

# Cardiovascular disease in people with serious mental illness

Experiences of people living with serious mental illness who are at risk of cardiovascular disease in south west London

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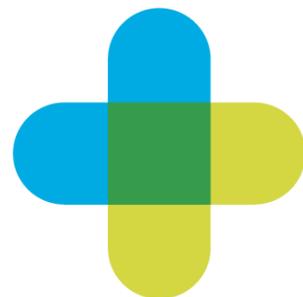
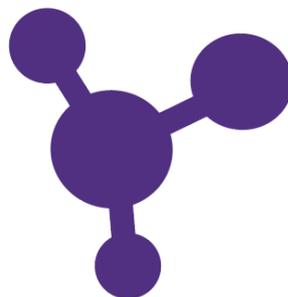
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# About

The Health Innovation Network is the Academic Health Science Network (AHSN) for south London, one of 15 AHSNs across England. As the only bodies that connect NHS and academic organisations, local authorities, the third sector and industry, we are catalysts that create the right conditions to facilitate change across whole health and social care economies, with a clear focus on improving outcomes for patients.

This means we are uniquely placed to identify and spread health innovation at pace and scale; driving the adoption and spread of innovative ideas and technologies across large populations.



## Chapter 1

# Background

The Health Innovation Network (HIN) and South West London & St George's Mental Health NHS Trust (SWLSTGs) are working together to explore ways to reduce cardiovascular disease risk factors in people with serious mental illness.

During the exploratory phase of this project, an initial focus group was arranged with people who had lived experience of both serious mental illness and cardiovascular risk factors, or caring for someone with these conditions, to understand their experience of accessing support for physical health issues and how services could be improved.

## Chapter 2

# Executive Summary

This report provides an overview of the experiences of people either living with, or caring for someone with serious mental illness who are at risk of cardiovascular disease in south west London.

The Health Innovation Network (HIN) engaged with 8 people in a focus group setting in November 2019. The participants were either living with, or caring for someone with serious mental illness who is at risk of cardiovascular disease. The recommendations below provide a summary of the main findings from this focus group:

- People with a serious mental illness should be informed of cardiovascular risk factors and the link with serious mental health conditions at the earliest opportunity, and supported to take preventative action
- In order to facilitate sustainable change, lifestyle interventions (e.g. weight management support, structured exercise programmes) should be holistic, taking into account individual emotional, physical, social and economic circumstances. Time limited programmes should actively signpost to community alternatives to support sustained change
- GPs are considered the first port of call for physical health support amongst people with serious mental illnesses and practices should ensure that they offer an accessible service to this group, e.g. ensuring availability of appointments and ease of booking
- Alternative sources of support, such as community pharmacies, online resources and peer groups, also have value for people with serious mental illnesses, and ought to be promoted as adjuncts to primary care provision
- Health and social care professionals who support people with a serious mental illness should have training in the inequalities faced by this group, the specific challenges they encounter in improving their physical health and wellbeing, and the impact of stigma on their experience of healthcare

## Chapter 3

# Demographics

Within south west London the prevalence of both common and severe mental health conditions is increasing, including the number of people recorded as having serious mental illness (SMI) (O'Donovan 2019). Latest data from GP Quality Outcomes Framework (QOF) indicates that between the boroughs of Kingston, Merton, Richmond, Sutton and Wandsworth, 11,653 people are living with SMI (NHS England 2019).

It is important to note there is no clear consensus on the definition of 'SMI'. NHS England (2018) defines the term as "all individuals who have received a diagnosis of schizophrenia or bipolar affective disorder, or who have experienced an episode of non-organic psychosis." Public Health England (2018) does not define the term according to diagnosis, but as "people with psychological problems that are often so debilitating that their ability to engage in functional and occupational activities is severely impaired". With this variation in mind, best estimates suggest that the prevalence of SMI in England is around 0.9% (PHE 2018).

People with SMI have a 53% greater chance of developing Cardiovascular Disease (CVD) compared with people without SMI. Life expectancy is shorter by 15-20 years compared to the general population and CVD is one of the major contributors to this mortality gap (NHS England 2018). Ensuring that people with SMI receive comprehensive physical health checks is a local and national priority. Nationally in Quarter 2 2019-20, only 30% of people with SMI had received a full check in the preceding 12 months. Between the boroughs of Kingston, Merton, Richmond, Sutton and Wandsworth, the average was slightly higher at 30.1%, equating to 3,557 of a possible 11,653 people on the SMI QOF register, although there was significant variation between boroughs with the highest performing achieving 43.2% (Kingston), and the lowest 18.5% (Merton).

## Chapter 4

# Methodology

The HIN approached South West London & St George's Mental Health NHS Trust's Involvement Team and a local branch of MIND to support the recruitment of participants from south west London who had lived experience of serious mental illness and risk factors for CVD. A flyer providing information about the project and the purpose of the group was provided, with contact details for interested people to get in touch. The Involvement Team sent this to their register of people with lived experience and the MIND representative contacted individuals who they felt would be interested in the group. A £15 shopping voucher was offered as an incentive for attendance.

Prospective participants contacted the focus group coordinator, who then arranged a phone call or email exchange to ensure that the person met the eligibility criteria:

- Currently living in Kingston, Merton, Richmond, Sutton or Wandsworth
- Lived experience of SMI and known cardiovascular risk factors, or caring for someone with SMI and cardiovascular risk factors
- Over the age of 18

For the purpose of the group, cardiovascular risk factors were defined as: current or past heart or circulatory disease, such as coronary heart disease, stroke or a heart attack; Type 2 diabetes; high blood pressure; obesity and high cholesterol.

A total of eight people (seven people with lived experience of SMI and one carer) participated in the focus group. The group comprised a mix of age groups, genders and ethnicities.

## Chapter 5

# Approach

A Darzi fellow, experienced in working with people with SMI, conducted the focus group with support from a HIN Project Support Officer. Four questions were devised to initiate discussion as listed below (see Table 2) and delivered using a semi-structured approach.

Participants were given an information sheet which reiterated the rationale for the focus group and explained how the resulting data would be used (Appendix 1). Each participant was also given a consent form to be recorded and photographed (Appendix 2), and were informed about how long the data would be stored for. Some participants were unsure about being photographed and it was therefore agreed that no photographs would be taken. All participants consented for the focus group to be audio recorded. Following the group, the recording was transcribed verbatim. Thematic analysis of the transcript was then undertaken to identify commonalities within the data.

**Table 2: Focus Group Questions**

Question
1. On the information sheet, we have listed the main risk factors for cardiovascular disease. What has been your experience of being informed about these issues?
2. What support have you had with managing your physical health and who has that come from?
3. Is there anything that's prevented you from following advice or accessing services for your physical health?
4. If you had a magic wand now and you could design some services to support you with your physical health – what would your ideal solution look like?

# Findings

## 6.1 Being aware of CVD risk

Experiences of being explicitly informed about cardiovascular risk factors within the group were mixed. Two participants stated clearly they had never been informed about the key risk factors and their link to CVD. Two recounted having conversations with their GPs about high cholesterol and the possible treatment options for these. One participant recounted being informed of the risks only after being diagnosed with Type 2 diabetes.

None of the participants could recall having their physical health discussed with them by a mental health provider, although it was noted that some had not been in contact with secondary mental health services for some time, having been discharged to GP care. One participant, who had more recent contact with secondary mental health services, felt that they would have welcomed more information from their mental health team about managing physical health issues. Four of the group were surprised by the link between SMI and CVD, having been previously unaware of this.

The emotional burden of living with risk factors and resulting physical health issues was raised by three participants and this was linked to taking additional medication, which had negative connotations, and worrying about the possible impact of their condition.

One participant was concerned about information not being shared between services, such as between GP practices, and felt this impacted on their clinical care.

Theme	Quotes from participants
<b>Lack of awareness</b>	<p>“No-one ever has told me about these. Not my GP, nor my psychiatrist.” – <b>person with SMI</b></p> <p>“The only person that has explained them was a nurse... I can’t remember what her organisation was called, but you can get referred to that.... apart from her and her organisation, in my life of mental illness, no one has gone through the risk factors” – <b>person with SMI</b></p>
<b>Information from GP</b>	<p>“I have got high cholesterol. It was about a year ago. My GP explained it well, he was very good.” – <b>person with SMI</b></p> <p>“About 2 months ago my cholesterol was quite high, it was 7.6. They were waiting to see if I could reduce it within 6 weeks period before referring me to the cholesterol clinic, so the doctor printed out the Mediterranean diet” – <b>person with SMI</b></p>

**Emotional burden** “This talk has given me a lot to think about. Because I smoke, I have high blood pressure, high cholesterol, obesity. But none of these affects my life at the minute, but it could in the future, like, you know it’s something I have to leave here thinking about” – **person with SMI**

“[My partner] also has bad depression, which is because of all the physical things that happened to them. I think the most vivid memory I have of [my partner] having it [a heart attack], was then going to see them in the cardiologist ward and mainly seeing the very elderly there – it was a complete shock.... And [my partner] was very distressed by that as well” – **carer**

“I think hearing that you’ve got another condition, kind of put me down. You know, made me feel a bit down a bit. And also we have cardiovascular disease in my family and it just made me think oh... Another thing.” – **person with SMI**

“When you take them [statins], then they are for life really and you can’t really stop and I just didn’t like the thought of taking another tablet” – **person with SMI**

**Information sharing**

“When I switched practice, which I’ve done a few times, the information doesn’t come through, so the practice realised that my blood pressure was high and started monitoring it, now I’ve come to a surgery up the road here [that information] hasn’t got through” – **person with SMI**

## 6.2 Getting support

Most of the group (six participants) had been referred to or participated in some form of diet and/or exercise programme, usually via their GP. Much of the feedback about these schemes was positive, although some participants felt that the programmes were too short, and one felt that the providers were not sufficiently aware of how to support people with serious mental health issues.

GPs were most commonly mentioned in terms of support with physical health, although getting appointments was noted to be difficult. Four participants mentioned the role of community pharmacists as a new, accessible source of both information about physical health medications and practical support with prescribing and dispensing; although the quality of the service provided was considered variable between locations and providers. Informal support, such as talking to other people, either through groups or online, was considered valuable. Some of this support was accessed via local charities and organisations, such as MIND.

One participant noted that support from the NHS tended to be reactive rather than proactive and suggested that a greater focus on prevention would be positive.

## Theme

## Quotes from participants

### Diet/exercise schemes - positive

"I did the 10 week one-to-one...It was really lovely. I was lucky to have a really nice trainer. And so, it was a focus every Tuesday and the hour, so yeah I did definitely feel better for having it." – **person with SMI**

"I went to a 'live well' exercise thing which was telling you about healthy eating and we also did exercises...we were given a goal... I lost weight and I did reach my goal about two days later – two days after the deadline I reached my goal!" – **person with SMI**

"I hurt my back, and I got this idea that when I'm sitting on the floor, that I can't get up by myself because of my back. And I discussed it with my trainer, and it was all here [points to head], because I can do it – you know she said show me how you get up and I suddenly got up off the floor and she said I'd got it fixed in my mind, which was really interesting that some of the things I thought I couldn't do, were in my mind." – **person with SMI**

### Diet/exercise schemes - negative

"I did that 10 week programme ... And I went to the gym then for 7 or 8 weeks ... but I stopped going because I thought it was too hard work like, you know, it just tired me out." – **person with SMI**

"Although my trainer was a very nice man, it was essentially like just going to a general trainer off of the internet, you know. So he was a nice man, but he had absolutely no...insight into mental illness." – **person with SMI**

"I think when it comes to physical health from your GP, they refer you, well from my experience, they refer you to these workshops that you've been speaking about, and they're always like 10 or 12 weeks but that's the problem, that they are 10-12 weeks and a lot of people will just stop at the end of the 10 or 12 weeks." – **person with SMI**

"Those groups are good, you know, but I just find them – that cut off – I find I get a bit down! Then I think well I've got to leave now" – **person with SMI**

**Pharmacists as a new source of support and information**

“You don’t always have to go to your GP. The pharmacist has the knowledge and experience to help you. They are doing more than what they used to do many years ago. My pharmacist, you know, they’re excellent! They know me. I ask any question about any medication, they give me details, they signpost me to the website. You know, any question I’ve asked them, they are always willing and keen to help me. I’ve seen a shift in the pharmacists, with their sharing of knowledge. Before, you did used to go in there and you know, pick up your medication and walk out – but now you can actually have a conversation with them. And even when I go in there and they say my name, I think that’s really nice” – **person with SMI**

“I was just going to mention the pharmacy. I have one, he’s good to me – they give me four weeks’ tablets at a time and they put them in the little boxes, like, all did up for me you know. It’s brilliant. Because I used to get about six boxes of tablets and have to start doing them up myself and it was a nightmare.” – **person with SMI**

“One time this year I went in: ‘Can I have my flu jab?’ – they said ‘Yeah, have it now’. You know, rather than go to the GP surgery” – **person with SMI**

“It’s just across the road from us and again, they’re absolutely marvellous because it’s a little one that you can go into now and because he doesn’t really like leaving the house, it’s just across the road. They’re very good like that” – **carer**

**Non-clinical sources of support**

“I did a couple [of health/wellbeing courses] and I find you meet people there who’ve got the same problems and you talk to them” – **person with SMI**

“And talking about things, I find you get more ideas [about healthy eating/exercise] from other people [in groups]” – **person with SMI**

“I follow a Weight Watchers profile on Facebook, I haven’t joined it, but I look at all the advice and the love from other people that goes with it and the support is quite good. And I haven’t got a clue what they’re talking about half the time, but I do know some things they say to eat sticks in my mind. They might say ‘I’ve been following this since whatever and I lost 4lbs this week’ and I’m thinking oh well done” – **person with SMI**

“One thing I am very positive about is how the NHS is collaborating with charities. So they don’t have time to work on prevention, in my opinion. But what I’m pleased about is the gym programme we’ve been on, you mentioned another one, and these charities are really helpful for us. There’s I think MIND in [local area] and they often have days based on exercise, wellbeing, healthy eating” – **person with SMI**

### 6.3 Barriers to improving health

Four of the participants felt that personal finances and cost were major barriers preventing them from following health advice. Accessing local gyms or sports facilities and buying healthy foods were both considered prohibitively expensive. Three participants also mentioned cuts to local services, changes to benefits and reduced services as having an impact, for example changes to personal budgets, Personal Independence Payments and Freedom Pass eligibility which prevented access to leisure centres and other facilities.

Four participants mentioned the impact of living with mental health issues on physical health and their ability to follow advice. Some participants were aware of what they ought to do, in terms of eating well and exercising, but struggled to find the motivation, especially when their mood was low. Three participants mentioned their relationship with food, and comfort eating in particular, as an issue. Three participants mentioned the impact of taking medications which cause weight gain and affect their food choices. However, three participants did feel that they had been able to make lasting changes to their diet by building and sustaining healthy habits. The stigma of living with mental health issues had made it difficult for two of the group to access support when needed, particularly at the GP. They felt that their mental health problems were not well understood by professionals. Again, support via more informal means such as charities, through peers and by looking online for advice were highlighted as valuable alternatives. There was a wealth of information about local services, groups and centres that could be accessed and participants were keen to share this knowledge between them.

Theme	Quotes from participants
<b>Costs and financial issues</b>	<p>"After ten weeks if you can't afford it, you just have to stop don't you, and you might have enjoyed it, but you can't continue because you can't afford it." – <b>person with SMI</b></p> <p>"I used to [cook] when my cooker was working! ...Because I lost my PIP, bang goes the cooker!" – <b>person with SMI</b></p> <p>"I think it is money. Yeah. Because not everybody can afford to eat good nutrition." – <b>person with SMI</b></p> <p>"But you see, not everybody has got one of those [a Freedom Pass]. That's the problem. And then you get penalised further. I've got one now, but it's going to run out in March." – <b>person with SMI</b></p> <p>"Our borough cut back on all of this [discounted access to leisure centres]." – <b>person with SMI</b></p> <p>"There's lots of cuts now and not as many day centres that there used to be ten years ago. I used to go to Family Actions and that was a drop-in, and that was wonderful and so many people going there, their health improved - then that closed down. Then I went to MIND... but you're budgeted now, so you can only come in certain days and it's not like it used to be. You come in you do your group, then you go. These things don't help." – <b>person with SMI</b></p>

“But it depends on budget. Personal budgets. But it was much nicer when you were able to drop-in – maybe just have a chat, not a group. All that’s gone now.” – **person with SMI**

### Impact of mental health issues on lifestyle

“When my depression is bad, I binge chocolates in bed at 1 o’clock in the morning. So a few days ago when my mood was very low and I was anxious, I ate probably 10 big bars of KitKat in one go at night. I’m back in primary care and I don’t think they’ve really got the expertise. All they can really say is don’t do it, but with mental illness all the various symptoms you get in mental illness, it’s easy to smoke, drink, binge, eat comforting comfort food, and so there is in my experience all they say to you is don’t.” – **person with SMI**

“The only thing I say to this question is not wanting to talk about your situation, I don’t know if that makes sense or not - your care workers, your service worker or MIND or whatever, you don’t want to talk about it because it’s easier not to talk about it, than it is to talk about your problems.” – **person with SMI**

“Yeah you need encouragement. It’s alright telling you ‘you need exercise’, what you supposed to do when you’re down?” – **person with SMI**

“For me, if I have a fridge of healthy food, sometimes I just don’t want it... And I know if I have healthy food and go out for a walk - but it’s the doing it. I know there’s a bag of spinach in there, I know there’s some carrots, I know not to eat too much chocolate, but when you’re not feeling well, that just goes out the door.” – **person with SMI**

“Mental illness is, you know, it’s everything. It affects the way you think, the way you act, the way you behave, your feelings, and that affects everything that you do” – **person with SMI**

### Impact of medication on appetite/weight

“I found that when I was diagnosed with severe depression, the medication that I was placed on, the anti-depressants, caused the weight gain. And, the weight gain then caused inactivity, because you’re now conscious of the fact, you know, things are changing, and then that led to high blood pressure. So it was sort of one thing triggering another thing, and then led to another thing.” – **person with SMI**

“I know that when I first went on medication, I lost weight and I was very thin at the time. So to lose weight was quite drastic, but then I was taken off medication and when I was put on medication again, the opposite happened - I put a lot of weight on” – **person with SMI**

“I’ve been on antipsychotic medication about 10 years ago when I was quite unwell – I did then lose that [healthy eating] I was craving all the junk food. I’m back eating more healthy again now.” – **person with SMI**

### Creating a habit

“So I started drinking 2 litres of water a day, I was eating fruit and veg every day. Not because I wanted to lose weight, because I was quite slim, but the more I ate that food, the more my body got used to it and I didn’t actually crave any – I didn’t want junk food. I just wanted to eat healthy food.” – **person with SMI**

“I have found that if you do stay off chocolate and unhealthy food for a while, it’s true what they say your taste buds do adapt and those sinful foods that you devoured in the past suddenly become unappealing.” – **person with SMI**

“So I don’t do baking now – when I start to make bread it’s funny I’m not really keen on jam or butter or anything, that affects my IBS, but I used to make the bread I used to add jam and cream – treat it like a pastry. So it’s funny. Definitely when I put on weight I don’t do the baking.” – **person with SMI**

### Mental health stigma

“Mental illness is crazy thoughts, crazy ideas. With my OCD I get intrusive thoughts, but my point is, if you have scary symptoms that the public; but also sadly doctors and nurses; are scared of, like psychosis, they see it as a problem and that will stop people accessing.” – **person with SMI**

“But they don’t always understand at the GP because one time I went and I had to see the doctor, and when I was waiting I took a long time in the toilet because of my IBS – ‘We’re going to call the Police if you don’t come out the toilet!’ – It’s all nonsense talk. Yeah they don’t always understand.” – **person with SMI**

## 6.4 Solutions and ideas

Throughout the focus group, the desire for discounted or supplemented access to local leisure/gym facilities was raised. Other suggestions included dancing lessons, cooking lessons and drop-in “motivational clinics”.

Two participants mentioned making unhealthy food less available, at an individual level through supervised diet plans, or at a wider level through taxation.

One participant mentioned the need for increased awareness of mental health amongst professionals and services.

Theme	Quotes from participants
<b>Discounted leisure/gym access</b>	“There was a guy who worked for MIND, and he arranged for us and I don’t know if we can do something like this, to go for the gym for free 1 day a week through MIND. I don’t know if we could do something to do it, if we can organise maybe through you, or someone? It was really good, we could either go to the gym or swimming on a Thursday.” – <b>person with SMI</b>

“Whereas, I think if they gave a little incentive, a little encouragement to carry on, it would be good. A discount, concession, anything, you know, because I do know some people will struggle, some people will be OK, for the ones struggling, you say poverty could be a factor, the ones that are struggling - help. Because then in the long run that person’s health would be better and then they wouldn’t need to use resources of the GP and the NHS!” – **person with SMI**

### Cooking/life skills support

“I think if you learn to cook you’ve got more choice, more options, it’s cheaper for you, a lot cheaper to cook fresh food than to buy £5 or £10 takeaways” – **person with SMI**

“I find cooking quite therapeutic as well. I find it quite calming.” – **person with SMI**

“Basic life skills should be opened up for everyone who wants to re-engage with cooking or, sewing or something. A lot of people don’t even know how to get a needle and put back a button! Or learning how to make a basic meal! I think basic life skills should be bought back so that people can get back into doing things for themselves.” – **person with SMI**

### Reducing access to unhealthy food

“I suppose one thought comes to mind is the availability theory, if you make unhealthy foods extremely expensive or stop producing them. That would stop us from you know, we go to the supermarket and can’t buy chocolate because it’s not there or it’s £10 a bar, that would be one way of stopping us from eating all that.” – **person with SMI**

“Totally unrealistic but for me it would help if I could go somewhere and a diet plan was written out and I was told, you’ve got to do this for a week – maybe staying in somewhere. And you’ve got to! It will bring down your cholesterol blah blah blah – but you’ve got to – I was supervised for the week. I know that’s totally unrealistic but in those circumstances I could do it for a week. I would probably be slimmer” – **person with SMI**

### Support with motivation to exercise

“If you tell us we need to climb Mount Everest, none of us will go, but if you tell us that there’s a fun disco here tomorrow, listening to our favourite 70s/80s music or whatever, just having fun, moving your body at a disco, is what you need” – **person with SMI**

“If you could possibly have like motivational clinics, so they are dotted around, quite a few in each borough if you are feeling a dip, go in and they’re like motivators? Sort of kick start you again and sort of, give you the, take the load off of you and say actually you’ve been doing really well and sort of motivate you back into the services again but...for physical health especially...Because there doesn’t seem to be like drop-ins, like they have for AA, so it’s very precise isn’t it? You have to be referred by your GP, or referred by somebody else. You just can’t drop-in and say I would love to get back into swimming.” – **person with SMI**

# Conclusion

This focus group explored the experience of eight people - seven with SMI and one carer – regarding support for reducing CVD risk and their views of how services could be improve

Experiences of being informed about cardiovascular risk factors, and the link with SMI, were mixed. Some participants had only been made aware of specific risk factors upon diagnosis, despite these being largely preventable conditions e.g. high blood pressure, high cholesterol, Type 2 diabetes. These diagnoses were then a cause of additional worry and distress to the person. This highlights a need for services to provide comprehensive information about preventing CVD to people with SMI at the earliest possible opportunity, rather than reactively treating conditions as they arise.

In terms of accessing professional advice and support around CVD, most participants identified their GP as being their first port of call, and most were positive about their GPs' perceived knowledge and understanding. GPs were perceived as being hard to access at times, whilst community pharmacists were identified as a new and valued source of information and practical support, offering a more convenient point of contact for people with SMI. The group largely found pharmacists to be welcoming, knowledgeable and helpful.

Managing CVD risk alongside SMI was particularly challenging for the group, due to symptoms such as low mood or binge eating, as well as the impact of mental health medications on weight and appetite. There was some feeling that mental health conditions are not well understood amongst staff outside of mental health services, e.g. at GP surgeries and by fitness trainers. At times, stigma remained a barrier to accessing care, indicating the continued need for mental health awareness amongst all health professionals. In addition, mental health services were not seen as having played a role in identifying or managing physical health issues. This may indicate a need for a greater focus on physical health amongst mental health professionals, although this finding may have reflected the demographic of the participants, most of whom had not been open to secondary care for some time.

All participants were aware of the importance of eating healthily and exercising to maintain their cardiovascular health and general wellbeing. However, this was easier said than done, and the group identified numerous barriers such as costs and accessibility of relevant services. Most of the group had accessed some form of healthy eating and exercise programme, via their health provider or MIND, and experience of these were mixed. Some valued the programme highly, yet others fed back that 10-12 week schemes were not long enough, that it was difficult to sustain the changes in behaviour and in one case, the trainer had not been sufficiently aware of mental health issues to adequately support the participant. The group identified the need for longer term provision and a greater range of affordable exercise options locally, such as subsidised gyms and swimming pools, to allow them to continue to sustain their exercise habits. It was evident that current provision

varied based on borough and benefits arrangements, which was frustrating for some participants.

The group identified valuable sources of informal support in managing their physical health. Meeting other people with similar health issues through groups, and then sharing ideas and supporting one another was considered valuable and motivational. Some of the group also made use of the Internet for information and support, for example joining weight loss groups on social media, or looking up healthy recipes. Participants all noted that having the opportunity to talk about their experiences had inherent value and most of the group commented that even participating in the focus group had been a positive experience for them.

## Chapter 8

# Recommendations

The views and experiences of the focus groups participants provided valuable insight into the experience of living with SMI and managing CVD risk, however recommendations are made with caution, given that their views may not be representative and/ or generalizable to all people with SMI in south west London. Based on the findings of this focus group, the following recommendations are made for improving care for people with SMI:

- In addition to general mental health awareness, all healthcare professionals (including those involved in the provision of diet and exercise programmes) should have specific training in the causes of health inequalities amongst people with SMI, including the effects of psychotropic medications, stigma and lifestyle factors
- People with SMI, and/or their carers, should be given comprehensive information about CVD risk factors at the earliest possible opportunity to support a preventative approach to physical health issues; this should be revisited at regular intervals by health professionals
- Diet and exercise programmes should be available for all people with SMI, regardless of borough, and should ensure that participants are supported to make sustainable, long term changes to their lifestyle, beyond the lifespan of the programme itself
- Income should not be a barrier to improving health. People with SMI should be offered personal health budgets, discounted or subsidised access to gyms/sport facilities and practical support with healthy eating, to support sustained behaviour change
- The NHS Long Term Plan supports the roll-out of Personal Health Budgets for people with long term mental health conditions; these should be more widely used to empower people with SMI in south west London to improve their physical health
- Physical health assessments and follow-ups for people with SMI must not overlook the emotional and psychological burden of their conditions and ought to incorporate a simultaneous review of mental wellbeing, motivation and support needs
- People with SMI value the convenience and accessibility of community pharmacies, and opportunities to expand the health promotion services available from them should be explored, e.g. smoking cessation and weight management services
- People with SMI value peer support, having the opportunity to talk informally and share ideas; establishing groups locally to facilitate this may be beneficial whilst drawing very little from scarce clinical time/resources
- Digital interventions for people with SMI should be actively considered; some people with SMI already use the internet as a source of information and support for improving their physical health

## Chapter 9

# Acknowledgements

The HIN would like to thank the all of the focus group participants that contributed their lived experiences to this report as well as SWLSTG's Involvement Team and the local branch of MIND for supporting the group.

## Chapter 10

# References

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# Appendices

## 11.1 Appendix 1: Participant information sheet

### Meet Izzy and Lydia from the Health Innovation Network

# Izzy

Izzy is a Project Manager in the mental health team.



# Lydia

Lydia is a Project Support Officer for the healthy ageing & mental health teams.



**Hello and welcome to our focus group. Thank you for coming!**

#### **Why are we running this group?**

South West London & St George's Mental Health NHS Trust and the Health Innovation Network are looking at ways to reduce the risk of cardiovascular disease for people with serious mental illness. In order to do this, we want people with lived experience of these conditions to help us to understand what is currently working well and where improvements could be made.

#### **What is cardiovascular disease?**

A group of conditions affecting the heart and blood vessels, which can cause blood clots and damage to organs such as the heart, kidneys and eyes.

Cardiovascular disease is one of the main causes of death and disability in the UK. The good news is that it can often be prevented by leading a healthy lifestyle.

The main risk factors for cardiovascular disease are:

- Smoking
- Diabetes
- High blood pressure
- High cholesterol
- Obesity
- Inactivity
- Age
- Certain ethnic backgrounds

### **What would we like to know?**

What your experience of living with these conditions has been like – what has worked well for you, what has not been so good and where you think improvements could be made in the current system. This might relate to your experience of mental health services, your GP practice, general hospitals or charities.

### **What will we ask you to do?**

- We would like you to engage in a group discussion, guided by some questions which we will put to the group
- We will ask you to talk one at a time, to ensure that everyone's voice is heard
- We will not ask you to share very personal information or stories if you don't want to, but you are invited to share as much as you are comfortable with

### **What will you do with this information?**

We will use the information you share with us to shape and inform our work. We will analyse the information that's collected and share this with others to help them understand the needs of people with serious mental illness.

### **Confidentiality**

You do not need to give us personal identifiable information about yourself. All information used in our study will be anonymous – it will not show your name, address or telephone number. We will keep all your information safe and confidential.

## 11.2 Appendix 2: Consent form

### Consent to be audio recorded and photographed

This focus group will be audio recorded to ensure accurate transcription and we may also take photographs. Anonymous quotes from the focus group will be included in our research report and may be used in presentations and publications. The audio recording will not be shared beyond the Health Innovation Network and will be deleted at the end of the project (in August 2020).

We are asking you to sign this form because you have agreed to be included. By signing this form, you agree to give the Health Innovation Network your consent to be audio recorded and photographed. The reasons for this work will be fully explained to you by Health Network staff carrying out the session and you will be told what the material will be used for.

You are under no obligation to agree to be included in the audio recording or to having our photograph taken. If you do not wish to be included, please let the staff know before the work takes place.

If you are happy to be included in the audio recording which is taking place, and to have your photograph taken, please sign and date the reverse side of this form. The staff member will help you to complete it. For any patient who is aged 16 or under, or who is unable to provide consent for themselves for whatever reason, another person (parent, legal guardian or representative) may sign the form for them, provided that both they and the patient are happy for the audio recording and photography to take place.

If you have any questions please contact [hin.southlondon@nhs.net](mailto:hin.southlondon@nhs.net)

**Health Innovation Network**  
Communications team

### Consent

#### Consent to be audio recorded, filmed or photographed for publicity, research, broadcast news or printed news coverage

To be completed by the staff member, patient (or their representative) and/or the staff member carrying out the filming/photography or the photographer.

Date	
Ward, department or location	
Patient / participants name	
Member of staff organising audio recording, filming or photography	
Organisation carrying out audio recording,	The Health Innovation Network

filming or photography	
Reason for audio recording filming or photography	For the use in research or publicity for the Health Innovation Network and its partners.
Signature of patient / participant OR	
Signature of patient / participants parent, guardian or representative if they are aged under 16 or unable to provide consent for themselves	
Please tick this box if you <b>do not</b> wish the Health Innovation Network to use this material for publicity purposes other than those you have already agreed to: <input type="checkbox"/>	
If you are happy for the Health Innovation Network to use this material for other purposes, please provide contact details here:	
Name and signature of staff member	
Photo reference (internal use only)	

Copies to be distributed as follows:

- One to be filed in the patient's notes
- One to be filed centrally by staff member supervising or photographer
- One to be offered to the patient or the patient's parent, guardian or representative