colonisation: seeking a place for mad people's knowledge in academia', *Disability and Society* 30 (1): 153-157

Rutterford, C. (2012) 'Research design' in Seale, C. (ed.) *Researching Society and Culture,* (4th edn), London: Sage

Sale, J.E.M. and Brazil, K. (2004) 'A strategy to identify critical appraisal criteria for primary mixed-method studies', *Quality and Quantity* 38: 351-365

Shenton, A.K. (2004) 'Strategies for ensuring trustworthiness in qualitative research projects', *Education for Information* 22: 63-75

Somerville, C. (2015) *Unhealthy Attitudes. The Treatment of LGBT People Within Health and Social Care Services,* https://www.stonewall.org.uk/sites/default/files/unhealthy_attitudes.pdf

Spicer, N. (2012) 'Combining qualitative and quantitative methods' in Seale, C. (ed.) *Researching Society and Culture,* (4th edn), London: Sage

Srivastava, A. and Thomson, S.B. (2009) 'Framework analysis: a qualitative methodology for applied policy research', *JOAAG* 4(2): 72-79

Thornicroft, G, Rose, D. and Kassam, A. (2007) 'Discrimination in health care against people with mental illness', *International Review of Psychiatry* 19(2):113-122

Whitelock, A. and Perry, E. (2014) *Influencing Mental Health Services. A Guide to Values-Based Commissioning,* http://www.nsun.org.uk/assets/downloadableFiles/Value_based_commissioning_report_V22.pdf

Working Group for Improving the Physical Health of People with SMI (2016) *Improving the Physical Health of Adults with Severe Mental Illness: Essential Actions (OP 100),* http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/op/op100.aspx

World Health Organisation (2013) *Mental Health Action Plan 2013-2020,* http://apps.who.int/iris/bitstream/10665/89966/1/9789241506021_eng.pdf

YouGov (2013) *Gay in Britain. Lesbian, Gay and Bisexual People's Experiences and Expectations of Discrimination,* https://www.stonewall.org.uk/sites/default/files/Gay_in_Britain__2013_.pdf

Appendix A: Background documents

Stolen Years Steering Group

Terms of Reference

Introduction

The London Mental Health Programme Board has endorsed a work programme to improve physical health outcomes for people with serious mental illness in London. A Steering Group has been established to develop priorities and lead delivery against an agreed work programme. The Steering Group will provide strategic leadership, clinical advice, oversight, cohesion and guidance for the transformational programme.

It will work in partnership with all key stakeholders in London who have an interest in improving physical health outcomes for people with serious mental illness in London.

Role

The purpose of the Stolen Years Steering Group is to focus on the development and implementation of a bundle of projects that together support strategic transformation of services and interventions to improve the physical health outcomes for people with serious mental illness in London. The Steering Group will be responsible for developing an evidenced based clinically led work programme and will be accountable for ensuring these projects are delivered.

The Steering Group will work closely with the London Mental Health Strategic Clinical Network and the London Mental Health Transformation Board. The Steering Group will be required to work closely with people with lived experience, commissioners, providers, Local Authorities, community and voluntary groups to deliver its projects.

Scope

The work of the steering group will focus on patients with schizophrenia, bipolar affective disorder and other psychoses as defined by the Quality Outcomes Framework.

Key functions

The Steering Group will:

- Develop an evidence based work programme that details specific projects to improve health care and outcomes for people with serious mental illness.
- Provide oversight and decision making for the Stolen Years work projects, focusing on those areas of work where collaboration across London offers the greatest yield in respect of outcomes

- Provide leadership for the work projects including monitoring and ensuring overall timely progress towards the groups' objectives.
- Support the formulation of key objectives and associated evaluation measures, develop project strategies and implementation plans, produce scoping documents and review delivery against key milestones;
- Resolve strategic and policy issues;
- Determine the best use of project resources;
- Ensure resolution of any escalated issues; and
- Link with external partners who may be invited to meetings when relevant.

Governance

- The Steering Group will report to the London Mental health Transformation Board, part of the Healthy London Partnership. This will be the vehicle for the Steering Group to be held to account to NHS England and London CCGs.
- The Steering Group will be required to seek clinical input and guidance from the Strategic Clinical Network and the wider Stolen Years clinical group.

Membership

Chair

The Steering group will be chaired by Dr Fiona Gaughran, lead consultant psychiatrist, National Psychosis Service, South London and Maudsley NHS Foundation Trust.

The vice-chair of the group will be Dr Bill Tiplady, consultant clinical psychologist, Central and North West London NHS Foundation Trust.

Members

Membership will be drawn from the key stakeholders involved in improving physical health outcomes for people with serious mental illness in London. People with lived experience and their carers will be included and an essential part of the project.

Linkages will also be made with key stakeholders and across other programmes within the Healthy London Partnership Mental Health programme.

Members are requested not to send deputies as substitution for their attendance.

Nomination

The Chair may approach nominating bodies or approach clinicians directly and ask for nominations that match the skills, backgrounds and expertise needed to complement existing membership. Membership will be drawn from across London.

Ad hoc attendees

To ensure a broad range of clinical input and perspective, clinicians and commissioners with relevant expertise may be required to attend Steering Group meetings to contribute to the discussion. As the Steering Group meetings are intended to be closed, ad hoc attendees may be permitted to join pending prior approval.

Declaration of interest

All members of the Steering Group are required to declare any professional or personal interests which may affect their contributions to the projects within the Steering Group's work programme. These interests should be declared to the Steering Group Chair and reviewed as and when they occur.

Meetings

Frequency

The Steering Group will meet every month.

If an interim meeting is required to address an urgent or pending issue, the Chairs will call a meeting outside the usual cycle.

Participation

It is expected that members will commit the time necessary to understand the issues considered by the Steering Group, participate vigorously and respectfully in debate and genuinely commit to identifying clinically based decisions on behalf of Londoners with serious mental illness.

Agenda and minutes

The agenda and any supporting documents will be circulated by email in advance of the meeting. Papers may be tabled pending approval of the Chairs.

Review

The Steering Group will review its purpose, work programme, function, performance, membership and terms of reference on an annual basis, due in January 2017.

Information about the National Survivor User Network

Care to join us?

The National Survivor User Network (NSUN) is a service user led mental health charity.

We encourage peer support and give information to people with experience of mental health issues so that we have a stronger voice in shaping policy and services.

Membership is FREE, confidential and gives you:

- Free members' magazine
- Emailed bulletins and web resources
- The chance to join others in shaping care and offering mutual support
- Invites to events, conferences and training

NSUN
27-29 Vauxhall Grove,
London, SW8 1SYg
t: 0207 820 8982

e: info@nsun.org.u
w: www.nsun.org.uk

The National Survivor User Network (NSUN) supports service user, survivor and user-led community mental health projects and groups as well as individuals, for whom mental health problems are often just one issue affecting their lives. NSUN's vision is to create a strong, sustainable and influential network of individuals and groups of mental health service users and survivors who are communicating and supporting each other.

There is recognised value in being supported by people who understand your experience rather than it being defined by 'experts' alone. NSUN's user-led nature is what sets it apart from other organisations in the field, and gives it unique insight and authenticity. No other user-led mental health organisation has created a sustainable co-ordinating body for collecting user concerns and channelling them to appropriate decision-makers.

NSUN provides a vital capacity building and collective empowerment function for marginalised voices on a national scale and is the only national user-led organisation providing information and support to challenge and inform existing policy and practice at national and local levels.

Appendix B: Project surveys and topic guides

Improving approaches to physical healthcare and physical wellbeing. A survey for people diagnosed with a serious (enduring) mental illness

The purpose of the survey

To understand your physical health needs, your current experiences of physical healthcare and any improvements which you think are needed. The survey is part of a Healthy Lives project about physical healthcare and physical wellbeing which has been set up by the **National Survivor User Network (NSUN)**, a service user-led charity.   People diagnosed with a serious (enduring) mental illness, unpaid carers/family members and professional workers are being invited to contribute their views to the project.

Who is carrying out the survey

The National Survivor User Network (NSUN). NSUN has been commissioned by the **Healthy London Partnership mental health programme** to undertake this survey. Sarah Yiannoullou, NSUN's managing director, can give you more information about the survey, if you contact her by email at Sarah.Yiannoullou@nsun.org.uk, or by phone on 020 7820 8982/07778 659 390.

How replies will be used

Your reply and replies from other people who take part in the survey will be used towards a report about physical healthcare for people with a serious (enduring) mental illness diagnosis. The report will include recommendations about physical healthcare and physical wellbeing approaches for people with a serious mental illness diagnosis. These recommendations will then be taken into account in the production of guidance and best practice documents which are being drawn up through the London Partnership mental health programme.

Confidentiality

Information which identifies you will not be collected, nor used in the report, guidance and best practice documents. In addition, only the NSUN project team will see individual replies. We may quote your answers in the report and in documents linked to the report, but will not do so in ways which could identify you.

Survey content

There are two parts to the survey. Part A is about your general background. We would appreciate answers to all the questions in Part A, unless there is a question which you find uncomfortable in some way. Part B is about your experiences of physical healthcare and physical wellbeing. If you can answer all the questions in Part B, it would be very helpful.

Improving approaches to physical healthcare and physical wellbeing. A survey for people diagnosed with a serious (enduring) mental illness

Part A: Some information about you

We are asking you to complete the questions in this section, because people’s experiences of services may vary according to factors such as their age, ethnicity, gender and sexual orientation and so we want to have as wide a mix of participants as possible. If there is any question which you are not comfortable answering, please just move on to the next question.

Age (Please tick one box only.)

18-25 ☐ 26-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 66-75 ☐

Over 75 ☐

Gender

(a) At birth were you described as ... (Please tick the answer that applies.)

Male ☐ Female ☐ Intersex ☐

(b) Which of the following options describes how you think of yourself now? (Please tick the answer that applies.)

Male ☐ Female ☐ In another way: .... ☐

Ethnicity (Please put a tick in one box only. If you tick ‘other’, please write your ethnic background next to the tick box.)

White		**Black British**	
British	☐	African	☐
Irish	☐	African Caribbean	☐
Other	☐	Other	☐
Asian/Asian British		**Mixed heritage**	
Bangladeshi	☐	White and African	☐
Indian	☐	White and African Caribbean	☐

Pakistani ☐

Other .... ☐

White and Asian ☐

Other…………………………......... ☐

Chinese

Chinese British ☐

Other Chinese ☐

Gypsy/Traveller

Irish traveller ☐

Gypsy ☐

Romany ☐

Other ethnic background

……………………………………………….. ☐

Sexual orientation (Please tick one box only.)

Heterosexual ☐ Gay ☐ Lesbian ☐ Bisexual ☐

Other: .... ☐

I have a physical, sensory, or learning disability (Please tick one box.)

Yes ☐ No ☐

If 'yes', please say what the disability is in the space below:
....

Part B: Your views about your physical healthcare and physical wellbeing

1. What do you already do to keep yourself physically healthy?

(a) ....

(b) ....

(c) ....

2. With which of the following would you like help? Please tick any which apply:

(a) Physical health checks	
(b) Healthy eating	
(c) Exercise	

(d) Weight reduction	
(e) Healthy teeth	
(f) Stopping smoking	
(g) Sexual health	
(h) Physical side effects of psychiatric medication	
(i) Alternatives to psychiatric medication	
(j) Dependence on alcohol, or illegal drugs	
(k) Something else. If you tick (k), please say what you have in mind in the space below:	

3. Where would you most like to receive help for the items which you have ticked in question 2? Please tick any of the places below which apply:

(a) At home	
(b) In a local community resource (e.g. Weight Watchers, a gym, or a further education class)	
(c) In your GP's surgery, or another community-based medical facility	
(d) By phone	
(e) Through an online consultation	
(f) At hospital	
(g) At a wellbeing resource provided by a mental health charity	
(h) At a centre offering complementary therapies (e.g. reflexology, aromatherapy, or herbal medicines)	
(i) At a wellbeing resource provided by a user-led group	
(j) In a mixed group (of people with and without mental health diagnoses)	
(k) In a same-sex group, or with people who share similar backgrounds (e.g. also belong to a black, Asian, or minority ethnic community)	
(l) Somewhere else. If you have ticked (l), please name the place in the space below:	

....	

4. Do you have any long term physical health conditions (e.g. diabetes, a heart problem, or cancer)?

Yes ☐ No ☐

If you have ticked ‘yes’, please say what these physical health conditions are in the space below and then answer questions 5 onwards. If you have ticked ‘no’, please go to question 8.

(a) ....

(b) ....

(c) ....

5. In what ways are you already good at dealing with the physical health conditions which you have named in question 4?

(a) ....

(b) ....

(c) ....

6. What help do you most want with the physical health conditions which you have named in question 4?

(a) ....

(b) ....

(c) ....

7. Where would you most like to receive help with the long term physical health conditions which you have named? Please tick any of the settings below which apply:

(a) At home	
(b) In a community-led resource (e.g. in a social venue with confidential facilities)	
(c) In your GP’s surgery, or another community-based medical facility	
(d) By phone	

(e) Through an online consultation	
(f) At hospital	
(g) In a recovery house	
(h) In a group with others who have the same condition	
(i) At a charity specialising in the condition	
(j) At a user-led resource	
(k) Somewhere else. If you have ticked (k), please name the place in the space below:	

8. What technology is useful for supporting your physical health? Please tick any of the items below which apply:

(a) Reminders by text (e.g. about appointments, or treatments)	
(b) Online programmes about managing your physical health	
(c) Apps (e.g. Pocket Yoga, or Workout Trainer)	
(d) Devices for monitoring your physical health at home	
(e) Activity-tracking devices (e.g. a Fitbit product)	
(f) Something else. If you tick (f), please say what you have in mind in the space below:	

9. What examples do you have of helpful support with your physical health?

(a) ....

(b) ....

(c) ....

10. Which, if any, of the items below make it difficult for you to look after your physical health? Please tick the answer for each item which fits your experience best:

A difficulty for me	**A lot**	**Sometimes**	**Never**	**Not relevant**
(a) Personal circumstances (e.g. a low income, or housing problems/homelessness)				
(b) The mental health problems/mental health distress which you are experiencing				
(c) Physical side effects of your psychiatric medication				
(d) The impact of psychiatric medication on a physical condition of yours				
(e) A lack of information about public health resources which can support your physical health (e.g. healthy eating advice, exercise centres, or smoking cessation programmes)				
(f) A lack of access to such resources				
(g) A shortage of community-led groups, charities and advocates				
(h) A shortage of user-led groups				
(i) Social exclusion				
(j) Something else. If so, please name it below:				

11. To what extent do you receive the help listed below from healthcare professionals? Please tick the answer for each item which fits your experience best:

Help received from healthcare professionals	**A lot**	**Sometimes**	**Never**	**Not relevant**
(a) A whole person approach (account taken of your personal, social and spiritual needs too)				
(b) Understanding of your physical health needs and relevant treatment for them				
(c) Professionals sharing information about you with each other, where you have agreed to this				
(d) Provision of integrated care by physical and mental healthcare professionals and other professions (e.g. social services and housing)				
(e) Partnership working between healthcare professionals and community-led groups, charities and user-led groups				
(f) Information about ways of managing your physical health				
(g) Physical health services which are respectful of your mental health difficulties/mental distress				
(h) Physical health services which are respectful and relevant to you in other ways (e.g. take account of your ethnicity, gender, sexual orientation, age, or learning disability)				

12. What most helps you to get involved in looking after your physical health?

(a) ....

(b) ....

(c) ....

13. How much choice and control do you have about your physical healthcare? Please tick whichever answer best fits your experience:

A lot ☐ Some ☐ A little ☐ None ☐ Not relevant to me ☐

14. What involvement do you have with the commissioning of physical health services for people diagnosed with a serious mental illness? Please tick whichever answer best fits your experience:

A lot ☐ Some ☐ A little ☐ None ☐ Not relevant to me ☐

15. Any other comments?

(a) ....

(b) ....

Thank you for completing this survey.

© National Survivor User Network 2016

Improving approaches to physical healthcare and physical wellbeing. A survey for unpaid carers and family members of people diagnosed with a serious (enduring) mental illness

The purpose of the survey

To understand your views about the physical health needs of your relative/the person you care for, his/her current experiences of physical healthcare and any improvements needed. The survey is part of a Healthy Lives project about physical healthcare and physical wellbeing which has been set up by the **National Survivor User Network (NSUN)**, a service user-led charity. People diagnosed with a serious (enduring) mental illness, unpaid carers/family members and professional workers are being invited to contribute their views to the project.

Who is carrying out the survey

The National Survivor User Network (NSUN). NSUN has been commissioned by the **Healthy London Partnership mental health programme** to undertake this survey. Sarah Yiannoullou, NSUN's managing director, can give you more information, if you contact her by email at Sarah.Yiannoullou@nsun.org.uk, or by phone on 020 7820 8982/07778 659 390.

How replies will be used

Your reply and replies from other people who take part in the survey will be used towards a report about physical healthcare for people with a serious (enduring) mental illness diagnosis. The report will include recommendations about physical healthcare and physical wellbeing approaches for people with a serious mental illness diagnosis. These recommendations will then be taken into account in the production of guidance and best practice documents which are being drawn up through the London Partnership mental health programme.

Confidentiality

Information which identifies you will not be collected, nor used in the report, guidance and best practice documents. In addition, only the NSUN project team will see individual replies. We may quote your answers in the report and in documents linked to the report, but will not do so in ways which could identify you.

Survey content

There are two parts to the survey. Part A is about your general background. We would appreciate answers to all the questions in Part A, unless there is a question which you find uncomfortable in some way. Part B is about your impressions of physical healthcare and wellbeing resources for the person you care for/your relative. If you can answer all the questions in Part B, it would be very helpful.

Improving approaches to physical healthcare and physical wellbeing. A survey for unpaid carers and family members of people diagnosed with a serious (enduring) mental illness

Part A: Some information about you

We are asking you to complete the questions in this section, because people's experiences of services may vary according to factors such as their age, ethnicity, gender and sexual orientation and so we want to have as wide a mix of participants as possible. If there is any question which you are not comfortable answering, please just move on to the next question.

Age (Please tick one box only.)

18-25 ☐ 26-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 66-75 ☐

Over 75 ☐

Gender

(a) At birth were you described as ... (Please tick the answer that applies.)

Male ☐ Female ☐ Intersex ☐

(b) Which of the following options describes how you think of yourself now? (Please tick the answer that applies.)

Male ☐ Female ☐ In another way: ....☐

Ethnicity (Please put a tick in one box only. If you tick 'other', please write your ethnic background next to the tick box.)

White		**Black British**	
British	☐	African	☐
Irish	☐	African Caribbean	☐
Other……………………………………….	☐	Other………………………………	☐
Asian/Asian British		**Mixed heritage**	
Bangladeshi	☐	White and African	☐
Indian	☐	White and African Caribbean	☐

Pakistani ☐

Other…………………………………… ☐

White and Asian ☐

Other……………………………… ☐

Chinese

Chinese British ☐

Other Chinese ☐

Gypsy/Traveller

Irish traveller ☐

Gypsy ☐

Romany ☐

Other ethnic background

……………………………………………….. ☐

Sexual orientation (Please tick one box only.)

Heterosexual ☐ Gay ☐ Lesbian ☐ Bisexual ☐

Other....................................... ☐

I have a physical, sensory, or learning disability (Please tick one box.)

Yes ☐ No ☐

If ‘yes’, please say below what the disability is:
....

Part B: Your views about physical healthcare and physical wellbeing for your relative/ the person you care for

1. What does s/he already do to keep himself/herself physically healthy?

(a) ....

(b) ....

(c) ....

2. With which of the following might it be useful for him/her to receive help? Please tick any which apply:

(a) Physical health checks	

(b) Healthy eating	
(c) Exercise	
(d) Weight reduction	
(e) Healthy teeth	
(f) Stopping smoking	
(g) Sexual health	
(h) Physical side effects of psychiatric medication	
(i) Alternatives to psychiatric medication	
(j) Dependence on alcohol, or illegal drugs	
(k) Something else. If you tick (k), please say what you have in mind in the space below:	

3. Where might it be most beneficial for him/her to receive help for the items which you have ticked in question 2? Please tick any of the places below which apply:

(a) At home	
(b) In a local community resource (e.g. Weight Watchers, a gym, or a further education class)	
(c) In his/her GP surgery, or another community-based medical facility	
(d) By phone	
(e) Through an online consultation	
(f) At hospital	
(g) At a wellbeing resource provided by a mental health charity	
(h) At a centre offering complementary therapies (e.g. reflexology, aromatherapy, or herbal medicines)	
(i) At a wellbeing resource provided by a user-led group	
(j) In a mixed group (of people with and without mental health diagnoses)	
(k) In a same-sex group, or with people who share similar backgrounds to his/hers (e.g. also belong to a black, Asian, or minority ethnic community)	

(l) Somewhere else. If you have ticked (l), please name the place in the space below:	

4. Does s/he have any long term physical health conditions (e.g. diabetes, a heart problem, or cancer)?

Yes ☐ No ☐

If you have ticked ‘yes’, please say what these physical health conditions are in the space below and then answer questions 5 onwards. If you have ticked ‘no’, please go to question 8.

(a) ....

(b) ....

(c) ....

5. In what ways is s/he already good at dealing with the physical health conditions which you have named in question 4?

(a) ....

(b) ....

(c) ....

6. What help might be most beneficial to him/her with the physical health conditions which you have named in question 4?

(a) ....

(b) ....

(c) ....

7. Where might it be most useful for him/her to receive help with the long term physical health conditions which you have named? Please tick any of the settings below which apply:

(a) At home	

(b) In a community-led resource (e.g. in a social venue with confidential facilities)	
(c) In his/her GP surgery, or another community-based medical facility	
(d) By phone	
(e) Through an online consultation	
(f) At hospital	
(g) In a recovery house	
(h) In a group with others who have the same condition	
(i) At a charity specialising in the condition	
(j) At a user-led resource	
(k) Somewhere else. If you have ticked (k), please name the place in the space below:	

8. What technology do you think is useful for supporting his/her physical health? Please tick any of the items below which apply:

(a) Reminders by text (e.g. about appointments, or treatments)	
(b) Online programmes about physical health management	
(c) Apps (e.g. Pocket Yoga, or Workout Trainer)	
(d) Devices for monitoring physical health at home	
(e) Activity-tracking devices (e.g. a Fitbit product)	
(f) Something else. If you tick (f), please say what you have in mind in the space below:	

9. What examples do you have of helpful support which your relative/the person you care for has received with their physical health?

(a) ....

(b) ....

(c) ....

10. Which, if any, of the items below do you think make it difficult for him/her to look after their physical health? Please tick the answer for each item which fits your experience best:

A difficulty for him/her	**A lot**	**Sometimes**	**Never**	**Not relevant**
(a) Personal circumstances (e.g. a low income, or housing problems/homelessness)				
(b) The mental health problems/mental health distress which s/he is experiencing				
(c) Physical side effects of his/her psychiatric medication				
(d) The impact of psychiatric medication on a physical condition which s/he has				
(e) A lack of information about public health resources which can support his/her physical health (e.g. healthy eating advice, exercise centres, or smoking cessation programmes)				
(f) A lack of access to such resources for him/her				
(g) A shortage of community-led groups, charities and advocates				
(h) A shortage of user-led groups				
(i) Social exclusion				
(j) Something else. If so, please name it below:				

11. To what extent do you think that s/he receives the help listed below from healthcare professionals? Please tick the answer for each item which fits your experience best:

Help received from healthcare professionals	**A lot**	**Sometimes**	**Never**	**Not relevant**
(a) A whole person approach (account taken of his/her personal, social and spiritual needs too)				
(b) Understanding of his/her physical health needs and relevant treatment for them				
(c) Professionals sharing information about him/her with each other, where s/he has agreed to this				
(d) Provision of integrated care by physical and mental healthcare professionals and other professions (e.g. social services and housing)				
(e) Partnership working between healthcare professionals and community-led groups, charities and user-led groups				
(f) Information about ways of managing his/her physical health				
(g) Physical health services which are respectful of his/her mental health difficulties/mental distress				
(h) Physical health services which are respectful and relevant to him/her in other ways (e.g. take account of ethnicity, gender, sexual orientation, age, or learning disability)				

12. Do you play a part in supporting his/her physical health?

Yes ☐ No ☐

If you have ticked ‘yes’, please say what helps you to get a voice about his/her physical healthcare in the space below and then answer the remaining questions. If you have ticked ‘no’, please go straight on to question 13.

(a) ....

(b) ....

(c) ....

13. How much of a voice do you get about the physical healthcare which s/he receives? Please tick whichever answer best fits your experience:

A lot ☐ Some ☐ A little ☐ None ☐ Not relevant to me ☐

14. What involvement do you have with the commissioning of physical health services for people diagnosed with a serious mental illness? Please tick whichever answer best fits your experience:

A lot ☐ Some ☐ A little ☐ None ☐ Not relevant to me ☐

15. Any other comments?

(a) ....

(b) ....

Thank you for completing this survey

© National Survivor User Network 2016

Topic Guide for the first workshop day on Wednesday 15th June

Focus group one: Ideal physical health and physical wellbeing services

1. What ideas have you had about ideal physical health and physical wellbeing services?

Probes:

- Physical health/public health
- Specific physical health conditions
- People from marginalised communities

2. What examples of good physical health/physical wellbeing services have you already experienced?

Probes:

- Physical health/public health
- Specific physical health conditions
- People from marginalised communities

Focus group two: Obstacles

1. What are particular obstacles to people with a serious mental illness diagnosis receiving good physical health and good physical wellbeing services?

Probes:

- Physical health/public health
- Specific physical health conditions
- People from marginalised communities

2. What do you think are reasons for the obstacles which you have mentioned?

Probes:

- Personal circumstances
- Mental health problems/mental distress experienced
- Side effects of psychiatric medication
- Shortfalls in information, access, or availability of resources (including community-based, 3rd sector and user-led resources)
- Location of resources
- Mental health discrimination/dual discrimination, status and power issues
- Professional approaches

Focus group three: What needs to change: commissioning?

1. What were your choices for changes in the process for commissioning physical health and physical wellbeing services and what reasons did you have?

Probes:

- Physical health/public health
- Specific physical health conditions
- People from marginalised communities
- Gaps
- Conflicts
- Other relevant points from focus group two

2. How might these changes be achieved?

Focus group four: What needs to change: services and resources?

1. What changes do you think that providers of physical health services and resources need to make?

Probes:

- Physical health/public health
- Specific physical health conditions
- People from marginalised communities
- Gaps
- Conflicts
- Other relevant points from focus group two

2. How do you think these changes might be achieved?

Focus group five: What needs to change: the influence of people diagnosed with a serious mental illness?

1. What extra influence would it be useful for people diagnosed with a serious mental illness to have over physical health services?

2. How might they become more involved in their own physical healthcare and physical wellbeing?

3. How might they have more influence over commissioning decisions?

4. How might they have more influence over the running of physical health and physical wellbeing services?

Probes:

- Physical health/public health
- Specific physical health conditions
- Status and power issues
- People from marginalised communities
- Impact of personal circumstances
- Impact of mental health problems/mental distress experienced

Topic Guide for the second workshop day on Wednesday 6th July

Focus group one: Personalised physical health services for people of varying genders and sexual orientations

1. What issues are there?

2. What good examples do you have?

3. What changes do you think are needed?

Probes:

- General physical health
- Long term physical health conditions
- Having involvement and influence: personal and at service and commissioning levels
- Sexual orientation as well as gender

Focus group two: Personalised physical health services for people from black, Asian and other minority ethnic communities

1. What issues are there?

2. What good examples do you have?

3. What changes do you think are needed?

Probes:

- General physical health
- Long term physical health conditions
- Particular physical health issues to which a particular ethnic group may be prone
- Having involvement and influence: personal and at service and commissioning levels

Focus group three: Physical healthcare for people with long term physical health problems

1. What issues are there?

2. What good examples do you have?

3. What changes do you think are needed?

Probes:

- Referrals for long term health conditions
- Consultants in secondary care

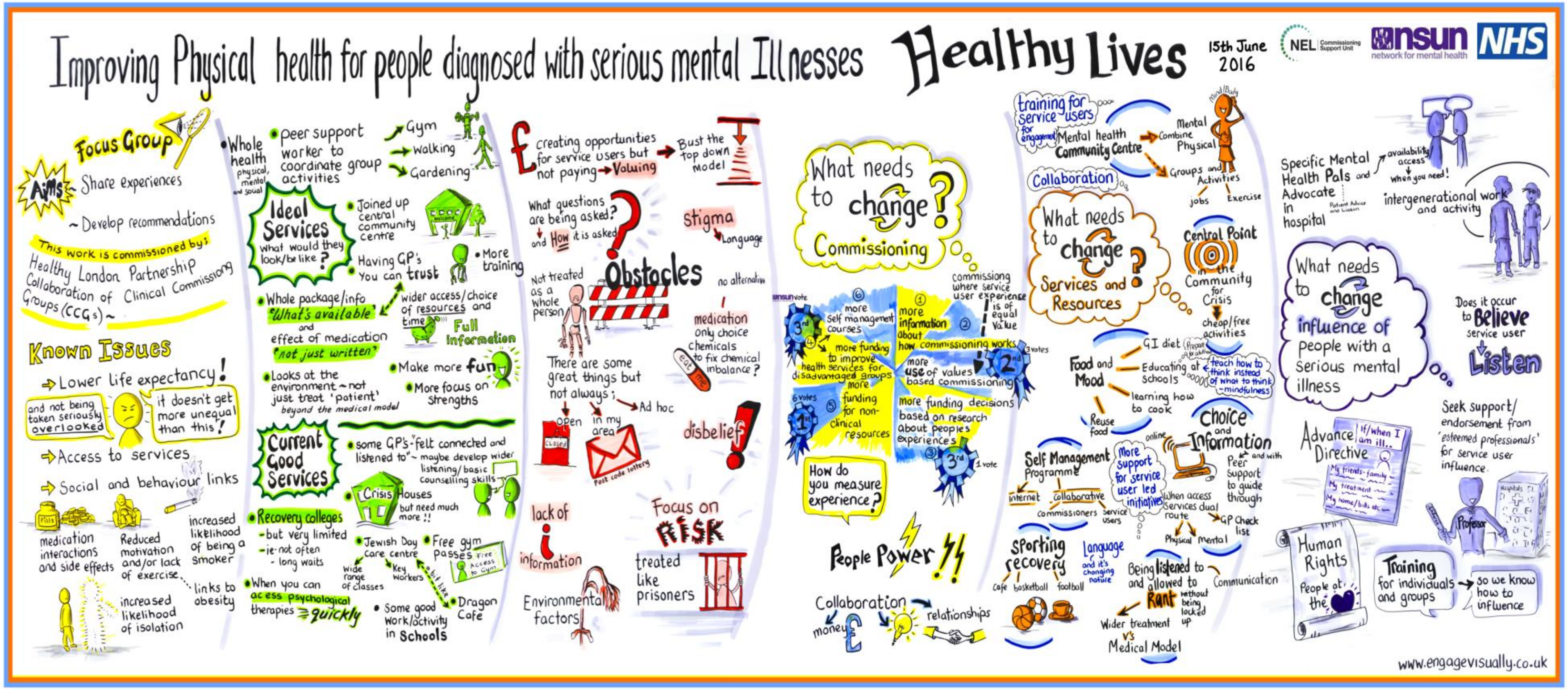
Focus group four: Key recommendations for action

1. What do you think key recommendations are?

2. What are your reasons?

Appendix C: Graphic recordings

The first workshop day[6]



---

[6] www.engagevisually.co.uk

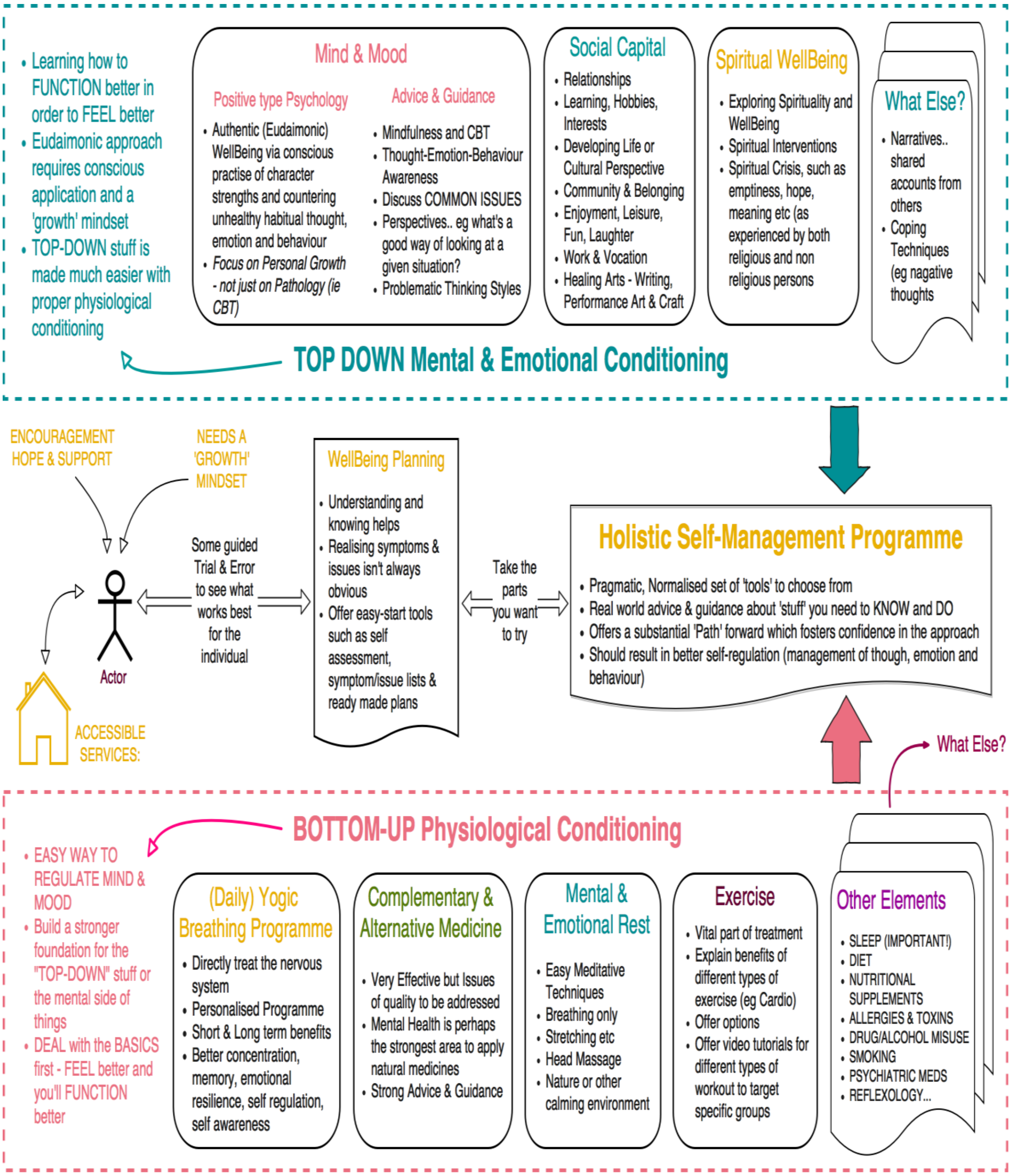
The second workshop day[7]

---

[7] www.engagevisually.co.uk

Appendix D: Lived experience models

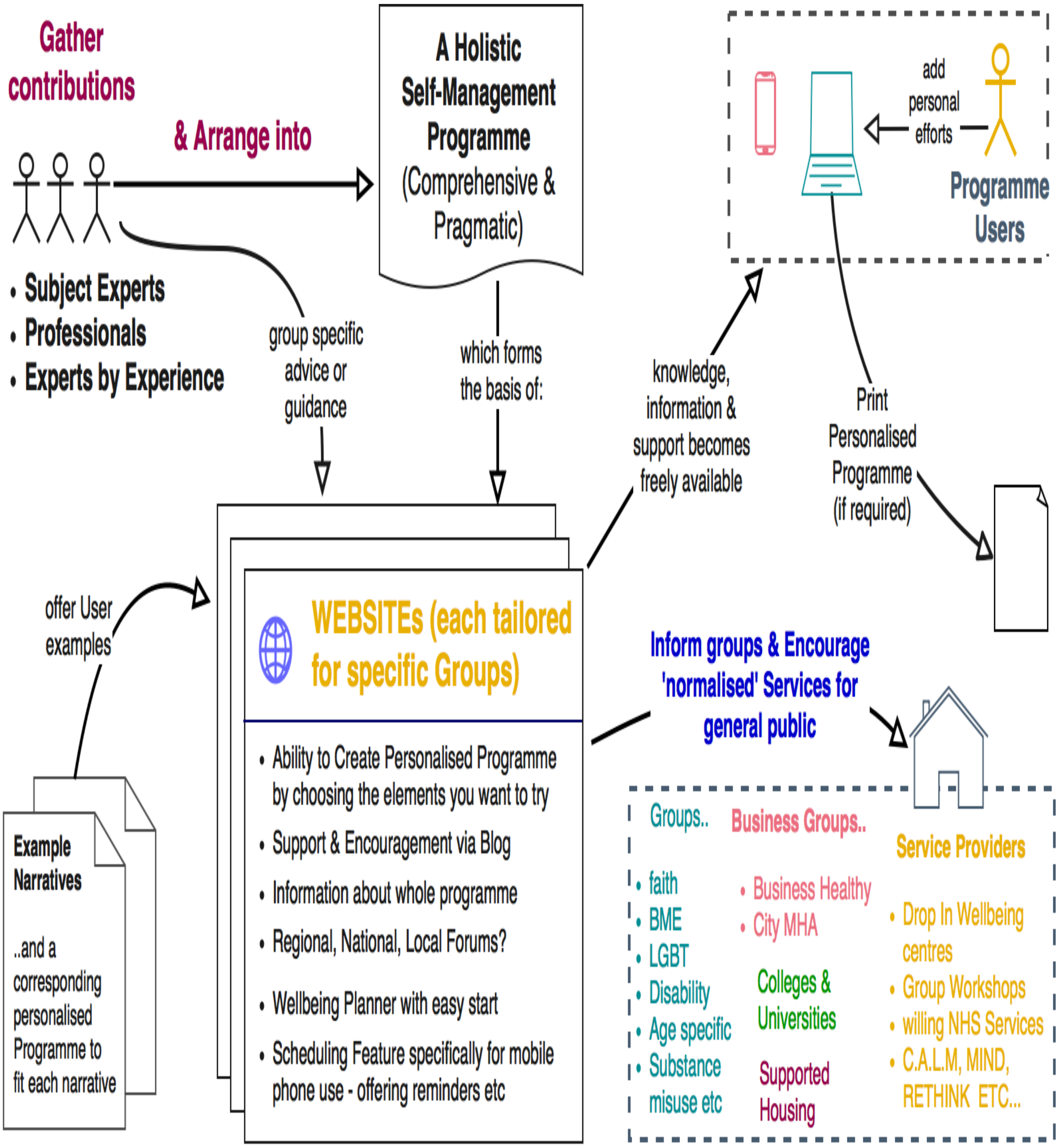
Wellbeing model[8]



---

[8] https://wellbeingwhatworks.org/

Holistic self-management[9]



---

[9] https://wellbeingwhatworks.org/

Appendix E: Survey results tables

Table One: Views of service user respondents from black and minority ethnic and white British communities about whole life and integrated care approaches from healthcare professionals

Help received from healthcare professionals	**A lot**		**Sometimes**		**Never**		**Not relevant**	
	BAME	**White British**	**BAME**	**White British**	**BAME**	**White British**	**BAME**	**White British**
A whole person approach (account taken of personal, social and spiritual needs too)	18% (n=10)	21% (n=10)	32% (n=18)	28% (n=13)	45% (n=26)	46% (n=22)	4% (n=2)	4% (n=2)
Understanding of physical health needs and relevant treatment for them	19% (n=11)	17% (n=8)	54% (n=31)	55% (n=26)	25% (n=14)	21% (n=10)	2% (n=1)	6% (n=3)
Professionals sharing information where this has been agreed	19% (n=10)	4% (n=2)	30% (n=16)	70% (n=32)	47% (n=25)	20% (n=9)	6% (n=3)	6% (n=3)
Provision of integrated care by physical and mental healthcare professionals and other professions (e.g. social services and housing	10% (n=5)	11% (n=5)	23% (n=12)	21% (n=10)	55% (n=29)	53% (n=25)	11% (n=6)	15% (n=7)
Partnership working between healthcare professionals and community-led groups, charities and user-led groups	8% (n=4)	13% (n=6)	28% (n=14)	20% (n=9)	60% (n=30)	54% (n=25)	4% (n=2)	13% (n=6)

Table Two: Views of service user respondents from LGB/other and heterosexual communities about whole life and integrated care approaches from healthcare professionals

Help received from healthcare professionals	**A lot**		**Sometimes**		**Never**		**Not relevant**	
	LGB/ other	**Hetero sexual**	**LGB/ other**	**Hetero sexual**	**LGB/ other**	**Hetero sexual**	**LGB/ other**	**Hetero sexual**
A whole person approach (account taken of personal, social and spiritual needs too)	14% (n=4)	20% (n=15)	25% (n=7)	31% (n=23)	57% (n=16)	44% (n=32)	4% (n=1)	4% (n=3)
Understanding of physical health needs and relevant treatment for them	11% (n=3)	20% (n=15)	71% (n=20)	49% (n=36)	14% (n=4)	26% (n=19)	4% (n=1)	4% (n=3)
Professionals sharing information where this has been agreed	0% (n=0)	17% (n=12)	75% (n=21)	38% (n=27)	21% (n=6)	39% (n=28)	4% (n=1)	6% (n=4)
Provision of integrated care by physical and mental healthcare professionals and other professions (e.g. social services and housing	4% (n=1)	13% (n=9)	18% (n=5)	23% (n=17)	61% (n=17)	52% (n=37)	18% (n=5)	11% (n=8)
Partnership working between healthcare professionals and community-led groups, charities and user-led groups	7% (n=2)	12% (n=8)	14% (n=4)	28% (n=19)	67% (n=19)	52% (n=35)	11% (n=3)	7% (n=5)

National Survivor User Network (NSUN)
27-29 Vauxhall Grove, London SW8 1SY
info@nsun.org.uk
www.nsun.org.uk

Registered charity number: 113598

© The National Survivor User Network and author 2016