Mobilise / Exercise / Socialise

Broadening the inclusion in physical activity research and physical activity interventions for people with severe mental illness

Dr. Katarzyna Machaczek, Dr. Emily Peckham, Dr. Joseph Firth, Dr. Nick Pollard, Dr. Caroline Mitchell, Dr. Helen Quirk, Mrs Hannah Burton, Ms Vicky Felton, Ms Stephanie Flanigam, Mr Andrew Todd, Mr Ian Henry and Professor Elizabeth Goyder.

Funder: NIHR CRN Y&H

December 2022

Background

Previous research has demonstrated that people with severe mental illness (SMI) engage in substantially lower levels of physical activity (PA) and higher levels of sedentary behaviour than those without SMI.

This might be because people with SMI face several unique barriers to engagement in PA such as high levels of mental-health symptoms, lack of social support and debilitating side effects of medication.

People with SMI face several unique barriers to engagement in physical activity

The groups most disadvantaged by these barriers are those from the most deprived and ethnically diverse communities. Limited by poverty, low expectations, and second or third language English competency, they rarely participate in PA research and programmes.

We conducted consultation with people who experience SMI and who live in the most deprived and ethnically diverse communities in one region of England (N = 21), including those who act as peer PA practitioners (N = 4), to find out from them what would help them to increase participation in PA programmes and research. This report outlines what we learnt from speaking to the participants and provides guidance on the timing, nature and forms of support found most valuable by people with SMI.

This preliminary study is an important step in developing strategies to increase participation and ultimately designing interventions to improve the physical health of this disadvantaged and vulnerable group.

The findings speak to these NIHR's priorities:

- Improving the lives of people with multiple long-term conditions through research;
- Bringing clinical and applied research to under-served regions and communities with major health needs; and,
- Embedding equality, diversity and inclusion across NIHR's research, systems and culture.

Recommendations:

Reach, recruitment and encouragement to participate in PA

Who will approach individuals with SMI?

- Staff in healthcare organisations. Examples: those who work in the NHS, including those in Mental Health (MH) hospitals (early intervention, MH liaison, enhanced care, crisis resolution or intensive home treatment services, clozapine clinics, or a member of a single point of access team), general practice, accident & emergency departments and recovery colleges.
- Staff of third-sector organisations such as MIND, Age UK, and Crisis.
- Current and former participants in PA programmes for people with SMI.

What they share in common?

- **Appreciation for PA:**

  Encouragement and referrals should be made by those who value PA.

  "...the most appropriate referrals are usually referred in by a person who values physical activity for themselves..."

When?

- As therapy alongside other treatment for SMI.

Key prerequisites for successful recruitment and encouragement to participate in PA

- **Based on trusting relationships**

  Consider the importance of good-quality relationships, which are based on trust, caring and respect; these can be therapeutic relationships with clinicians or good relationships with a trusted person.

  "I think [PA practitioner who was offering PAs to the patient] made me feel really secure and at ease and safe when I first met her and I trusted her and I think that were a really big part of it, that I trusted what she said to me and I believed that, and I think without that I don't think I would have gone on to meet everybody else if I hadn't have met [PA practitioner] first".

- **Offered in a kind manner:**

  Be encouraging and kind.

  "Not too much pressure on them, no, because it all could backfire on you, yeah".

  "She says, here, have a look at that. So I phoned up, asked some questions. Oh, she were pleasant and that were absolutely vital...".

Developing recruitment materials

Important considerations:

- **Co-produced:**

  Develop materials with people with SMI, including those from underserved ethnic groups.

- **Diversity and cultural differences:**

  Remember that one size does not fit all, instead, acknowledge and address cultural and social differences.

- **Multiple formats:**

  Such as flyers, posters, brochures, but... do not send letters! Here are some comments from the study participants about the receipt of letters:

  "Brown envelopes through the post absolutely terrify the majority of people with mental health, so I would suggest if there were any communication, not to put it in a brown envelope. It paralyses people because they've got to a stage they can't deal with it. Work, they can't pay their bills, there's a demand, there's a responsibility and you just can't do that and it paralyses you. To think that a brown envelope comes through the post and it paralyses..."

  "When I was ill I often thought about taping my letterbox up. It frightened me that much, I felt like taping it up. The sound of the letterbox going used to fill me with dread."

  Also, short films and videos should be considered:

  "Ideally videos as well, if someone can actually see what a session looks like, because writing just descriptions of 'it's a badminton session at two o'clock' you don't know if it's going to be really competitive or it's going to be relaxed, so if there's something visual, I think that's a good suggestion."

- **Social media advertisements:**

  Make more use of Twitter and Facebook and other social media platforms.

- **Disability inclusive:**

  Develop recruitment materials which are designed for people who are living with SMI and have learning and physical disabilities.

- **Facilitating word-of-mouth recruitment:**

  Develop verbal scripts for word-of-mouth promotion.

> Disability inclusive: develop recruitment materials for those with comorbid SMI and learning disabilities.

What to include in recruitment materials

- **The content of interventions:**

  Describe each activity in detail.

  "...Each activity needs an explanation of what it is. For instance, a girl said, she come on a bike ride, but she didn't know if, do you get a bike, do you not get a bike, do you need a helmet, do you not need a helmet, what do you need, so each poster would explain. I mean, it'd have to be a big poster but they would know what to expect..."

- **The nature of interventions:**

  Emphasise fun and enjoyment.

  "Like I don't make a point of saying, 'it will benefit your health and wellbeing', I tend to say, 'yeah, it's just nice and casual, come and have a bit of a laugh'.
  I don't try to put a lot of emphasis on health and improving health and I just say, 'come along because it's nice, it's a nice group, we go, we have a laugh, we have a drink', and it's more trying to engage them from the social point of view rather than a physical health point of view, because obviously if you've got, I spent a lot of years being very isolated, so for a lot of people it's the company and the social side that grips them more perhaps than thinking, 'I'm going to go for a bike ride because it's going to raise my heart rate and I'm going to lose a bit of weight', because that doesn't necessarily work, people come for the social, to meet people, and then they get the benefit from the PA. That tends to be a secondary thing to what keeps people going."

  Emphasise that activities are not competitive.

  "You just put friendly game with friendly, sociable, so it's not a competitive game."

  Emphasise that activities are tailored to people's abilities and needs. For older or those with physical comorbidities it will be important to encourage participation in low-intensity activities. For others (younger patients) it might be important to emphasise the challenge inherent in activities.

  "...Walking sounds a bit boring, perhaps say 'why not see if you can still run', and as, in a way, of let's test, why not test yourself, because a lot of people like a challenge."

  Emphasise that people do not have to be fit or know the rules of the game/activities to attend.

  "It's getting across that it's not about how good someone is at that activity, there's good players, there's players who've not played much before but that everyone's welcome."

- **Inviting:**

  Include photos in leaflets.

  "I think having a picture of the peer support workers on the front is powerful so that you see that they're human beings, you actually see them before you meet them."

  Offer testimonies from those with SMI who have participated in the activities:

  "...Having individuals with lived experience statements on the flyer, you know, with mental health, having our statements on, because knowing that participants and staff have their own lived experience really puts people at ease, knowing that there's going to be somebody there who might have been in the same situation as them, so hearing the words from that person themselves reassures them that it's a safe space to be in."

> People come for the social, to meet people, and then they get the benefit from the physical activity

- **Enrolment:**

  Provide contact details/phone numbers.

  "Provide a phone number on a leaflet: Yeah, you don't need to use a computer. I can struggle with phones, the noise of the phone just sent me wappy. That you're in control of that and you would make that decision that it would be the best thing for you."

- **Other things to consider:**

  Weigh up whether or not to advertise the social aspect of participation. For some people, the social aspect is the key reason why they decide to participate, but for others, it is the key reason not to participate.

Language

Mental health - shall we mention it?

We must be culturally aware. It is not always appropriate to label activities as for those with SMI. Phrases such as "wellbeing-friendly" or "mental health-friendly" might be useful alternatives. Consider these quotes:

"'Mental health' may discourage participation among members of certain groups..."

"I wouldn't say schizophrenia or anything like that to them, because of the stigma [among people with a black Caribbean background] because people don't understand and they are scared".

However, it's often necessary to label activities as for those with SMI, as highlighted here:

"I know some service users, they don't want to intermingle with the public but they get on really well with other service users because they've been in the same situation as them so they find it easy to talk to them, so they feel a bit intimidated around the general public".

"Yes, we did use the words 'mental health', yeah, because we used to say that, 'we are the learning disability and mental health and that's what these sessions are closed for', which, in the long run, it helped because everybody understand everybody".

The necessity of being culturally aware point us back to the importance of co-production with members of local communities.

Physical activity - what to call it?

Activity or physical activity?

The word 'activity' might work better than the phrase 'physical activity', which has been recognised to be overwhelming to some participants:

"When I first started, if someone would have said to me 'physical', like 'physical health', I wouldn't have been ready".

"If I offer them a leaflet, I say, I use the word 'activities' to them, 'these are the activities', I don't say, 'these are the physical health and wellbeing activities', I just say 'activities".

Vocabulary that describes intense forms of PA, such as the word 'running', have been identified as overwhelming and not suitable for use in leaflets and referrals:

"I tend not to say 'running' to some, you say, 'you start off with a walk'. So, if you say to someone, 'you're going to do 5K', they'd run a mile".

Delivery – practicalities to increase participation in PA

- **Accessibility**

  PA venues/meeting-point locations should be close to public transport routes.

  "Try and do things where there's public transport so they're accessible."

  Activities should be offered in various locations.

  "Do things in different areas, so it's like the runs are central so you know everybody's not having to travel loads."

- **Travel to PA venues/meeting-point locations**

  Offer support to get to activities.

  "Arrange bus passes."

  "Just give lifts to people. I pick another lady up who comes because she lives local to me and don't drive. I don't drive, my partner brings us. So, it's if we live local to people we'll give lifts and make sure that people can still get to the activities, yeah."

  "Support somebody to go on the bus the first time so they know where to go. I've met a few people that, when they've been under the crisis team, would drive normally but because of the medications and things are not able to drive, but they've not been on public transport for however many years because they've not needed to, so it can be quite nerve- racking the first few times if people don't know where to go and things like that"

- **On arrival:**

  Offer one-to-one support during the first few PA sessions: provided either by a peer or by a practitioner who is trained to support people with SMI.

  "...Just said a name of somebody that would meet me, a point of contact, just going back to my experience, if that leaflet had have come through the door, feel free to come, I wouldn't have gone on my own, no chance."

- **Graded approach**

  Develop a graded and gentle approach

  "...and then you build on it, don't you, because like I started off with walking and that were the first thing and that were a mammoth task to go and do walking - even with the support of the other people and, I mean, now I'm going round walking round [...] Castle on my own and taking dog. I go swimming twice a week, I'm doing yoga, I'm doing Tai Chi. And I go to all these on my own and I'm absolutely fine."

  "It's just to watch to start with, then slowly getting involved within like, say, five, 10 minutes, then gradually build on that."

  "Yeah, yeah, really low-key, like we've said, maybe just meet a few people or a couple of people, whatever...small steps, baby steps."

  Short sessions should be available.

- **Fair and equitable treatment**

  Do not favour some participants over others

  "You just can't say, oh, he's a good player, pick him as the man of the match every week because he's the best player on the pitch, it doesn't work like that."

Environment

- **Mistake-friendly:**

  Create an environment in which it is okay to make mistakes.

  "If you're dealing with mental health or learning disability, you've got to be a bit softer, not as harsh or *telling them off for things, encouraging rather than, like a professional team will do something wrong, oh, what you doing that for, oh, you should be doing this, blah-blah-blah, if somebody does something wrong at our football session, it's, oh, it's alright mate, just keep playing. You don't criticise anybody, do you?"*

- **Emotionally safe:**

  Organisers should offer reassurance and create an emotionally safe environment.

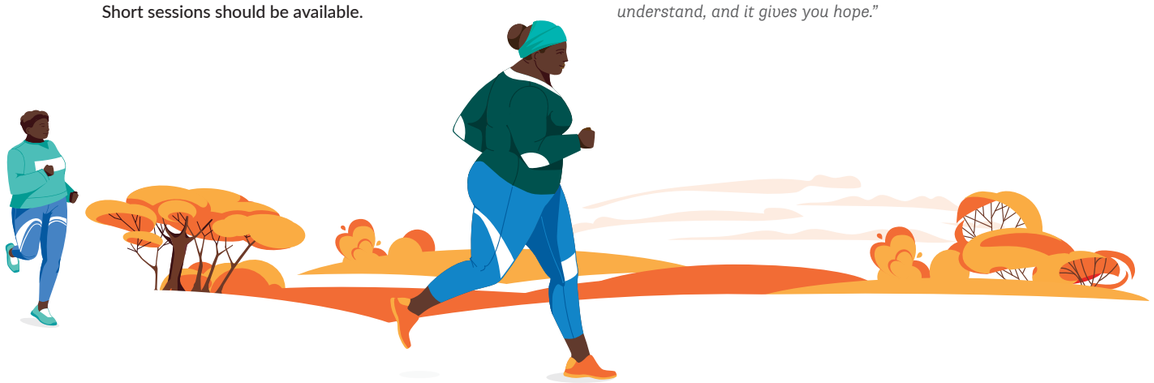
  'reassurance and safety - when I first arrived I had to cry a bit. I suppose though, crying in front of people's hard, isn't it, unless you feel safe?"

- **Establish a buddy/peer-support system**

  "I think you just need someone that's been down that road, that's sociable and outgoing, that's willing not to judge and try and get along with everyone and take things step by step and know the boundaries and know when to back off, when to put a little bit of kick up backside pressure on them in words to egg them along and when to back off and that."

  "I suggest it to people, so telling people that started, like the pupil becomes the teacher kind of thing, that people get a little bit better and then they encourage other people to go, like I have done with a few people and somebody took me there. I wouldn't have gone on my own, I wouldn't have gone, but, you see, I knew it were there, but I wouldn't have just turned up in a room full of strangers and sat there on my own, because there's not enough staff, there's probably, let's say, 30 people in there and two staff, there's not enough to go around, there's not enough for one-to-ones, so, like I say, people..."

  "You can share experiences and you can share things that have worked for you and a lot of the time it is trial and error, but that being able to share, not only is it sharing the different tips and different ideas, but it's also...lets you know that other people understand, and it gives you hope."



Delivery - practicalities (continued)

- **Tailored sessions**

  Make your offer inclusive for people with learning and physical disabilities:

  "I'd adapt things, adapt what I was saying and everything, making sure that they understood me."

  "It's tailoring it to each person as well, so it's being individual and we had to be reactive with you because you deteriorated, didn't you, with your physical health, so we had to change what we were doing, what we were able to offer."

  "So, keep people happy and give them what they want and let them do what they want. There's a man what comes here now, they call him C, and he's learning disabilities and everything - can hardly communicate, does a lot of laughing, does a lot of walking about like that, he might touch the ball three or four times in a game. What we'll do is we would play him the ball, we'd pass ball to him and we'd run half a pitch, he'd run half a pitch with ball, [PA peer practitioner] dives to one side, hit ball through [PA peer practitioner], he's scored a goal, he's like that. And that's made his day."

  "Sometimes he'll lose concentration and starts walking round. [Participant's name]! He goes, oh yeah, yeah, I'm playing football and get back into it. Yeah, I like him, he's always talking to me, he'll stand next to me talking to me while I'm at net and I'll say, [Participant's name], you're meant to be playing football, oh yeah, yeah, and he'll go back playing. He'll wander round in front of you."

Create positive feedback loops

"Once people feel the benefits for themselves as well, they're more inclined to look for perhaps other activities or things that interest them, because they can feel the benefit. And also about us looking at, reminding them from where they've come from as well so they've got that journey. It's not always easy to remember how far you've come.

So you feedback and just that after a game, you played brilliant, well done, or give them a well done through the game and everything, come on, you're doing well, come on, keep going."

- **Organisers should ensure that practitioners who deliver PA sessions receive mental health training and that peer supporters are supported themselves adequately.**

  "It's making sure they're supported well enough and I think some people have struggled with not knowing exactly what their role is, so yeah, but it would definitely help with physical activity, I think, definitely help with the groups we have in the community, for example, the badminton and football I'm thinking particularly, to have those roles would be great."

  > Keep people happy and give them what they want and let them do what they want

  "I think he benefitted from talking to me because he could share his problems. They always say a problem shared is a problem halved."

- **Organisers may want to consider using platforms such as WhatsApp.**

  "And it's very good because we support each other. You might message in and say, I'm not coming on a ride today because I'm not feeling too great but then you're always, oh, you'll be missed, so you're always getting that positive encouragement, hope you get well soon, and we all know then that that person's not feeling great as well and if you're friends with that person, or not, you can message them privately and, you know, there's, I just love it, I think it's a good way of doing it anyway."

  "It potentially might not be answered and we try and respect that, there's sometimes they're on a little bit early, but it's just a really easy way to communicate and if you're not feeling so well sometimes it's easier to message rather than speak to somebody, so, for us, it seems to work very well."

Implications for strategies for recruitment of research participants

Individual (eg. severity of symptoms), interpersonal (eg. fear/ perceptions of embarrassment), organisational (eg. limited PA facilities in mental health hospitals) and socio-economic (eg. educational status and financial constraints) predisposing factors must be addressed, as should group customs and values, and the diverse nature of various groups.

A considerate and trusting partnership should be the goal among individuals with SMI, community organisations and researchers.

The creation of such a partnership necessitates the establishment of payment methods to cover, for example, recruitment expenses incurred by community organisations.

Recruitment approaches and communication strategies should be created, evaluated and disseminated with people with SMI from various ethnic groups.

Traditional marketing techniques (posters/outdoor banners/ flyers) should be created through community-based participatory approaches, and opportunities should be taken to encourage social interaction via word-of-mouth communications.

For social marketing, a branding strategy which conveys feelings of enjoyment and fun, and which creates a sense of belonging should be considered.

Additional environmental interventions and multi-level approaches may be required to fully engage people of low socioeconomic status. These include environmental changes, e.g., the creation of trails or bike paths.

Sheffield Hallam University
Knowledge Applied

MANCHESTER 1824
The University of Manchester

UNIVERSITY of York

The University Of Sheffield.

General Practice at the Deep End
Yorkshire and the Humber

doi.org/10.7190/shu-reports-22001