

Meeting of the 'Interim External Reference Group' (ERG)

held on 4th May 2010 at The County Hostel in Chelmsford.

Present: Monika Brzozowska-Neroth (LINK Hertfordshire), Wai Young (LINK Essex), Julie Lockhart (Lay member and Stroke Patients Group), Tracey Johns (CLRN), Caroline Gunnell (CLRN), Gill Green (Research Design Service for East of England), Oksana Hoile (CLRN)

Apologies: Dawn Bostock, Nalima Vaswani

Introductions and General discussion

Oksana Hoile, Senior Manager of the Essex & Hertfordshire CLRN, welcome all to the meeting. The group introduced themselves briefly outlining what expertise they bring to the meeting.

There was a general support of using this opportunity to explore possibilities of working together to promote and support PPI involvement in health research. There was also an acknowledgement of PPI in research remaining a mystery to the majority.

Agreed that although dissemination of information about PPI role in research is important, it is likely to be challenging because of potentially competing goals and aims of not only different research organisations but also amongst the many and varying stakeholders within PPI. Through this Group there will be opportunities for shared learning therefore exchanging of information about each organisation's role would be of benefit.

Draft aims of the Group were discussed and agreed to be taken forward

Regardless of the objectives of each organisation and individuals involved, the underlying principle for this Group will be not to end up with a tick box exercise.

The meeting proposed to use each others' expertise and knowledge to establish mutually acceptable communication pathways between NHS research community and the public in order to:

- Enable the public to be aware of research being undertaken locally and offer them the opportunity to take part in it
- Offer those with experience of taking part in research and/or NHS services the opportunity to take part in supporting research teams when writing research proposals and devising better study recruitment plans
- Provide NHS researchers with a route for contacting a wide range of the public to seek lay advice

- Provide a route through which members of the public can feedback their concerns to NHS research community about getting involved with health research

Practical solutions for increasing public awareness were discussed:

Both LINKs confirmed that they have an opportunity to promote NHS research via existing infrastructure, e.g. websites, public meetings and special interest groups.

Example was provided such as using existing public meetings which attract anything up to 80 people, (including members of the public, representatives of voluntary organisations, health and social care professionals from all sectors), as an opportunity for the CLRN/RDS to provide some information for distribution or do a presentation.

Other options for communicating with the public include:

LINKs' weekly E-bulletins which are sent out to their members to keep them abreast of the latest developments and initiatives in health and social care and opportunities to become involved.

Quarterly newsletters – a glossy A4 size paper with news on events taken place with case studies and information on the progress of the LINK and initiatives organised by their stakeholders.

Locality meetings – LINK Area Coordinators in Essex regularly organise meetings for members residing in the 5 PCT areas (mid, north east, west, south east and south west Essex). There can be a slot in the agenda for the CLRN/RDS to deliver specific messages.

Social care seminars – one of the LINKs is in the process of setting up a series of seminars on the subject social care which could include CLRN/RDS agenda.

What is next? Setting provisional agenda for the ERG

It was agreed that the national agenda for research is very wide and the Group should focus on practical issues of public participation and influence. A number of areas were discussed and considered as being relevant to the future agenda of the ERG:

- To use existing and new publications to increase public knowledge of research in NHS and opportunities to get involved with the NHS R&D agenda;
 - To have a hyperlink to the National Health Institute of Research (NIHR) world of research added to the LINKs websites
 - To develop a message that can be used to engage the public in the NIHR agenda as a member of the NHS
- To initiate a working group to explore innovative ways for promoting studies that are carried out in the local NHS
- To develop a Code of Practice for the CLRN member NHS trusts emphasising research participants' experience

- To develop a local guidance outlining core expectations of research participants and consideration of practical arrangements that could enhance the experience of research
- To assist CLRN with a review of any complaints from research participants to provide learning for all organisations involved;
- To contribute to the discussions held by CLRN Local Specialty Groups, (these assess logistics and appropriateness of running individual studies in local NHS), and RDS's network of PPI staff and volunteers;
- To contribute to development of visual material, e.g. CLRN DVDs for patient waiting areas currently piloted etc., in collaboration with other regional research organisations;
- To develop a feedback form for existing members of LINKs (4 or 5 questions) to establish general level of awareness and attitude towards clinical research (LINK in Essex has agreed to test this via their members);
- Members of the ERG are invited to attend Essex & Hertfordshire Comprehensive Local Research Network (CLRN) Board meetings (14th October)
- To have a 'patients/participants view section regularly in 'The Researcher' (the CLRN newsletter).

Funding to compensate lay members for time spent on contributing to the ERG and associated travel expenses will be managed by the CLRN according to the NHS policy.

Specific actions to take forward:

- CLRN Office :
 - To collate comments from all present (by 20th May) and produce a summary **Action by: Oksana Hoile**
 - To arrange another meeting (provisionally agreed November 2010) **Action by: Oksana Hoile**
 - To keep all involved informed of any new developments **Action by: Oksana Hoile/Tracey Johns**
- Hertfordshire LINK - to make contact with The Centre for Research in Primary and Community Care (CRIPACC) PPI group (based at the University of Hertfordshire) who are very active in research in Hertfordshire **Action by: Monika Brzozowska-Neroth**
- Essex LINK – to consider options for surveying members **Action by: Wai Young**
- Notes from the meeting on 8th April - to obtain a copy of the notes collated by Dawn Bostok when met in Latton Bush **Action by: Julie Lockhart**
- **ACTION BY ALL** – to forward to Oksana Hoile examples of information describing their organisation role/ lay member expertise they bring to the Group and to identify people to invite for the future meetings.