

CLAHRC EoE Patient and Public Involvement (PPI) Coordinating Group Patient and Public Representatives - Role Description

BACKGROUND

CLAHRC East of England

Collaborations in Leadership in Applied Health Research and Care East of England (CLAHRC EoE) is a partnership of 3 universities and all NHS organisations in this region. We work together to improve the way health and social care research is undertaken, and the way the results of research are used in everyday practice. Our research focuses on the needs of people with complex health problems including the frail elderly and those with dementia, learning disabilities, acquired brain injuries or mental ill health. We aim to make sure that the findings of our academic studies can be used to make a real difference to front-line care.

Patient and Public Involvement (PPI)

Patient and Public Involvement (PPI) is where patients and members of the public are actively involved in research projects and organisations. The 'Patient' in PPI means anyone who sees themselves as a patient, service user or carer (either now or in the past).

CLAHRC EoE and PPI

CLAHRC EoE has a strategy describing the overall vision for how CLAHRC supports PPI, and finds out how PPI in research can be successfully carried out. This strategy can be seen in the appendix. One main area of the PPI work in CLAHRC can be classed as 'Operational PPI'. This means ways in which PPI is carried out in the planning and organisation of CLAHRC EoE. It also refers to ways in which CLAHRC supports researchers, patients and the public in carrying out PPI activities.

We are seeking two members who represent patients and the public to become part of our CLAHRC EoE PPI Coordinating Group. We are looking for people with a keen interest in:

- health related research
- how CLAHRC partners can work together to raise awareness of PPI
- supporting both the public and researchers to carry out PPI throughout the research process

This PPI Coordinating Group's role is to support the operational PPI in CLAHRC in line with our strategy. The group will:

- look at what PPI is happening in the CLAHRC research areas
- share ideas for activities, events and training in PPI
- work to support the aims and objectives of CLAHRC's PPI strategy
- link in with our Regional and National partner organisations to share PPI information and ideas

This is an exciting opportunity to bring fresh ideas and new perspectives around PPI to CLAHRC EoE.

CURRENT GROUP MEMBERSHIP

There are two Co-Chairs who run the group and meetings: Lorna Jacobs, the CLAHRC Core PPI Lead; and Graham Rhodes who is a member of the public.

There are also six researchers, one from each of the following CLAHRC research themes:

- Dementia, Frailty and End of Life Care (DFEOL)
- Enduring Disability and / or Disadvantage (EDD)
- Health Economics (HE)
- Innovation and Evaluation (IE)
- Patient Safety (PS)
- Patient and Public Involvement Research (PPI)

ROLE AND RESPONSIBILITIES

Responsibilities of all members of the PPI Coordinating Group are to:

- bring their own views and perspectives to group discussions
- read papers and proposals, and give their perspective on the contents
- champion the diversity of patient and public views (and not only representing their own personal experience)
- attend quarterly meetings of the PPI Coordinating Group in Cambridge, with email communication used between meetings to conduct business

MEMBER ATTRIBUTES

We are looking for people who:

- have some understanding of the importance of applied health and social care
- may already be aware and / or have experience of PPI in the research process
- may be aware of CLAHRC, but ideally have had minimal involvement to date
- are committed to helping to develop strategic PPI in health research across the region
- can give objective input about the priorities of patients and the public for PPI in research
- have the ability to communicate well with a wide range of people
- demonstrates a strong commitment to equality and diversity
- understand the need for confidentiality where appropriate
- are willing to commit to a two year term involving approximately three to four meetings a year during the working day

SUPPORT AND REIMBURSEMENT

Support will be provided by Lorna Jacobs, Senior Programme Support Officer and PPI Lead CLAHRC EoE.

An induction will be set-up prior to joining the group, and any training needs to enable your active participation in the group will be discussed.

You will be reimbursed for your travel to and from meetings, for mileage or use of public transport. Time spent preparing and taking part in meetings will also be reimbursed. Rates for travel and time will be in line with Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) policy. *(CPFT is the host organisation of CLAHRC EoE).*

EXPRESSING AN INTEREST IN BEING A LAY MEMBER

Please express your interest in being a lay member by email or post to Lorna.Jacobs@cpft.nhs.uk

Miss Lorna Jacobs
CLAHRC Senior Programme Support Officer and PPI Lead
CLAHRC Office
Douglas House, 18 Trumpington Road
Cambridge CB2 8AH

Please outline the following in your email / letter (maximum 2 sides of A4):

- why you are interested in this role
- how you feel you meet the person specification
- any previous experience you have had of patient and public involvement in health and social care research
- what support and training you feel you may need in the role
- your contact details

The Co-Chairs will consider each expression of interest with the role description and member attributes in mind. The people most suitable to the role will be invited for an informal discussion with the Co-Chairs to find out more.

A decision will then be made and formal invitations to join the group will be sent out.

Closing date for expressions of interest: Tuesday 14th March 2017

CONTACT AND QUESTIONS

If you have any questions about the role and / or expressing an interest, please do not hesitate to contact:

Lorna Jacobs: 01223 746148 or Lorna.Jacobs@cpft.nhs.uk

Graham Rhodes: jgrhodes43@hotmail.com



CLAHRC EoE

Patient and Public Involvement and Engagement (PPIE) Strategy 2016

Background

All NIHR-funded research is required to demonstrate good quality PPI and to have a clear pathway to demonstrate its impact. These considerations have been shown to have a strong relationship with the production of more relevant, feasible and acceptable evidenced interventions and research designs. There were a number of major developments in the CLAHRC for Cambridgeshire and Peterborough such as the development of effective means to include people with learning disabilities in the research process. This has been achieved in a meaningful way through Service Users Advisory Groups (SUAG) which involves patients (Service users), carers and the wider public in our research. CLAHRC East of England (EoE) continues to support a step-change in the strategy for public and patient involvement, by researching and developing the best ways to achieve PPI in applied health research, implementation and innovation. The aim of our PPI research theme is to define best practice through research and to ensure a legacy of PPI in applied health research, nationally.

CLAHRC EoE made PPI a cross-cutting research theme in order to include and investigate PPI at all stages of the research process, from design to implementation, to evaluate its impact and set new standards for PPI practice. The implementation of our proposed programme of research and activity will enable more strongly conceptualised and evidenced effective contribution of PPI to diverse health care research and interventions. The comprehensive and innovative nature of the planned CLAHRC-programme will provide an unusually-focused, well-contextualised and innovative body of PPI-enabling knowledge and practice to be developed to inform NHS research and practice more widely. The formal research programme will continue to be led by Professor Fiona Poland, Professor of Social Research Methodology University of East Anglia.

The goal of understanding PPI in research will enhance the relevance, quality of experience and impact of NHS research for patients. In the context of CLAHRC EoE, our core strategic principles for PPI are that it is “embedded, comprehensive and active” in each CLAHRC project and for this to be further developed and conceptualised over the duration of CLAHRC EoE. To this end our PPI strategic review workshop held in April 2016 served to review progress and delivery of our PPI strategic priorities and the summary report serves to support this strategy. PPI lay representatives were also involved in ratifying this strategy.

Priorities

The priorities will be achieved by an overall strategy with the following objectives:

- ◆ PPI volunteers and activity will be supported through dedicated time and resource with all CLAHRC projects continuing to be encouraged to identify 5% resources to support project-specific PPI.
- ◆ Information about CLAHRC EoE related PPI activities, experiences, training outputs and projects will be communicated on the CLAHRC EoE website, displayed using social media and sent to PPI members and CLAHRC EoE research teams and partners to ensure knowledge mobilisation.

- PPI initiatives being clearly recognised as an important CLAHRC EoE Key Performance Indicator (KPI) and used to evaluate each project.
- The PPI research theme organisation and projects will provide an evaluative and supportive role across CLAHRC EoE where a PPI plan will be linked to each project, theme and overarching Programme.
- PPI representatives will continue to be supported within the CLAHRC EoE governance structure.
- PPI co-ordinators for each theme continue to report back team efforts to a PPI coordinating group led by the Core, reviewing project teams progress in actively identifying and engaging in PPI.
- Plans should demonstrate commitment to including diverse populations and seldom heard groups throughout the research and implementation process to dissemination.
- Links between PPI stakeholders and initiatives at local and regional levels of CLAHRC EoE will be encouraged, to support active learning and collaborative working.
- Training and mentoring initiatives will be developed and supported.
- CLAHRC EoE will continue to align its priorities with regional PPI groups and partner organisations and act as an exemplar of PPI practice in research.

Over the duration of the CLAHRC we will continue to regularly hold events which share developing knowledge of issues, strategies and resources with stakeholder groups. We will seek publications on findings from individual projects and also the implementation study of the programme itself in high impact academic and practitioner journals. The process and projects should allow for outputs to be selectively produced and published annually from eighteen months from CLAHRC-start to the CLAHRC-end.