

Patient and Public Involvement (PPI) in Research – Case Study

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How patients and the public were involved

Example 1: Drs Katharina Wulff and Iona Alexander

We are currently carrying out a research project in a secure mental health institution run by Partnership in Care (PiC). All patients have had behavioural problems in the past and the aim of their stay is to help them to be re-integrated into the community. The patients have individual en-suite bedrooms and use of a common room and the garden for social activities, and special rooms for workshops and activities. Our role is to help the institution to improve living and working conditions for patients and staff, with special emphasis on light hygiene. We are assessing sleep-wake patterns, in- and outdoor light exposure, and a number of demographic, medical and working routine aspects.

How we involve patients and staff in our research:

18 January 2015: Discussion rounds, PiC staff and patients, ‘The Importance of Light and Sleep’.

18 February 2015, Engagement with Mental Health Partners, education of staff and patients of Partnership in Care: "When sleep disobeys the clock" A talk about scientific measures of sleep, mood and biological clocks at Partnership in Care, Nottingham.

March 2015: Start data collection. In dialogue with staff and patients while collecting data – adapting techniques, e.g. straps of watches, diaries, instruction sheets for urine collection, tight time schedule of staff on the ward.

Forthcoming: Explaining each individual their data; first-level analysis; discussions, adaptation according to findings

Example 2: Drs Katharina Wulff and Iona Alexander

During Brain Awareness Week, we shared our knowledge about the function of the brain in a series of workshops such as ‘Explore your senses’ and ‘Sleep and Learning’ with children in a Buckinghamshire Primary Village School from Foundation (age 4) up to Year 6 (age 10+). There were about 200 children in the school. Each class had two workshops in the morning, which was then followed up by the teachers in the afternoon. Workshops included demonstrations such as comparative anatomy of the brain (mouse [real] vs human [model]), hands-on creative activities to build a neuronal network from plasticine, explore the world of a blind person using all senses, except vision and use reaction-time rulers using vision or sound. We ran three workshops a day from Monday to Friday with an opening assembly at which we invited all children to participate in a sleep experiment and a final assembly presenting the results of the experiment. It was reported on the weekly newsletter for All teachers and teaching assistants were very supportive and we received excellent feedback from the children.

The impact of involving patients and public in the study

Example 1:

Institution is a residential and work place – empirical data can lead to adaptation:

- Acceptance from public, staff, patients that research with severely behaviourally-disturbed individuals is possible and necessary

- Focus of research on environmental factors for very complex systems such as sleep, body rhythms
- Chronotype (essentially, whether you are an early bird or a night owl) is important for shift-work staff – experimenting with work schedules
- The quality and time of light has an effect on our body clock and performance – is there room for improvement, e.g. installing lighting systems with LED of purpose-specific colour temperature
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Example 2:

Involving schools and children is important for preventative research:

- Schools recognise the fact that sleep is important for their pupils
- Children talk to their parents, siblings, friends and increases awareness of both, sleep hygiene and useful research that reach the community (children asked whether their diary data are really in the graph)

The importance of involving patients and the public in research

As a researcher in biomedical sciences, we get carried away from the human being for various understandable reasons such as the pressure to publish or secure funding for research projects. Involving patients and the public in research allows reflecting on what and how we carry out projects – among those the most important for me is - do we ask the right questions? Can our understanding be useful for prevention, interventions, and recommendations? Listening to the questions and comments of lay people helps to identify gaps and increases lateral thinking, e.g. reading journals from other fields.

The biggest challenges in PPI and what might help to overcome them

Time management - To make time for it while there are important documents waiting to be finished, e.g. manuscripts, reports, funding applications.

It may be worth having a dedicated and experienced person/team for PPI. Although the main work is thinking, how to do it, what to include, what to exclude and developing a detailed programme, if this person is involved in this early stage, they can prepare things as planned.