

Getting past the gatekeeper: overcoming a barrier to research participation

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Background

People with severe mental ill health can be a hard to reach population when recruiting to clinical trials. One of the main reasons for this is clinicians' reluctance to refer or invite people with severe mental ill health (SMI) to take part in a clinical trial. This may be due to:

- Misplaced view that it would not be in the persons best interest
- Involvement in studies may lead to a deterioration in their mental health
- Perception that people with SMI are not interested in taking part in research

We think the TWiCS design might be an appropriate design that is easy for participants to engage with and doesn't cause moral dilemma's for the recruiting clinician about whether or not it is in the participant's best interest to take part in a simple survey (promoting autonomy).

Methods

We have set up the Lifestyle Health and Wellbeing Survey to ask people with SMI simple questions about diet, fitness, alcohol and smoking.

We are then piloting this methodology by looking at peoples answers to the questions to determine whether they are potentially eligible to take part in a study aimed at helping people with SMI to quit smoking (SCIMITAR+ study).

The HWB Survey has received REC approval and REC approval has also been granted to invite people from the HWB survey to take part in SCIMITAR+ provided that a member of their care teams believes it is suitable for them to take part (non maleficence).

Initial findings

So far 661 participants have been recruited into the HWB study and 10 participants have been recruited to SCIMITAR+ via the HWB Survey.

From SCIMITAR+ we know that clinicians have been telling researchers that smokers on their caseload are not interested in cutting down or quitting smoking however 58% of participant's in the Health and Wellbeing Survey who smoke indicated that they would be interested in doing something about their smoking.

Therefore people who could potentially benefit from taking part in research are being denied the opportunity to do so.

Future work

We are hoping to collect data on participants views on taking part in the HWB survey and participants views on the TWiCS design and how/ whether it affected their decision as to whether or not to take part in research. We are also interested in clinicians views on whether the HWB survey affected their decision about whether or not a study would be suitable for a potential participant e.g. whether knowing that a potential participants has expressed an interest in doing something about their smoking, losing some weight, taking more exercise etc. would make them more likely to feel it was suitable for the person to be invited to take part in a study of a lifestyle intervention.

