



Mental Health **TOGETHER**

Engaging with Derby and Derbyshire

Physical Health and Severe Mental Illness (SMI) Final Report - January 2021



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voice of experience*

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This project is commissioned by NHS Derby and Derbyshire Clinical Commissioning Group and funded by Health Education England.

If you would like to know more about this project, or the other work carried out by Mental Health Together, please contact us:

Email: Enquiries@mentalhealthtogether.org.uk or Telephone: 01773 880786

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Executive Summary

In spring 2019, NHS Derby and Derbyshire Clinical Commissioning Group (NHS DDCCG) secured funding from Health Education England (HEE) to enable us to undertake a project focussing on the physical health of people with a severe mental illness (SMI).

Phase One

We used a survey, delivered both in-person and online, to investigate the barriers that people with an SMI experience in relation to their physical health. We focussed in particular on experiences relating to annual physical health checks. The uptake of these health checks is still relatively low, currently an average of 25% in Derbyshire, and is of great concern given the significantly lower life expectancy of this cohort of people.

The survey also provided the opportunity to gather information from the wider community of people with mental health conditions, and these findings were presented alongside those for the SMI cohort in our [Interim Report](#).

Survey results showed:

- Approximately half of the respondents with SMI know they are entitled to an annual health check
- **79% of respondents with SMI who have attended an annual health check found it helpful** to varying degrees
- Lack of confidence, lack of motivation and side effects of medication are the top three barriers to physical health for people with SMI
- People with SMI expressed the need for more support and information especially regarding the medication side effects which affect their physical health
- 75% of all respondents (including SMI) worry about their physical health, with many reporting a cumulative impact of multiple physical health barriers amongst others
- People expressed a need for better understanding of their diagnosis, personalised health advice, easier access to longer GP appointments, more involvement in the choice of treatment, and access to ongoing affordable physical health activities
- Carers expressed a need to know if the person they care for is on the SMI Register and should be receiving annual health checks. They urge GP practices to actively involve them with annual health checks with the consent of the patient.

Phase Two

Following the completion of the interim report, we continued to gather survey feedback. We hoped to be able to focus on groups underrepresented in the first phase of the project:

- People from a more diverse range of communities across Derbyshire and Derby City
- People less connected into health and social care services

- Younger people, particularly those receiving care from the early intervention in psychosis services
- People 65 years and over including people with dementia and their carers
- We also wanted to engage with people attending the physical health clinics offered by Derbyshire Healthcare NHS Foundation Trust (DHcFT). In particular, we sought to understand what a good transition of physical health care to their GP practice would look like.

Unfortunately, restrictions due to the COVID-19 pandemic, and the understandable focus elsewhere, has meant that we have not been able to engage as fully as we would have liked with the groups identified for the second phase of this work. However, we have established a relationship with Derbyshire's Asian Association to engage with a more diverse population and visited Derby Refugee Advice Centre (DRAC) to reach those less connected into services.

We have also been able to interview nine SMI patients who attend the physical health monitoring clinics run by DHcFT and make a number of associated recommendations. Full details are available in the section titled '[Key findings and recommendations – physical health monitoring clinics](#)' of this report, but include **recommendations around the themes of:**

- The referral process – including review of the information leaflet and more opportunity for discussion
- Invitation to attend the clinic – including better information and appointment reminders
- Carer involvement
- Clinic setting/venue
- Test results and follow up
- Transition from the physical health monitoring clinics to primary care for physical health checks.

We have also made a number of **recommendations to primary care** based on the survey feedback, and further engagement with both Derbyshire's Asian Association and Derby Refugee Advice Centre (DRAC). Again, full details are available in the later section of this report titled '[Key findings and recommendations – primary care](#)', but includes recommendations around the themes of:

- Communication regarding placement on the SMI Register
- Invitation to attend the physical health check – including better information and appointment reminders
- Carer involvement
- Mental health training for practice staff
- Test results and follow up
- Addressing medication side effects

- Providing a holistic and culturally sensitive approach
- Transition from secondary to primary care.

We would like to thank everyone who has contributed to this work and hope that the implementation of the recommendations made will enable a larger number of people with SMI to benefit from annual physical health checks in the future.

We would also encourage commissioners and clinicians to consider the feedback that survey participants gave regarding barriers to good physical health, and urge them to make adjustments to address these barriers.

What is Mental Health Together (MHT)?

MHT is the engagement service in Derbyshire for people living with a mental health condition and those who care for them. We are funded by NHS DDCCG and Derbyshire County Council (DCC) to ensure that the voices of experts with lived experience feed into decision making about mental health services and social care. Our key role is to recruit, train and support people as Experts by Experience and enable them to have a voice in the shaping and commissioning of services in Derbyshire. We also engage as much as possible with the wider community to pick up feedback about current services. Our team of Experts by Experience have been an invaluable source of advice to us in shaping and delivering this project to date.

As part of our commitment to this very important piece of work, the staff and Experts by Experience at Mental Health Together have together become members of Equally Well UK <https://equallywell.co.uk/> and have signed the Charter for Equal Health for people with severe mental illness. By signing the pledge, we are agreeing to work together to help reduce health inequalities for people living with severe mental illness in our region.

Background and introduction

In 2019 NHS Derby and Derbyshire Clinical Commissioning Group (NHS DDCCG) secured funding from Health Education England (HEE) to enable us to undertake a project focussing on the physical health of people with a severe mental illness (SMI). According to the NHS England guidance 'Improving physical healthcare for people living with severe mental illness (SMI) in primary care – Guidance for CCGs (2018):

'SMI refers to all individuals who have received a diagnosis of schizophrenia or bipolar affective disorder, or who have experienced an episode of non-organic psychosis.'

This guidance also indicates that compared to the general population, individuals with a severe mental illness face one of the greatest health inequalities and, as a result, their life expectancy is significantly lower than the general population (up to 15 - 20 years lower). This vulnerability is a result of various issues including medication side effects and lifestyle factors. It is therefore imperative that they have the opportunity to have their physical health monitored regularly. People with an SMI diagnosis should be on the SMI Register at their GP practice and should be invited for an annual physical health check to detect and treat any existing health problems and prevent other serious problems from occurring.

In Derbyshire the data tells us the number of people attending physical health checks is not where it should be (currently about 25% of those eligible). This, of course, raises concern for

their physical health and a key aim of this project is to try to understand why this is the case. To explore the barriers that prevent people from attending this annual check with those who are directly affected. NHS DDCCG also asked us to explore how people feel about their physical health, what broader barriers they face in trying to stay physically well and what they feel would support them to achieve better physical health for themselves. This second aspect of the project covers both people with SMI and people with other long-term mental health conditions.

Key aims

- **Explore the barriers to people with SMI attending annual health checks**
- **Explore wider barriers to staying physically well (both SMI and non-SMI)**

In January 2020, we presented the findings of the first phase of this project in an interim report, which is available to view in full from the Healthwatch Derbyshire website:

<https://healthwatchderbyshire.co.uk/wp-content/uploads/2020/04/Physical-and-Severe-Mental-Illness-Interim-Report-Jan-2020.pdf>

Having concluded the first phase of this project we were able to reflect on what we had learnt to date, see where the gaps in knowledge and information remained and plan our second phase accordingly.

The COVID-19 pandemic has meant that we have not been able to investigate these areas as fully as we would have liked. However, we have still been able to gather further feedback and make a series of recommendations to improve the experience of patients in both primary care and at the physical health monitoring clinics provided by DHcFT (for patients in the first year following an SMI diagnosis).

Our approach – Phase One

Our project worker set about identifying as many initial points of contact as possible where she could engage with the people at the heart of this project. In Phase One she visited numerous voluntary and community groups across Derbyshire and Derby City including a number of carers groups. She also attended several outpatient clinics and a Clozapine clinic run by Derbyshire Healthcare NHS Foundation Trust (DHcFT). Individuals were interviewed in person, on the telephone and via hospital visits undertaken with the support of staff and patients representatives.

Individuals were invited to share their experiences by completing a questionnaire, in paper form or electronically. Support was offered whenever needed or requested. When visiting groups such as carer groups and peer support groups their feedback as a group was gathered into trends and themes to support our findings.

At each stage of designing the questionnaire, we invited our Experts by Experience, Healthwatch Derbyshire (HWD) colleagues and NHS DDCCG commissioners to have an input into shaping it. At the time of preparing the interim report **168 surveys had been completed, 66 of these respondents identify themselves as having an SMI, 73 categorised themselves with a different mental health condition and 29 chose not to state their diagnosis.**

We have also had some limited contact with GP practices to find out their perspective and how some of them are successfully encouraging more of their patients to attend their annual health

checks (see Appendix III: Feedback from GP practices achieving good annual health check attendance).

Summary of key findings after Phase One

- 1) Approximately half of the respondents with SMI know they are entitled to an annual health check
- 2) 79% of respondents with SMI who have attended an annual health check found it helpful to varying degrees
- 3) Some groups of people with SMI will need health checks to be taken to them as a peer-supported experience
- 4) Lack of confidence, lack of motivation and side effects of medication are the top three barriers to physical health for people with SMI
- 5) People with SMI expressed the need for more support and information on medication side effects which affect their physical health
- 6) On average all respondents (including SMI) rate their physical health at 5/10
- 7) 75% of all respondents (including SMI) worry about their physical health
- 8) All respondents (including SMI) report a cumulative impact of multiple physical health conditions and other barriers
- 9) People expressed a need for better understanding of their diagnosis and more involvement in the choice of treatment
- 10) Solutions to barriers experienced in relation to physical health include:
 - person-centred and consistent support – available individually and/or in groups
 - access to on-going affordable physical health activities
 - help with anxiety around travelling alone on public transport
 - personalised health advice
 - more information, support and choice regarding medication and side effects
 - easier access to longer appointments with GPs who have a good understanding of mental health.
- 11) Carers need to know if the person they care for is on the SMI Register and should be receiving an annual health check
- 12) Carers urge GP practices to proactively involve them with annual health checks, with the patient's consent.

Next steps identified at the end of Phase One

As we reflected on Phase One of the project we recognised that the next steps needed to include further efforts to:

- Engage with people from a diverse range of communities across Derbyshire and Derby City
- Engage with people who are less connected into health and social care services
- Engage with younger people, particularly with people receiving care from the early intervention in psychosis services
- Engage with people of 65 years and over including people with dementia and their carers
- Engage with those people who are currently attending the physical health monitoring clinics (PHMC) provided by Derbyshire Healthcare NHS Foundation Trust. It is important to understand what a good transition would look like once their physical health is transferred to the care of their GP practice.

Phase Two – the reality with COVID-19 restrictions

In Phase Two of this project, the survey remained open to enable us to gather feedback electronically. Unfortunately, the additional face-to-face engagement that we had hoped to undertake came to an abrupt halt due to COVID-19 restrictions. Consequently, the number of additional surveys completed was limited and did not give us any significantly different results.

Although not able to visit the physical health monitoring clinics run by DHcFT, our project worker was able to carry out nine in-depth telephone interviews with patients currently attending the clinics. The interviews were conducted by telephone using a prompt sheet that allowed patients to share their experience from the referral stage right through to transfer back into primary care. Despite the fact that none of the patients interviewed had actually reached the point of discharge and transfer to primary care, they were able to share their thoughts and concerns around this.

In an attempt to encompass a more diverse range of communities across Derbyshire and Derby City, our project worker did manage to visit both Derbyshire's Asian Association (where she was able to speak with staff and volunteers), and Derby Refugee Advice Centre (DRAC) where she engaged with both volunteers and refugees supported by the service.

Key findings and recommendations – Physical Health Monitoring Clinics

It is important to highlight that the feedback from the interviews with this group of patients indicated that overall the clinical care received from the staff felt very positive. It highlighted the significant benefit of regular physical health monitoring for patients' overall physical and mental wellbeing.

“On arrival in the clinic, I was welcomed and put at ease. The staff were lovely and that the appointment was very good”.

It also highlighted areas where development could improve the patient experience further and support the transition of patients into primary care for the continuation of physical health monitoring.

Findings and recommendations have been grouped around stages in the patient’s journey from referral to the physical health monitoring clinics, through to transition to GP practices for physical health care. A summary of patient comments at the end of this section also highlights the things that are important and things that patients find difficult.

1. Referral to the Physical Health Monitoring Clinic

- 1.1. The current Physical Health Monitoring Clinic (PHMC) leaflet that is supplied to patients is informative, but lengthy and may put patients off reading it. The ‘Frequently Asked Questions’ section could be transferred to a one page A5/A4 flyer and given to patients.

It should explain:

- a. Why physical health monitoring is needed
- b. What the appointment involves e.g. so I can wear appropriate clothing
- c. How long it will take
- d. How often I will be seen by the clinic
- e. Whether I can bring someone with me to my appointments
- f. Do I need to bring anything or do anything before my appointment?
- g. What happens with my results?
- h. How will I know my next appointment?
- i. What other services can you offer me?

(This flyer would need to be accessed in different languages with the option of an Easy Read format if needed)

- 1.2. For the professional referring the patient to the PHMC to discuss the leaflet with the patient to ensure they understand the reason for referral and allow the patient an opportunity to ask questions
- 1.3. If the patient has someone involved in their care - to allow the patient the option to involve their carer in the discussion around physical health monitoring, either in person or by letter
- 1.4. For positive real-life case studies to be used as a way to reassure and encourage patients to attend and the health benefits of doing so. This would also support the case for ongoing physical health checks in primary care once discharged. The case studies could include written, online versions and could include the use of approved video/YouTube clips.

2. Letter of invitation

The majority of patients felt the invitation letter did not explain the purpose of the appointment and what would happen once there.

“The letter was very basic and said it was important to attend, but it didn’t give a reason why.”

“I received a letter for my first appointment but I didn’t know what was going to happen when I got there. It would have been helpful to know; I didn’t feel prepared for having an ECG done.”

“It would have been helpful to have a broader idea of what was going to happen and over what period, perhaps in a leaflet form”.

Recommendations:

- 2.1. A new template for the patient invite letter to be designed with Experts by Experience. This letter could include the flyer, or in the main body of the letter:
 - a. An explanation of the purpose of the appointment
 - b. Clear directions on how to find the clinic
 - c. What will happen during the appointment and how to prepare for it
 - d. Reassurance that that patient can bring a carer, or another person along with them for support. This may have been explained at a previous appointment with the psychiatrist, however, the feedback has highlighted that some patients like to have information repeated as there is often a lot to take in and it is easy to miss things
 - e. Feedback also indicated that patients find text reminders helpful closer to the appointment. One patient said, *“To receive a text a few days before and again on the day before the appointment would be useful”.*

3. Clinic setting/venue

It was clear from some of the feedback received that the clinic location/setting was very important. Patients expressed feeling anxious when attending their appointment, particularly the first one. The challenge of locating venues and attending clinical environments caused heightened anxiety amongst patients.

“The venue was not easy to find and there could have been better directions/instructions on how to get there. The clinic was at the back of the building and this was not easy to locate.”

“It was difficult to find and not clearly labelled. It was difficult to park and there was no on-site parking. It’s not the nicest of areas and I felt unsafe – if I had really bad anxiety I would not have attended.”

Recommendations:

- 3.1. Clear and easy directions to the clinic site sent with the invitation letter
- 3.2. Review of clinic sites - how easy the venues are to find and physically access

- 3.3. At the address – is there a clear sign to indicate the whereabouts of clinic location? If the venue is at the back of the building - is it well signposted and easy/safe to access?
- 3.4. Is it in a safe area, well lit, etc?
- 3.5. Is it easily accessible to patients? Close to public transport and has convenient parking nearby?
- 3.6. Is the venue/area accessible to patients with a physical disability?
- 3.7. Is there access to close disabled parking/toilets?
- 3.8. Further research may be beneficial – to focus on the patient experience of using the current sites - inviting feedback on what feels important to patients when considering suitable future venues; to include the clinical environment where the physical health checks take place
- 3.9. The consideration of holding clinics in community settings such as, community centres and other non-clinical environments where patients feel less intimidated.

4. Test results/follow-up

The patient's test results go to the consultant psychiatrist who forwards the results to the patient's GP. Electrocardiogram (ECG) results are attached to the PARIS system for the consultant to view. Clinicians inform the consultant immediately if an ECG result has been returned and comes under the category of RED or FULL AMBER. The patient is informed if there are abnormalities, and/or if tests need to be repeated.

One theme that has been apparent throughout this project is that many patients feel they would like to be informed of their results, regardless of the outcome. Waiting for results and not knowing, can cause extra anxiety and worry for SMI patients. Patients have expressed feeling a sense of lack of involvement and control over their health as a result.

"I was told that I would only hear back if there was an issue with my results. Results are only for the doctors but it would be nice to be included. Unless you ask to be included in the letters being sent out about your health, you don't get a copy sent to you."

"I would have like to have known my results, it would have put my mind at ease."

Recommendations:

- 4.1. A system put in place to inform patients of their results regardless of whether they are normal or not
- 4.2. Patients to have their results explained and be offered a copy of their results.

5. Transition from physical health monitoring clinic to primary care

In general, patients were unclear about the process of coming to the end of their time at the physical health clinic and being transferred back into the care of their GP practice for their ongoing physical health monitoring. Patients felt they benefitted from their time at the clinic but the issue of transfer from secondary care back into primary care was an issue that raised concern and uncertainty for patients.

“Nothing has been mentioned but the thought of it is quite daunting. I will have no chance of getting GP appointments and there will be no follow up. I have genuine concerns about how things are going to be when I’m discharged from the clinic.”

“I am not sure what will happen with my health checks after this, I haven’t come across this, I don’t know.”

Recommendations:

- 5.1. A patient discharge letter to be designed with Experts by Experience. The letter to be sent to patients on discharge from the PHMC and a copy sent to their GP. This letter to highlight that the patient will be added to the practice SMI Register and the reason why
- 5.2. Put a plan in place to support the patient with the transition from secondary care into primary care for their physical health monitoring. To include guidelines on how to help prepare the patient for the discharge and to take into account support regarding any anxieties/barriers expressed by the patient
- 5.3. If the patient has a carer/loved one involved in their care, give the patient an option of including this person/s when discussing discharge
- 5.4. To develop and build on relationships with primary care teams/Primary Care Networks (PCNs) to identify a link person/SMI nurse who can act as an ‘a bridge’ to secure a seamless transfer for the patient where possible
- 5.5. To work with primary care to support the preparation and transition of patients into their care/onto the SMI Register
- 5.6. Whilst primary care and secondary care are operating on different patient record systems (PARIS/SYSTM ONE), a secure email address could be used to support communication between the physical health monitoring clinic and primary care link worker.

6. Summary of patient comments

What is important – as expressed by patients of the Physical Health Monitoring Clinic

- Knowing that you can bring someone to the appointment with you for support
- Being welcomed and put at ease
- Staff explaining the process – what will happen at an appointment and what will happen following the appointment
- Seeing the same clinician each time. Continuity of care is really important
- Repeating information so that the information is remembered and understood. Write it down for patients
- Building trust with staff
- Staff adapting to your individual needs

- The patient's GP, psychiatrist and the Physical Health Monitoring Clinic all working together as "part of a circle" is reassuring for the patient
- Being sent a text reminder of appointment the day before
- The option of having a home visit.

Things that can be difficult – as expressed by some patients of the Physical Health Monitoring Clinic

- Clinical settings too difficult to cope with – waiting rooms can increase anxiety. Setting can feel *"like a custody suite"*
- Appointment times that work for that patient. First thing in the morning can be difficult for some. It can be hard trying to change appointments and deal with receptionists
- Not being able to get through to the clinic number to change appointments and not having calls returned when voicemail left - 03007906265
- Transport is an issue, including parking, particularly in Derby
- Contacting GP practice and getting through – takes a long time
- Anxiety around having blood tests.

Key findings and recommendations – Primary Care

It is worth highlighting that people who were attending their annual physical health checks reported definite benefits (79% were 'somewhat satisfied' or 'very satisfied'). This is very encouraging and should be a key motivator when considering how GP practices can make these vital check-ups more accessible for people with a severe mental illness.

Every stage of the patient journey offers potential for improving both the experience and engagement of people with SMI. Even small barriers can feel like a mountain to climb and therefore every small adjustment can make the world of difference to people's attendance and health outcomes. The following YouTube video illustrates this point excellently, highlighting many aspects of our recommendations: <https://www.youtube.com/watch?v=gw4qt5lbVls>

Recommendations below have been grouped into themes, some of which relate to stages in the patient's journey.

1. Putting patients onto the SMI Register

Most SMI patients were not aware of the SMI Register and that their details may be held on a register within primary care practices. They receive a letter of invite for a health check but there is confusion around why they have received it. When a patient is being added to the SMI Register this presents a good opportunity to engage well with the patient (and carer) right from the beginning. It can promote greater understanding and involvement in the process with significant potential for improving the uptake of annual physical health checks.

Recommendations:

- 1.1. For the patient to be informed, in person, and with a follow-up letter that their details have been placed on a register. The template for this follow-up letter should be co-produced using Experts by Experience, and Mental Health Together could support this if required
- 1.2. The initial explanation and the letter should include the following explanations and assurances:
 - a. What the benefit is to the patient of being on an SMI Register – how this can help to prevent some serious long terms conditions and improve their quality of life
 - b. That this is a different check to other physical health checks they may receive e.g. over 40s or other specific long-term condition checks e.g. diabetes, asthma
 - c. What tests will be done during an annual physical health check - so that the patient can feel prepared and have no surprises on the day
 - d. Assurance that they are welcome to bring a carer, or another support person to the appointment with them
 - e. What will happen after their physical health check – results and follow up
 - f. An opportunity to get in touch if they have any questions/concerns around the contents of the letter.

This letter needs to be sent also to any agreed carer/support person who has been identified by the patient so they too understand the importance of the annual check (see [section 3](#) below as well).

2. Inviting patients to their annual physical health check

A lack of awareness of annual health checks and the importance of them was expressed by some respondents who found the letter inviting them for the health check confusing and lacking in explanation. Letters are often not personalised but are simply addressed 'Dear Patient'. It is sometimes unclear whether the appointment is for a medication review or some other health check and as a result, this lack of information and clarity heightens the risk of non-attendance.

"The letter I got said to come for my health check, it wasn't clear what kind of check it was. It was only when I got there that I realised what it was."

"I didn't understand what was going on at the health check."

Recommendations:

- 2.1. For GP practices to adopt the Physical Health Check invite letter as designed by Experts by Experience and included in this report see [Appendix II](#). This letter has been annotated to explain why it has been designed in the way it has e.g. research tells us that when letters are personalised and offer a specific appointment the likelihood of attendance is significantly increased.

Experts by Experience are also designing a flyer to raise awareness of annual physical health checks, which could also be used as a resource when ready.

See also [Appendix I](#) for additional recommendations from Experts by Experience about how to structure letters to SMI patients.

- 2.2. Timely reminders of the appointment and friendly encouragements to be offered to this group of patients (*"I need reminders, I forget a lot"*). This should be via whatever form of communication is preferred by the patient e.g. text reminders, emails etc. Where a carer is identified by the patients the reminder must also be sent to the carer
- 2.3. For each practice to have a named nurse or doctor who is the designated lead for SMI physical health checks to ensure appropriate communication around health checks and ensure that lessons are shared across the practice. That named person could also link in with the overall PCN lead for mental health to share good practice. See [Appendix III](#) for some shared examples from three GP practices in Derbyshire
- 2.4. For each person with a severe mental illness on the register to have a named GP who is responsible overall for their healthcare. This on-going relationship to a named person will encourage attendance at annual health checks
- 2.5. For practices to fully embrace the concept of 'Making Every Contact Count' - engaging in conversations with SMI patients/carers about physical health/health checks in normal times/consultations and looking out for opportunities to reach SMI patients who do not attend their health checks but are attending the surgery for other reasons.

"Making every contact count (MECC) is an approach to behaviour change that utilises the millions of day to day interactions that organisations and people have with other people to encourage changes in behaviour that have a positive effect on the health and wellbeing of individuals, communities and populations." (Health Education England)

<https://www.makeeverycontactcount.co.uk/>

3. Involving carers of people with SMI

Some carers expressed frustration around the lack of inclusion in physical health checks and wider care of their loved one/person they care for. Carers have also expressed a lack of knowledge about the support available to them in their community, as a carer, and also for the cared-for person. Carers often do not live with the cared-for person and may not be aware of an upcoming physical health check appointment. Having this knowledge, and understanding the importance of it, would enable them to support the patient to attend.

Respondents also rated highly the need to have someone to go with them to appointments, and activities related to physical health, indicating again, the importance of involving carers and those who support SMI patients.

"I need somebody to go with me to make it better. Sometimes I have difficulty understanding what to do and why."

"I would like GPs to talk to carers as well as the person they care for."

"If I am sent a copy of the invite letter I will remind and support the person I care for to attend."
(carer)

Recommendations:

- 3.1. GPs to ascertain from the beginning whether their SMI patients have a carer, or someone involved in their care and whether the patient wishes to involve the carer in their annual physical health checks. GPs also to clarify whether the patient is happy for their carer to receive a copy of the letter inviting them for an annual physical health check. The patient's preference should be noted clearly on the patient's file
- 3.2. Primary care to provide carers with information and signposting to services that can support the physical and mental wellbeing of carers as well as SMI patients.

4. Mental health training for practice staff

Some patients reported barriers when speaking with practice staff and feel that their mental health needs are not always understood or respected. They feel the attitudes of staff can impact on their wellbeing and crucially their willingness to engage with health checks.

"I would like to know that the person conducting the health check would be suitably empathetic to the needs of mental health service users."

"Better trained health professionals are needed and mental health training on how to approach the patients, bearing (in mind) equality and diversity regulations and attitudes."

"The health professionals need to reach out to us more because it can be harder for us to reach out to them, To phone us, or message us with any information that will help and to send out leaflets."

Recommendations:

- 4.1. For staff coming into contact with SMI patients, and other patients with mental health conditions, to receive Mental Health Awareness/Mental Health First Aid training and for this to be updated regularly. Practice receptionists are a particular priority, as they are regularly the first point of contact for patients
- 4.2. For clinicians who are carrying out annual physical health checks with SMI patients, to not only have Mental Health Awareness training but also have a good understanding of the crucial importance of physical health monitoring for SMI patients
- 4.3. For mental health to be included in staff supervision and practice learning sessions with the aim of challenging the stigma that can attach itself to mental health and promoting confidence amongst staff to talk about it, both for themselves and also with their patients
- 4.4. For information and publicity about mental health to be made visible on the practice website and within the practice surgery
- 4.5. For a mental health champion to be nominated within practices, staff and/or Patient Participation Groups (PPGs), to enable a positive focus on mental health. Mental health champions could be introduced across practices/PCNs and form a working group where matters such as, how to better reach SMI patients for their physical health checks, could be discussed and ideas shared
- 4.6. For active members of PPGs to be included in any mental health training and to proactively recruit patients (and carers) who have a severe mental illness to their

membership. Reasonable adjustments made where necessary to enable their participation

- 4.7. To work towards having an SMI patient representative on each PPG across PCNs where possible. To create a network of SMI patient representatives across PCNs, co-ordinated and supported by an SMI nurse/link worker, or another staff member who has an interest in, and has been trained in mental health. This could link in with the above recommendation for a mental health champion.

5. Providing patients with test results/follow up

Another clear theme from the findings of our research was that patients felt the follow-up after their health check was sometimes poor. They were often left wondering if their results were okay. This would impact upon their mood and raise anxiety with knock-on effects on their mental health in general.

Some patients expressed frustration at not being included in the management of their own health and this resulted in them feeling despondent and having a 'why bother' attitude to the health checks.

Recommendations

- 5.1. For patients on the SMI Register to be personally contacted and informed of their results with a clear explanation of any actions that are needed. For this to be done as soon as possible to avoid unnecessary anxiety. The message that patients will be contacted only if there is a problem is not helpful to SMI patients and does not encourage them to keep returning for their annual physical health checks
- 5.2. For the patient to be given appropriate information and signposting to local health improvement services (voluntary/statutory) and for the patient to be linked into a designated person (care co-ordinator, social prescriber) who can support them to access health improvement services. Thus ensuring the person can receive appropriate support to have a healthier lifestyle.

6. Importance of addressing medication issues and side effects

The top three barriers to good physical health and attending health checks as expressed by SMI patients included medication side effects. In our survey, 47% of SMI respondents highlighted that what would help them overcome this barrier was personalised advice concerning their medication to understand side effects and to help minimise the impact on their lives.

"Speaking to the pharmacist about the effects of medication was good, but I wasn't able to speak to a doctor about my condition, which was bad."

"I get really tired on my medication and then it is hard to be motivated."

"More understanding is needed – GPs don't want to know when you are being prescribed medication by your psychiatrist, I feel there needs to be more understanding in this area of mental health."

Recommendations:

- 6.1. For patients to be given a specific opportunity, either at their health check or in a separate consultation with a GP, to raise any concerns they have about their medication side-effects
- 6.2. To be given relevant information to enable them to understand and make informed choices about their medication and any possible changes. 'Consultant Connect' can be used as a resource by GPs to ensure they can access specialist advice to share with patients
- 6.3. For patients to be supported through the process of any changes to medication by offering a follow up phone call or appointment to check that the patient is happy with the outcome.

7. Providing a holistic and culturally sensitive approach

Findings from this project highlighted that 75% of all respondents, SMI and those with other mental health conditions, said that they worry about their physical health, which in turn raises anxiety and has a negative impact on their mental health. Many individuals voiced the wish for their appointments to encompass both their physical and mental health and for this not to be separated. Frustrations were expressed about not having physical concerns taken seriously due to having a mental health diagnosis. Many respondents reported difficulties managing various long term physical health conditions, alongside their mental health diagnosis and the overwhelming impact this was having on wellbeing. The juggling of both physical and mental health conditions can impact the ability to attend health appointments.

"The GP or nurse never asked me how my mental health was and if I was coping alright. It only attained towards only physical aspects. No one has got the time to listen to your mental health needs properly! If I was asked about my mental ill-health it would feel like someone at least does care!"

"Certain doctors do not take you seriously when you have a mental health diagnosis. This happened recently when I had a physical problem. I ended up having to arrange another appointment with another GP who would take me seriously ... this really upset me."

Recommendations:

- 7.1. For longer than normal appointments to be offered to patients with SMI to allow time to discuss both their mental and physical health. Always bearing in mind the combined impact of several long term conditions and how these may be alleviated
- 7.2. For the patient to be given medical advice about setting realistic personal goals to help improve both their physical and mental health and signposting them to appropriate support in the community when needed
- 7.3. For practise staff to be mindful of any cultural barriers or concerns for SMI patients from the BAME community, particularly:
 - Ensuring that all individuals, whose first language is not English, have access to translators for their health check and are allowed longer appointments to provide for this

- Ensuring that any cultural sensitivities around the gender of the GP/nurse carrying out annual physical health checks are addressed for the patient
- Ensuring that factors such as the importance of Vitamin D for people from the BAME community are considered in health checks.

(See [Appendix IV](#) and [Appendix V](#) for more details)

8. Ensuring a smooth transition from secondary to primary care

Many newly diagnosed SMI patients will now receive their initial 12 months of physical health monitoring from physical health monitoring clinics within mental health services. It is crucial to ensure a smooth and joint approach to the transitioning of patients from secondary to primary care for their physical health checks. It is also vital to ensure important test results are not missed but are followed up with the person. The existing electronic note systems in primary and secondary care services (PARIS and SystmOne) currently presents challenges. This is due to be rectified in the fairly near future but in the meantime, some recommendations could be adopted to ensure better communication across teams.

Recommendations:

- 8.1. Develop and build on the relationships between primary care and secondary care teams. Whilst both are operating on different patient record systems a secure email address could be used to support communication between the person's GP practice and the physical health monitoring clinic
- 8.2. To Identify a link person/SMI worker in primary care and within the physical health clinics who can act as a bridge between both – with the ultimate aim of ensuring a smooth transition of care for SMI patients and to prevent important information related to the patient's physical health from being missed
- 8.3. Support the patient with the transition from secondary into primary care for their physical health monitoring by including the patient in any hand-over correspondence which explains the new arrangements. This should be followed up with an introductory phone call and/or letter from the GP Practice letting them know they have now been put on the SMI Register at their practice and will be invited to annual health checks. Introductory process as per recommendations under [section 1 - Putting patients onto the SMI Register](#).

9. Maintaining communication between primary and secondary care

Once a smooth transition has been achieved for the patient, and he/she is attending their annual physical health checks, it is important that the connection between services is maintained. This enables the patient to feel treated as a whole person and be reassured that if any problems are identified during health checks they will be looked at holistically. This communication should be of benefit to all parties encouraging a joint risk and responsibility approach from primary and secondary care.

- 9.1. GP practices to ensure that the patient's psychiatrist is informed of their annual Lester tool health monitoring results. This liaison with secondary care is vital to ensure that any preventative action can be taken in a timely way to avoid more serious health complications developing down the line

- 9.2. In the event of the patient wishing to address health risks (e.g. obesity or smoking), the GP should consider the need to liaise with the person's psychiatrist in relation to necessary medication adjustments. This will ensure that the patient feels fully supported in their efforts to improve their physical health.

Actions taken by MHT

- ✓ Signed-up to Equally Well UK to connect with national initiatives and good practice
- ✓ Co-designed a new 'Patient Invitation' letter for annual health checks
- ✓ Completed the first phase of survey work and produced an interim report.
- ✓ Interviewed SMI patients attending physical health monitoring clinics
- ✓ Engaged with representatives of the Asian, asylum seeker and refugee community
- ✓ Started to develop a physical health flyer with our Experts by Experience, aimed at all those with a mental health condition but highlighting the importance of annual health checks for those with an SMI
- ✓ Shared recommendations with commissioners, primary care and DHcFT.

What next?

We will:

- Continue working with providers and commissioners who have received recommendations to follow up on actions taken in response to this work, and feedback to participants
- Use the learning from this project in future engagement and transformation work
- Complete development of the physical health flyer with our Experts by Experience.

Conclusion

The findings and recommendations from this project will serve to give excellent insight into the barriers and views expressed by people with severe mental illness and their carers.

In Derbyshire, we are in a very new and exciting phase with the establishment of PCNs and the transformation of community mental health support & services and the new Living Well Derbyshire project. These will run alongside the implementation of the new Community Mental Health Framework, which, as part of its key aims, puts people with mental health problems at the very centre of the care/support they receive.

“People with mental health problems will be enabled as active participants in making positive changes rather than passive recipients of disjointed, inconsistent and episodic care.”

This statement will be the basis for transformation going forward and it reflects some of the feedback we received from people with mental health conditions. This is a fundamental principle of the work of Mental Health Together, the belief that Experts by Experience, patients and their carers, are best placed to inform the design and the delivery of the support services available to them. A strong theme apparent throughout this project is that people with mental health conditions, and their carers, are as equally concerned about their physical health, as they are about their mental health and are wanting to be genuinely involved and included in the management of their overall health/wellbeing. This will require fresh thinking that offers a more pro-active, flexible and empowering approach.

MHT would like to thank all participants who gave their time to talk to us about their own experiences of annual physical health checks, physical health clinics and their overall physical wellbeing. We also extend our grateful thanks to the many groups, services and individuals who supported and cooperated with this engagement activity.

Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients and carers (formal and informal) experiences of physical healthcare but offer useful insight. It is important to note that the engagement was carried out within a specific time-frame and therefore only provides a snapshot of patient experience collected then. They are the genuine thoughts, feelings and issues that patients and carers have conveyed to us. The data should be used in conjunction with, and to complement, other sources of data that are available.

Appendices

Appendix I: Brainstorming session with Experts by Experience on a physical health check invite letter

Appendix II: Physical health check invite letter designed with Experts by Experience

Appendix III: Feedback from GP practices achieving good annual health check attendance

Appendix IV: Additional barriers highlighted by Derbyshire's Asian Association

Appendix V: Additional barriers highlighted by those supported by Derby Refugee Advice Centre (DRAC)

Appendix I: Brainstorming session with Experts by Experience on a physical health check invite letter

Brainstorming session – suggestions of what to consider in a letter inviting patients to an annual SMI physical health check (Experts by Experience peer support meeting)

GROUP 1 FEEDBACK

- Clear and concise
- Not medical terminology
- Mention 'person-centered'
- Reason for the health check
- Benefits of monitoring physical/mental care / self-care
- Reason for request
- Advice can update on signposting.

GROUP 2 FEEDBACK

- A clear explanation (in plain English) as to the reason for the health check
- Explanation of the benefits
- Explanations of what the tests are/how invasive or not. Issues with needles! Need warning to mentally prepare yourself
- What is the follow-up after the test?
- Can I bring someone with me?
- Can I have a choice of gender (nurse/GP)?
- Who will do the tests?
- Don't send in a brown envelope!
- More friendly-looking letters as a bit stark, formal, clinical
- Text reminders are important
- How long will the appointment be and how soon will I get my results?
- Separate leaflet with the letter – FAQs, attractive looking.

GROUP 3 FEEDBACK

- The letter needs to explain why the health check is important, i.e. more complex physical health needs (but don't scare with life expectancy figures)
- Health check due to the medication you take, including side effects
- What will the checks be? (Blood pressure etc.)
- Needs to be clear it is a physical health check
- What happens to the information? Does the psychiatrist know?
- Consistency in the letters which GPs send out in Derbyshire.
- Do people know if they are on an SMI Register and why?
- Follow-up call and repeat letters if people do not attend.
- A letter giving you an appointment, rather than you having to book one
- Receptionist needs training as to what the appointments are about
- Nominated person/carer to also get the letter/text reminders.

Appendix II: Physical health check invite letter designed with Experts by Experience

Front page

Very important to make this a personal invitation

This letter has been written in plain English and kept as brief as possible whilst giving necessary information

Dear (insert **name** of patient),

Your **yearly** physical health check appointment is:

(Date and time) with (name of doctor or nurse)

We invite all our patients who are registered as having a severe mental illness (SMI) because this may put you at higher risk of certain physical health problems. As a practice, we are committed to giving you the best healthcare we can and would like to help you avoid these health risks.

Your health check will last **about half an hour**. Your health check will be a good chance for you to talk about any questions you have about your health and your medications. You might like to **write down anything you want to talk about on the form provided on the back of this letter** and bring it with you to the appointment.

Please contact our reception if you cannot make your appointment time and we can make another appointment for you. **You can ask a family member, carer or friend to come with you** to the appointment if you would find it helpful.

We look forward to seeing you at your appointment.

Yours sincerely,

Dr X

Research shows that patients with SMI are more likely to turn up to a specific appointment time than an open invitation. It is important however that the appointment is not too early in the morning when effects of medication might cause problems

The length of the check is a selling point as people with SMI often need more time than normal appointments allow

This will help the person to see it as a useful opportunity to share any concerns and to remember what they wish to raise

Very important to make it clear that you welcome someone to accompany the patient

My Yearly Health Check

Questions I would like to ask about:

My Medication

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My Physical Health

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My Mental Health

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Appendix III: Feedback from GP practices achieving good annual health check attendance

Surgery 1

Like other surgeries, we do struggle to ensure patients with SMI attend for their annual health checks. The physical check is done at the same time as the comprehensive care plan update. On last year's Quality and Outcomes Framework (QOF) mental health register we had 58 patients (mainly patients with schizophrenia, bipolar affective disorder and other psychoses and other patients on lithium therapy).

We achieved 84.8% (min 40% - max 90%) so achieved 5.4/6 points

(The percentage of patients with schizophrenia, bipolar affective disorder and other psychoses who have a comprehensive care plan documented in the record, in the preceding 12 months, agreed between individuals, their family and/or carers as appropriate).

To improve attendance we currently:

- Put a recall on each patient's notes which states the date of the next (or overdue) annual review. This will appear on the patient's 'home page' for each consultation
- We add a reminder on the patient's notes if they have failed to attend their review. This will also appear when the patient's notes are initially opened.
- We start to write to patients in September/October onwards up to 3x to invite them to attend for their annual check
- We attach a letter / add a note to the prescription counterfoil if the patient's annual check is overdue (encouraging patient to book an appointment for the annual check) and the current authorisation of their repeat medication has expired (though - in general terms - we would not usually refuse to issue the medication a patient with SMI even if they repeatedly did not attend their health check due to the possible negative impact of doing that).

Surgery 2

Overall the view is that the attendance is good and only a few do not attend. They highlighted that they work closely as a team and with the Community Mental Health Team (CMHT) concerning this, and all liaison to and from the surgery is done with the patient's consent. They regularly complete the physical health section of the pre-Care Programme Approach (CPA) meeting forms that the CMHT complete before the CPA meeting. This means that the person's mental health and physical health is all linked together.

'When it is all shared, there can then be mutual supporting of the patient and of course there are occasions for example when a particular aspect of physical health has led to a lack of progress with mental health as well as vice-versa but the psychiatric nurses have been able to establish exactly what about their physical health is the problem, liaising with us and in turn us being able to offer something to improve that aspect and hence then their mental health, as well.'

Regular communication happens at this level. The practice manager stated that historically the surgery has had a very good reputation concerning the support of patients with mental health needs. They make every effort to know and support their patients.

Surgery 3

The practice manager reported that at present 84% of patients have attended health checks and is confident that they will reach the remaining 16%. It was highlighted that when someone does not show for their appointment the GP will ring them and chase it up. The surgery also monitor letters that they receive, such as from outpatients departments, to see if checks have been done in other settings. The surgery also encourage people who do not want to have a formal health check to come in and use the machine that takes blood pressure (BP), Pulse, body mass index (BMI) as an option also. This prints two tickets with results and one goes to reception for the patient's notes. The nurse then follows this up, for example, if someone needs support around BP or weight management. It was noted that attendance can drop later in the year at which point the GPs split the patients between them with the view to follow up/chase. Staff all get mental health training too, including the receptionists.

Appendix IV: Additional barriers highlighted by Derbyshire's Asian Association

- Access was described as the main barrier to physical/mental health services for members. This includes language difficulties – not being able to speak English, or not having confidence in doing so. No access to translators
- The gender of a health professional can also be a barrier - females may not want to speak to, or be treated, or examined by a male for example. This was reported to be a significant issue for members who access the Mental Health Project. Not knowing the person and not having a relationship of trust is a significant barrier also
- Vitamin D deficiency was highlighted as a concern within the Asian community and in particular, for those who lived in a hot climate and moved to the UK. This issue reportedly presented itself on several occasions – members experienced low mood and depression and a general sense of poor health
- Differences in the health care system - in this country as opposed to in India. A representative highlighted that, *“The healthcare in the UK is good but there is also an element of people needing to take charge or manage their health”* this may be difficult bearing in mind some of the barriers already raised. *“In India, it is all private healthcare and health insurance companies are very active/involved in supporting the management of people’s health, in terms of guidance and reminders of health appointments.”*
- Person-centred working - It was highlighted that, *“Within India alone, there are 29 states, and in that, you have thousands of official languages, many different cultures, different beliefs and different expressions and ways of living. You can't treat all people from an Asian background in the same way. Asian people, like any other person or group, are influenced by their own experiences, upbringing, teaching and need to be treated for their individual physical/mental health need.”*

Appendix V: Additional barriers highlighted by those supported by Derby Refugee Advice Centre (DRAC)

- **Access** and language barriers, including the lack of access to interpreters when attending appointments and receiving care
- **Lack of understanding and respect** was felt by some individuals when accessing care. There was a belief that professionals did not understand, or take into consideration, the trauma experienced by having to leave their home country and family
- **Deterioration in mental health** due to what individuals have been through and the difficulties with adjusting to the UK, often resulting in alcohol dependence as a coping mechanism
- **Feeling discriminated against** and not being listened to or believed. A sense that professionals were suspicious about their immigration status and their motives for accessing care. The lack of language support/translators magnified this sense of exclusion and misunderstanding

Other wider barriers included:

- Temporary accommodation and negative experience of such was described as a factor that greatly impacted mental health and overall wellbeing
- Finances and a lack of money to access activities to support physical exercise, a healthy diet and overall wellbeing
- Helplessness and anxiety about the future, which was impacting on mental health

“Nobody can understand what we are thinking, our future, our family, every minute we are under depression.”

“My friend had depression and the doctor did not believe him, he went to the detention centre and attempted suicide.”

“I went to the doctor with depression and the doctor said, ‘If you have depression why are you tidy and clean?’”

The following link from the British Medical Association (BMA) highlights the unique health challenges faced by refugees/asylum seekers and provides information on overcoming barriers to accessing care. The BMA have a downloadable health resource that can support health professionals provide care to refugees and asylum seekers.

<https://www.bma.org.uk/advice-and-support/ethics/refugees-overseas-visitors-and-vulnerable-migrants/refugee-and-asylum-seeker-patient-health-toolkit/unique-health-challenges-for-refugees-and-asylum-seekers>