

## **Patient and Public Involvement in Comprehensive Local Research Networks: A Discussion Paper.**

Aims of the paper:

- To stimulate thought and discussion at both national and local levels about the role and benefits of PPI in the activities of CLRN
- To aid CLRN staff and those patients/public members already being involved/consulted to develop their plans for PPI in their CLRN
- To examine the role of PPI in increasing accrual and recruitment

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### **Introduction**

The purpose of this paper is to consider a number of issues about Patient & Public Involvement (PPI) in Comprehensive Local Research Networks (CLRN) for the purpose of discussion and subsequent practical development work. The paper looks at some general issues about PPI in CLRN and then goes on to explore the potential in recruitment and accrual.

### **Background**

Different CLRN have discussed and planned a variety of approaches to implementing PPI, either following initial Coordinating Centre guidance closely, reinterpreting and developing variations on this approach, disagreeing with the approaches suggested and developing alternatives or have not yet begun to implement PPI.

It is important to remember that PPI is still very new compared to other more traditional health research activities. Whereas the value of PPI may be better developed in the context of health and social care research itself, its role, and therefore value in the context of the clinical networks is not as clear because there is less experience. For example, given that most clinical research projects that reach CLRN for support are already adopted onto the Portfolio, and can therefore no longer be altered, where and how can patients and public have influence for patient benefit?

There are further challenges for the CCRN compared to the Topic Networks because of the diversity of research topics handled and the consequent need for greater diversity in patient expertise if PPI is to be helpful.

PPI in any context is usually best seen as work in continued evolution, starting modestly

by developing constructive and mutually helpful dialogues between professionals, patients and carers where everyone learns, and aiming to expand and develop activities in a considered and structured way over time. One of the paradoxes of PPI is that often these dialogues are needed to develop PPI well in an organisation.

## Added value

**Given the purpose of CLRNs, how can PPI in their activities add value for patient benefit in the long term?**

The developmental and evolutionary nature of PPI tends to be, not only helping us understand patient perspectives in the aims of the clinical research world, but also improving the processes by which these aims are achieved. That is, there is a learning curve for both patients and CLRN network staff in developing a new kind of relationship that will enable organisations to be relevant to their beneficiaries.

We need to find out how to do PPI well in CLRNs by applying it where we think it would be effective, but being willing to review the process with patients, carers and members of the public, and improve as we go along. This means that there are real opportunities for innovation and creative thinking, provided plans are within realistic parameters and address the most relevant end points for CLRNs and patients.

In doing this there is a range of considerations in planning:

- The **purpose and remit** of a CLRN
- The **different operational functions** of a CLRN
- **Resources** available; not duplicating what other organisations are doing but considering the benefits of local partnerships to support PPI activity in research across the local area.
- **Sustainability**
- The **demands** of deadlines/targets (often external) and recognition of the need for flexibility/open-mindedness by all involved.

There are also considerations in how to approach PPI:

- Utilising PPI to develop, build on and **evolve processes** to contribute to the achievement of CLRN tasks.
- **A focus on long term NHS patient benefit** as the ultimate end point
- Being clear about the **different roles and activities** in which patients and public perspectives are likely to have leverage and add value to the above

- Being clear about **managing expectations** both ways between patients and professionals, and allowing space for dialogue, choice and development.
- Being aware there are choices to be made about the different **levels** of involvement; from consultation to partnership, to patient leadership according to tasks and what is feasible for CLRN.

**Question to consider: Do these descriptions best describe the CLRN situation and issues?**

The remainder of the paper sets out to explore the different facets of PPI in CLRN providing some examples along the following lines:

- The different roles and functions in PPI
- Tackling issues such as recruitment and retention
- As advisors, door openers and in training

The final section provides a summary and some useful contacts.

## **The different facets of PPI in CLRN**

It is important to consider that PPI can mean different kinds of input and relationship at different organisational levels and in different network activities. PPI is never one thing, and there are likely to be different ways to add value for different levels and types of activity. Most important is being clear about the task at hand, then what kind of perspectives, experience, and expertise are needed to achieve it.

It slightly complicates the issue that as professionals we cannot always anticipate the full scope of potential added value before involvement is attempted simply because we are necessarily limited to a professional perspective. There are many examples in the research world where patients have asked to be involved in an activity because they can see value in

Example: In one PCRN LRN two patient/carers were recruited through an open recruitment process to the management group. At one of the management group meetings, they considered some suggestions in a paper as to how patients and carers might be able to help out when there were difficulties with recruitment in a project. The patients/carers felt that it would be more helpful for them to be involved in looking at all research protocols adopted onto the Portfolio to make any comments and suggestions as to how they might be approached as part of the development of a recruitment plan. It was agreed to take this forward in a systematic way.

doing so, whereas the professionals might not have previously considered the merit of this involvement.

### **Examples of different roles for PPI in CLRN**

- **CRN CC Guidance has suggested involving patients and public at Board and/or management group level. What does this mean?**

The role of the CLRN Board is advising the work of a network by bringing in stakeholder organisations. It might be appropriate here to involve public members who are already involved, or are willing to be involved with the new Local Involvement Networks (LINKs) which have a health service scrutiny role locally, although at time of writing they are very much in development<sup>1</sup>.

So on a Board the PPI role might concern:

- being part of overseeing the general direction of CLRN strategy and operation, particularly with regard to PPI,
- considering transparency in the use of publicly funded resources,
- helping to ensure PPI is being appropriately considered,
- helping to ensure priorities agreed reflect the interests of patients and public, and
- making suggestions about the value of PPI in operational aspects of the network.

**Question to consider: What skills, experiences and knowledge might a member of the public or a patient require to function well on a CLRN committee or board?**

Patients and public members on the Board could also be involved in other aspects of CLRN work. On the other hand other work may require different individuals to be involved. Some other examples of potential PPI pertinent to the work of CLRN whether or not they involve the same people on the CLRN Board are:

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<sup>1</sup> Local Involvement Networks (LINKs) aim to give citizens a stronger voice in how their health and social care services are delivered. Run by local individuals and groups and independently supported - the role of LINKs is to find out what people want, monitor local services and to use their powers to hold them to account. LINKs will be established in most areas by the end of 2008. Each local authority (that provides social services) has been given funding and is under a legal duty to make contractual arrangements that enable LINK activities to take place. See [http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/dh\\_076366](http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/dh_076366)

- **Commenting on difficult or potentially problematic proposals where a patient perspective would help a decision.** For example, this could concern:
  - Local feasibility due to the quality and nature of the study protocol/design.
  - Suggestions for local approaches to proceeding with this type of study and recruitment plans.

This role requires some patient/public expertise through experience. The recruitment of patients/carers/members of the public to local Specialty Groups or establishing links between these groups and patient organisations could be a helpful way of obtaining these perspectives. It is also likely to be appropriate for those patients/carers/members of the public involved across Specialty Groups to have the opportunity to form their own group, not only for support and shared learning, but also to form the basis of a reference group to support other CLRN activities. Resources available may determine what can be done, but such groups could be resourced by partnerships of research organisations in the area and serve the range of PPI needs.

- **PPI networking:** All NIHR CRN LRNs have a role in helping to promote patient engagement in relation to research in general as well as in respect of specific trials locally. It is about investing in the quality and relevance of research for the future by making links with patient groups to raise awareness of research and the potential for future involvement as trial participants, or as research partners.
  - Working with Topic LRNs, PCRN LRNs, and RDS, and other organisations across the geographical area to increase knowledge of local patient/public groups and networks.
  - Taking occasional enquiries from patients, carers and members of the public who might want to be involved and signposting them to organisations that can help with PPI opportunities locally e.g. RDS, local CTU, local research charity groups/branches.
  - Helping to develop individual patients and carers already involved with the CLRN by signposting them to opportunities in other organisations, or in further education for example.
  - Links with RDS are likely to be important in helping to influence for better quality research for which it is easier to recruit in the future. This should be in the interests of CLRNs and local patients/members of the public. Links could helpfully be established between PPI activity in the CLRN and the RDS to this end.

## **PPI in recruitment and retention of research participants**

Outside industry-led research, the practice of developing a strategy for effective recruitment and retention of research participants for individual studies, surprisingly, is relatively patchy. The NIHR 'Best Research for Best Health' Strategy emphasises the importance of ensuring successful completion of studies, whilst their completion depends on the robustness of 'feasibility' assessments that would ideally be carried out before studies are funded.

The first-hand experience of NHS services and treatments places patients and public in a unique position to support CLRNs in developing effective recruitment and retention strategies. Combining that experience with the NHS staff's knowledge of clinical pathways and flows could enhance the work of CLRNs and ensure the satisfactory completion of research projects.

### **Patients/the public as trainers and advisors of research and CLRN staff in approaches to reaching particular patient groups.**

It is important that CLRNs develop an understanding of the patient/voluntary groups that exist and operate on their patches; and what knowledge and expertise could become available through these. This would allow both, PPI and CLRNs, to benefit from varied and flexible options for engagement.

Accessing relevant PPI experience and expertise could be achieved through word of mouth and existing local patients and voluntary groups. Lists of such groups are relatively easy to obtain via Strategic Health Authorities, PCTs, District Voluntary Services offices, and the Association for Medical Research Charities (AMRC) for example.

Patients and the public could be interested in being part of a training team and in the same way they contribute with real life scenarios in medical and nursing education.

CLRNs may find it useful to explore with their local higher education institutions what opportunities for the above are out there. At the time of writing, the national provision of PPI related training and 'learning opportunities' such as these are currently being considered by the NIHR CRN CC Workforce Development team through a special working group on PPI.

### **Patients and carers as trial advocates**

CLRNs could tap into a new world of support for studies through encouraging an environment where patients/members of the public with an interest in research could become effective advocates for individual trials and the local research agenda as a whole.

Some patients may be interested in being permanently affiliated with a particular Local Specialty Group; others may become engaged only for the duration of a trial. Many may feel particularly passionate about a specific research topic. There are some good examples where a patient/member of the public has been buddied up/partnered with a researcher/research team, to work as a team throughout the life of a study providing opportunities from advertising for participants, to monitoring progress, to reporting outcomes, in a lay-friendly language, targeting the right people.

Patients and the public could offer their knowledge of the best places for displaying information about research studies that are open to recruitment, help to develop studies' promotional material and run support groups for research participants. As relationships and skills mature, PPI could help CLRN in delivering presentations for local communities aimed to demystify research and raise awareness about the benefits and importance of participation in NIHR portfolio studies. Building this 'critical mass' outside the immediate professional environment could help CLRNs raise awareness amongst local healthcare staff about what types of studies local people are interested and willing to take part in.

Example: A local patient charity with a national membership, approached a CLRN with a suggestion to include information about the remit and purpose of the NIHR networks in their regular newsletter. The newsletter has a national coverage and is a main source of information for patients with thyroid illnesses about new developments in clinical research, treatments and care. The charity also has a website which allows member interaction and facilitation of appeals. This helped to raise awareness of CLRNs amongst the readership so individuals could approach and engage with their local networks on a more informed basis.

### **Utilising patient networks and organisations**

Through engagement of local patients, CLRNs are likely to find themselves in a position to access much wider networks and support which, otherwise, might not be obvious.

## Conclusion

In all of this it is important to remember that PPI has to evolve, and it is not just about the systems set up but also the relationships and the learning that is developed through dialogue with patients and the public.

PPI can be driven from the grassroots, not just by the researchers and research organisations that seek it. Some of the best examples of this in the networks, are where patient groups have been set up, and over time they have been able to define and develop their own roles and influence for involvement where **they** see it to be important and significant for long term NHS patient benefit. Understanding of the research environment has been developed alongside the opportunity for choice and empowerment. Ultimately it is the quality of the dialogue which makes the difference.

For example: one CLRN worked with other local networks, research centres and their local Research Design Service to put on a successful local research event for patients & public and research professionals on a Saturday. Out of this a single reference group and a wider network of people that the different research organisations can interact with are emerging. To the patients involved there was a wider frame of reference than just the CLRN. They wanted to interact with their local research environment with all its range of activities. There are clearly potential long term benefits, and for the CLRN, a local resource for all kinds of interaction over a range of issues such as those already mentioned.

It is important to define the role of PPI for it to be meaningful. PPI is about improving processes as well as outcomes in clinical research. Fitting PPI into what we already do will not in the long term benefit what we are trying to achieve. We must be prepared to change the way we do things to embrace PPI so that our systems and process are more geared towards patients and patient centred outcomes in the research networks. After all, in the networks we are working within the NIHR research strategy<sup>2</sup> that has patients at its centre.

For example: There are many instances of patients or carers relating how they have been involved in a management of steering group where they have not understood what someone has been saying because of the specialised language used. When the speaker has been asked by the patient/carer to explain it again in plain English, other professional around the room appeared to breathe a sigh of relief, as they had not understood it either. Sometimes PPI can improve the way we do things for everybody.

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<sup>2</sup> Best Research for Best Health DH (2006)

## Links, contacts and resources

There are helpful resources already available that will give guidance on principles of good practice. We particularly recommend INVOLVE publications as a starting point, although they do not address the specifics of Local Research Network activity. The leaflet '**Good practice in active public involvement in research**' is a very concise initial at 'a glance guide', See <http://www.invo.org.uk/pdfs/GoodPracticeD3.pdf> . Their guide for patients and public 'Public Information Pack' is also an excellent starting point for patients interested in getting involved in research.

A very good recent publication geared towards PPI in the NHS in general is '**Real Involvement: Working with People to Improve Health Services**' (2008) DH. See [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_089787](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089787) This goes into good practice in involvement in the various processes, such as meetings and focus groups that often take place in the NHS.

Also recommended is attending the NIHR CRN national training on patient and public involvement in research. See:

<http://www.crncc.nihr.ac.uk/index/training/courses/ppi.html>

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