



How has Public and Patient Involvement work helped the TULIPS Project?

What is the TULIPS project?

TULIPS is a research project that seeks to design a therapeutic model that will help improve access to therapy, management of individual mental health conditions and help inform a personalised recovery for individuals with severe mental health problems/issues on inpatient wards. Inpatient care refers to care for individuals who are admitted over night to hospital/wards. During the initial stages of the project a trial study was run. The trial study used information gained from reviewing previous research about what helps and prevents access to these therapies in addition to, interviewing the patients themselves, their staff/careers about how they think these therapies should be delivered; to adapt existing therapies for inpatient settings. During this trial the different ways of delivering therapies was also assessed using patient feedback about what works and what does not. All this information was then collated and reviewed by researchers and experts in this field to help design a

new therapeutic model. This new model is now being tested across 34 wards across England and Wales. The services users and staff that are using this model are then interviewed across different time points about their experiences with the therapy and assess if the therapy is working. Ward visits are also made to observe how the therapy is being delivered.

Public and Patient Involvement in TULIPS.

People with experience of inpatient mental health care as either patients or carers have been involved with the TULIPS project before the project was funded by the National Institute of Health Research and throughout all stages of the project thereafter. A group of 4-8 carers and former inpatients have come together at various intervals during the project to help shape the project. We also have a patient representative who sits on the trial steering committee (the independent group) that oversees the conduct and progress of the study. This leaflet details some of the specific ways in which Patient and Public Involvement has contributed to the TULIPS project.

How did patients and carers help before the study was funded?

Before studies are funded, researchers need to complete an application form which they submit to

funders. The application sets out the reason for undertaking the research and the key methods. When we were developing the ideas for TULIPS, we took our ideas to two groups of people with experience of mental health problems. We also had detailed feedback on our form from a very experienced carer and user of mental health services. Patients and carers helped us to make a case for the need for the study based on their own negative experiences in inpatient care and lack of access to therapy. Patients and carers also highlighted the importance of access to therapy in reducing risky incidents on the wards and the importance of having this as a key outcome in the trial. Carers in our groups highlighted the value of interviewing carers as part of the project and considering their role in the study.

How did patients and carers help us to tackle some ethical dilemmas?

Designing and running the project brought up some ethical dilemmas which our patient and care group helped us to resolve. For example, we wanted to observe how staff and patients interacted on the ward but it would be tricky to get everyone's consent to do this. Members of our group, therefore suggested putting posters up on the wards telling people where and when researchers would be on the ward so people could avoid that area if they did not want to be observed. We also wanted to include people in therapy even if they weren't involved in the main trial. The patient and

carer group helped us think through how we could explain the ward psychologist's role to people who weren't in the trial.

How did patients and carers help us design our study materials to promote the study?

Our patient and carer group commented on our initial drafts of participant information sheets, study adverts and helped us develop them so they were more accessible and appealing to potential participants. They also advised our researchers about how they might sell the project to ward managers, ward staff and patients on the ward.

How did patients and carers help us to design study interviews and other measures?

Our patient and carer group looked at drafts of our interview guides and advised on wording of questions and the things we might want to ask to answer our overall research questions. Group members also took part in pilot interviews with our researchers to help train them in interviewing techniques.

There were a range of different outcomes that we wanted to measure in the study, but we couldn't measure everything as this would overburden

people. Our patient and carer group therefore helped us to prioritise what to measure.

We have collected ward level data on serious incidents as part of the study but these data sets are huge and include anything from non serious mix ups with meds to suicide. Our patient and carer group helped us to decide which categories of events to focus on for the trial.

How did patients and carers help with analysing the study data?

We typed up interviews between researchers and study participants. Our researchers coded this data to help identify key themes, but we weren't sure if these themes were meaningful to other people. To help make sure that the research data was meaningful, we took examples of quotes from interviews and asked people what they thought the quotes meant. We then added our group's thoughts to the thoughts of the researchers. This data including patient and carer interpretations was written up in a journal paper and has been presented at conferences. We have also distributed findings to study participants and the patients and public more generally. We have lots more interview data from our bigger study and we'll be asking our group to help us make sense of this extra data in same way.

How did patients and carers help us to promote our study findings?

Our patient and carer group helped us to generate lots of ideas about how to get our research and findings across to the general public and other patients and carers. Some members of our group are well connected with mental health and carer organisations and they linked us up with people from these organisations so we could tell them about our research. The group also looked at posters that we developed about our findings and helped us to make them more accessible and appealing to others.

Contact us.

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