

SPCR PPI Workshop

4th July

The NIHR School for Primary Care Research is committed to involving the public and patients in the research it funds and supports. These workshops are designed to help inform FR15 and 16 applications.

The aim of these workshops is to bring together researchers and public contributors to discuss research interests and methodologies at the idea generation stage of funding applications. A further aim is to discuss issues that surround involving the public and patients in generating research questions and designing projects. We will support the most popular workshops, and as such need to gauge interest in each proposal.

For more information about any of the proposed workshops, please contact Emma Palmer-Cooper emma.palmer-cooper@phc.ox.ac.uk

# Clinical Trials - online recruitment and retention

Patients can be recruited online and followed up via databases (primary care databases and HES), to avoid the high drop-out rates often associated with online recruitment to trials

Online trials are gaining in popularity, especially in traditionally taboo areas such as alcohol and substance use, sexual health, and mental health. Recruitment to online trials is generally good, however retention to such trials is poor. This is particularly the case in studies involving younger patients who engage in high-risk behaviours such as substance abuse, alcohol consumption, or risky sexual behaviours.

This workshop proposes to a two-part PPI session. The first would be an open discussion about individuals’ motivations for signing up to trials and studies, and what might make someone likely to remain involved or drop out. The second would be study specific, where research groups can discuss with PPI contributors the issues they have identified in certain contexts, and possible ways to address them.

This workshop would benefit any researchers using methodology that involves use of health care services that are documented in accessible electronic health records, and where an intervention being trialled could have a measureable impact on use of these services.

# Involving the public, patients and practitioners in general practice workforce research

Public involvement in health services research has become a well-established activity; a means of bringing together researchers and those whose conditions, treatments or perspectives they propose to investigate. PPI groups have readily identifiable roles including; highlighting priority topics, assisting with research design, guiding recruitment strategies and materials, and facilitating dissemination. Their involvement adds value and purpose to the work of research teams. Existing PPI activities appear to be effective mechanisms for connecting patient and public voices with research proposals across a broad spectrum of research. However, it could be argued that because PPI group members are often excluded from experiencing what happens for those working behind the scenes in health care, it would be useful to discuss the ways in which their input could contribute to studies which focus primarily on issues affecting the healthcare workforce. Studies of workforce-related issues could benefit from the ‘insider perspectives’ of members of the workforce under investigation in addition to those of patients and public members. Design and realisation of these studies would be enhanced by a shared dialogue between current PPI groups and health service providers and practitioner groups, who could work together to understand the connections between what works for patients and what works for practitioners. Priorities could be identified for health care as they are determined by workforce issues (access, skill-mix, patient journey between practitioners, team expertise etc) and probe how the proposed research will affect the experiences of delivering and receiving care across that interface.

This workshop proposes a two part PPI session. The first would be an open discussion between researchers, the public and the health services workforce, about the ways PPI can be utilised in the conception, design and dissemination of workforce research, and build meaningful connections between multiple perspectives. The second would be study specific, where research groups can discuss with PPI contributors and stakeholders the issues they have identified in certain contexts, and possible ways to address them.

# Public involvement with Children and Young People in Primary Care Research

There are a number of Patient and Public Involvement initiatives for children and young people in illness specific research and inpatient care. There is, however, little evidence that the same opportunities exist for children and young people who access primary care services for more common ailments, such as infections and common childhood illnesses. Many primary care research projects will potentially involve participants who fall into this age category, but providing access to interested individuals can take time and is not often possible.

This workshop aims to convene a panel of children, young people and, where appropriate, their parents/guardians, to allow researchers the opportunity to involve younger individuals in the prioritising and planning of research projects. This workshop proposes a two part PPI session. The first would be an open discussion between researchers and contributors about the ways PPI can be utilised in the conception, design and dissemination of research in this population. The second would be study specific, where research groups can discuss project ideas with PPI contributors.

This workshop would be of use to any research project or team looking for input from PPI contributors under the age of 18.