UK Clinical Research Network

UKCRN Patient & Public Involvement

Strategic Plan: 2006-2008

UKCRN Coordinating Centre
Arthington House
Cookridge Hospital
Hospital Lane
Leeds LS16 6QB

Dr Marianne Miles
UKCRN Patient & Public Involvement Lead
Telephone: 0113 392 4398; Fax: 0113 392 4349
Email: m.miles@ukcrn.org.uk

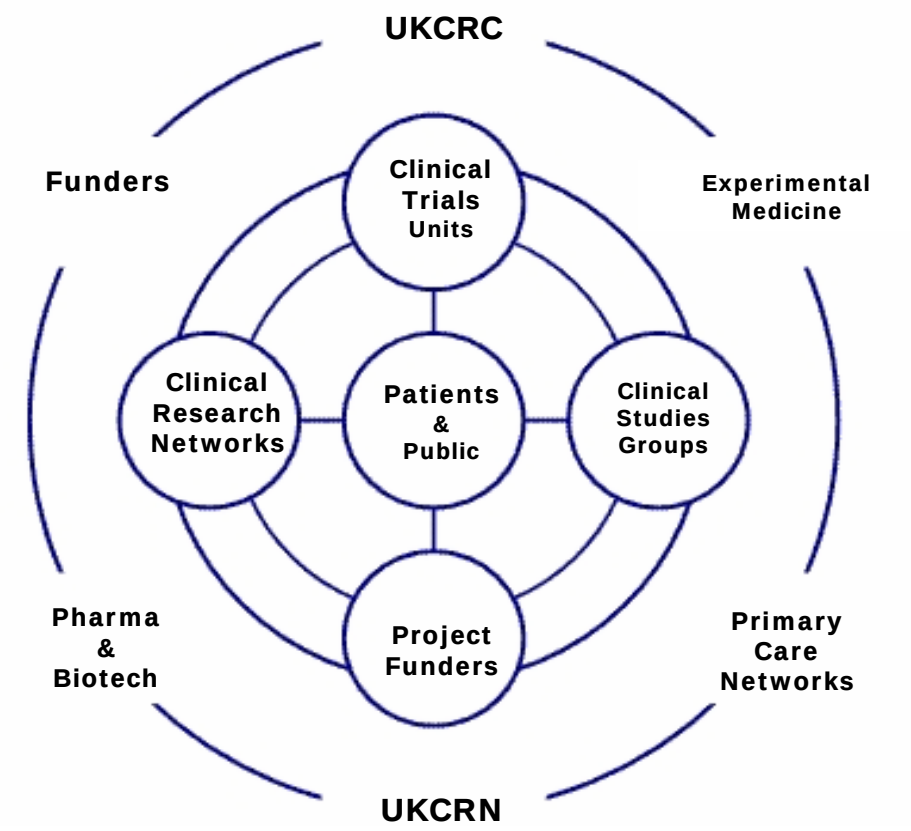
www.ukcrn.org.uk

Contents

1. Background

The UK Clinical Research Network (UKCRN) is one of the key components of the UK Clinical Research Collaboration (UKCRC). UKCRC is a partnership of organisations including governmental, public sector, charitable and industrial funding bodies, working to establish the UK as a world leader in clinical research. UKCRN is in place to facilitate the conduct of clinical trials and other well-designed studies. It is tasked with developing a world class infrastructure to support clinical research in the UK, with the ultimate aim of improving patient care and allowing people across the country access to the best treatment. The UKCRN believes that active patient and public involvement (PPI) is needed and essential if it is to deliver a programme of research which directly reflects the priorities, needs and views of patients and the public. Therefore a key theme that runs throughout its work is PPI. Indeed PPI is central to all UKCRN relationships, as shown below in Figure 1.

Figure 1: UKCRN relationships



UKCRN is building on the work of the established Research Networks (cancer and mental health), and the more recently established Research Networks in four priority topics: dementias and neurodegenerative diseases, diabetes, medicines for children, and stroke, together with a new Primary Care Research Network (PCRN) in England. In order to provide support to clinical research in all diseases and areas of health care, UKCRN is now developing the National Institute for Health Research Comprehensive Research Network (NIHR CRN) which will cover the whole of England. The UKCRN Coordinating Centre is also working with the Devolved Administrations which are undertaking parallel activities to ensure UK wide provision of support for clinical research. By working closely with UKCRC, and in partnership with patients/the public, clinicians, health care professionals, researchers and academics, UKCRN aims to produce guidance that ensures active and effective PPI, addresses patient/public issues, and reflects their views, to improve clinical research across the UK. This document sets out the UKCRN PPI Strategy, with a focus on the Topic-Specific Clinical Research Networks (TCRNs) and PCRN, to

ensure that those working across the organisation are committed to effective PPI to inform the research programme. As UKCRN becomes clearer about the shape and organisation of the NIHR CRN, consideration will be given to appropriate PPI in this evolving area.

2. Why Involve Patients and the Public?

Patients play a fundamental role as participants in research studies, but this is not the only role they should have. Research is about asking and answering questions and patients/the public should be able to contribute to the development of those questions. The methods used by researchers should be transparent to patients, and the outcome measures used by researchers should include measures considered to be important by patients. A research question thought to be important by researchers might have different importance for patients, emphasising the need for PPI to be integrated as part of the research process. Clinical studies developed in partnership, involving patients/the public, researchers, clinicians and healthcare professionals, are likely to be studies patients will be more likely to want to enter. From the patients view and from UKCRN's view, timely accrual to studies is crucial to ensure that results and new treatments, or better standards of care, can be delivered more speedily.

Patients and members of the public who become involved in clinical research have well recognised reasons for wanting to get involved:

- a sense of giving something back
- recognition of their own experience and its value in shaping the future
- a desire to change systems to make them better based on personal experiences
- a wish to see the development of new treatments to benefit patients

At the same time they recognise that they are taking on responsibilities and they need to be supported appropriately if these are to be fulfilled.

3. The UKCRN Vision for Patient and Public Involvement

UKCRN's vision for active PPI is that it should become embedded throughout the UKCRN as part of mainstream clinical research activity, delivery and performance. By adopting a proactive and inclusive approach to effectively involving patients/the public at all levels, the aim is to achieve a portfolio of the highest quality clinical research studies, reflecting the priorities and needs of patients/the public, with an ultimate goal of ensuring improved patient treatment and care in the UK. Involved patients and members of the public also have an important role as ambassadors for clinical research, raising awareness, breaking down barriers (whether real or perceived) and helping to improve understanding so that participation in research progresses in a fully informed way.

Initial plans relate to achieving successful PPI across those Networks already launched: the Topic-Specific Clinical Research Networks (TCRNs), the PCRN, and also the UKCRC Framework for Experimental Medicine. However, the creation in April 2007, of the NIHR CRN in England, will encompass the full spectrum of disease and clinical need. UKCRN will develop the NIHR CRN and this requires immediate thought about best practice of PPI in clinical research, which supports PPI across all disease areas (similar to the PCRN, Experimental Medicine and the Medicines for Children Research Network). Therefore PPI best practices that are both disease-specific where necessary to meet specific needs, and generic to allow cross-working where practical, need to be established.

3.1 Core Principles

The UKCRN PPI Strategy is built on the following principles:

- UKCRN believes that patients/the public should be actively involved at all levels of clinical research activity, and that procedures for involving them must be clear and transparent.
- There should be commitment from each Coordinating Centre (UKCRN/PCRN and TCRNs) and the clinicians, researchers, healthcare professionals and academics working across the Networks, to the principle of PPI in clinical research at all stages and at all levels.
- Patients/the public should have access to relevant information about UKCRN, the TCRNs and PCRN, and other research partners (e.g. Clinical Trial Units) and related research activities, to support their involvement.
- Patients/the public should be supported to ensure effective and active involvement.
- Professionals working within the UKCRN should be encouraged and supported to enable PPI in their work.

3.2 Key Objectives

Alongside these core principles, a set of key objectives has been identified to provide a frame of reference for the UKCRN PPI Workstream. These are:

- To coordinate the planning and development of a strategy for PPI in clinical research in the UK, initially across the TCRNs/PCRN, taking into account other PPI initiatives and activities within the Devolved Administrations, and working towards the development of a programme of PPI in the NIHR CRN.
- To positively influence and increase public awareness of clinical research, with UKCRC.
- To increase researchers' awareness of the possible benefits of PPI in research, by suggesting ways of working with them and supporting them to achieve effective PPI.
- To identify and address barriers to involvement from the perspective of both professionals and patients/the public.
- To enhance the overall quality and relevance of UK clinical research for the benefit of patients.

The UKCRN PPI Strategy has been developed, discussed and shared with the TCRNs/PCRN, and the Devolved Administrations. It will also be disseminated to patient/public groups being set up within the Research Networks, to ensure the content of the strategy, as it continues to develop, benefits from the experience and expertise of relevant stakeholders.

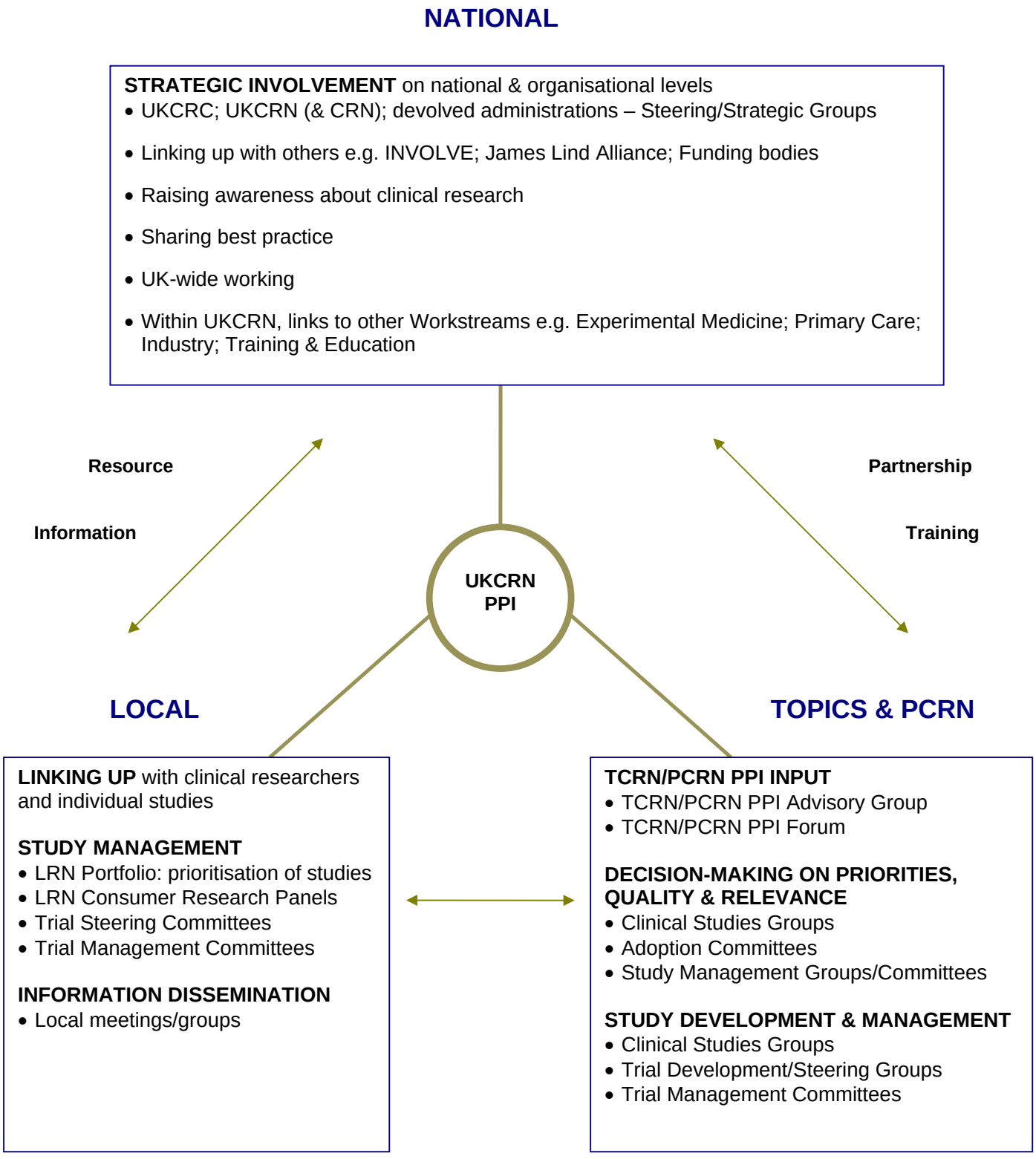
4. Patient and Public Involvement across UKCRN

A number of potential mechanisms, structures and levels exist to involve patients/the public, namely:

- *Strategic direction, oversight and decision-making:* by engaging with patients/the public as partners in the strategic management of research activities, via membership of Operational Steering Groups, Strategic Planning Groups, Working/other Groups.
- *Research and study development:* by ensuring that patient/public membership of Clinical Studies Groups, Trial Development Groups and Adoption Committees takes place in a supported and informed manner, allowing representatives to develop a full participation as equals in the processes.
- *Study funding:* by liaising with clinical research funding bodies and their involved patients/public to ensure that their needs for effective PPI in study design and peer review are met.
- *Study management*: by directly involving patients/the public in the running of clinical studies, via Local Research Networks, Trial Steering Committees and Trial Management Groups.

These are summarised in Figure 2.

Figure 2: PPI in clinical research – Where?



5. Commitment

UKCRN is committed to engaging with patients and the public as key stakeholders, in its strategic direction and decision-making and in the design and conduct of clinical trials and other well-designed clinical studies. By empowering patients and the public to work as partners alongside professionals, UKCRN recognises that it will ultimately deliver benefits to patients through better quality research. To support PPI in clinical research, a number of key working relations have already been established, described below.

5.1 Working in Partnership with UKCRC

UKCRC and UKCRN, with all UKCRC partners (including INVOLVE, the Medical Research Council, the Royal College of Physicians, the National Institute for Health and Clinical Excellence, the Association of Medical Research Charities, and the Wellcome Trust) have set up a UKCRC PPI Project Group with individuals who lead on PPI in each organisation. This Group will identify areas/projects which add value to current PPI activities within individual organisations at a national level, and ensure that practices are not duplicated. The Group plans to address high profile issues regarding PPI within clinical research that cannot easily be tackled by individual organisations. Four initial projects have been identified, described in Appendix 1. It is important that the work of the UKCRN is compatible with UKCRC's PPI activities.

5.2 Support within the UKCRN

Within the UKCRN Coordinating Centre, the PPI Lead will coordinate PPI activities across the Networks, working closely with the UKCRN Joint Director overseeing this workstream, and the UKCRN Associate Director for PPI. The PCRN will be supported directly via the UKCRN Coordinating Centre by the PPI and Primary Care Leads. The six TCRNs each have an established Coordinating Centre, within which there are committed resources to support PPI, with a dedicated post in place. In addition, each individual topic will establish its own PPI Expert Advisory/Reference Group, and Patient/Public Forum (see 6.1). The current structure of the UKCRN PPI workstream is shown in the diagram in Appendix 2, in addition to PPI Leads based in the TCRNs, and other key stakeholders.

A UKCRN PPI Working Group has been established to bring together the TCRN PPI Leads, as well as representatives from INVOLVE, and the Devolved Administrations. This Group will discuss and review issues related to the development, implementation and evaluation of the UKCRN PPI strategy, ensuring knowledge of other PPI activities occurring outside UKCRN. The Terms of Reference and composition of the Group are detailed in Appendix 3. In between formal meetings, more regular communication will occur between the UKCRN PPI Lead and TCRN PPI postholders across the Networks, with a view to agreeing both topic-specific, as well as generic PPI projects, where appropriate. As soon as practicable a nominated member of each TCRN's group of involved patients/public forum will join the Group.

The structure of the NIHR CRN is in the process of being finalised. It will consist of a number of Comprehensive Local Research Networks (CLRNs) covering the whole of England. CLRNs will be the primary vehicle for providing NHS service support for research. The structure and organisation of each CLRN will vary according to the demographic make-up of the local population and the nature of the service providers within it. However each CLRN will have a management structure consisting of an Executive and a Board, and patient/public membership of such structures will be considered alongside the professional membership.

5.3 Working in Partnership with INVOLVE

A new post, Public Involvement Advisor, has been created within INVOLVE (a UKCRC partner) to focus half-time on the promotion of public involvement in clinical research. INVOLVE is a national advisory group, funded by the National Institute for Health Research, which aims to promote and support active public involvement in NHS, public health and social care research. This post includes working with the UKCRN PPI lead.

5.4 Financial Resources
It is recognised that there are financial implications in establishing PPI within each TCRN/PCRN and that current financial arrangements differ. A small budget is held within UKCRN Coordinating Centre to facilitate generic activity. The NCRN has core funding to enable expenses and attendance allowances for the members of its Consumer Liaison Group (representatives on Clinical Studies Groups), and to support the group's work. At this stage, other topics have a limited PPI budget. UKCRN is considering the resource implications in relation to the principle of offering payment/honoraria (reimbursement of all out-of-pocket expenses is universally agreed).

6. Short-Term Key Targets

The main short-term targets for the UKCRN are:

6.1 Establishment of Topic-Specific PPI Expert Advisory/Reference Group
Establishment of a PPI Expert Advisory or Reference Group within each topic. This Group will be led by the TCRN Associate Director for PPI and the TCRN PPI post, and consisting of experts who have experience and/or an interest in actively involving patients/the public in research (including clinicians, researchers, healthcare professionals, medical research charity representatives, and ideally, PPI 'champions' from the Local Research Networks); and people directly affected by these conditions with some experience of being actively involved in research. A similar Group should be established for the PCRN. This Group will lead and advise on the development and implementation of PPI and monitor its progress. Each TCRN and the PCRN should advertise for members of the Group, and should agree Terms of Reference, adapting generic Terms provided by UKCRN.

Key target:
- Establish Group, plan first meeting, and agree Terms of Reference within each TCRN and the PCRN by May 2007.

6.2 Establishment of Topic-Specific PPI Forums
Establishment of a 'Forum' of patients/members of the public, within each topic, consisting of people directly affected by these conditions who are also members of Clinical Studies Groups, Local Research Network activities, Study Adoption Committees, serve on study Steering/Management Groups and other Groups/structures. As well as supporting Forum members to become actively involved by directly engaging with clinicians, researchers and healthcare professionals via key structures and groups, this Forum will have a number of other functions, including:
- Involvement in the production and dissemination of clinical research information via websites, meetings, conferences and other channels of communication.
- A channel through which best practice guidelines for PPI are shared within the TCRN and, through UKCRN, with others.
- Discussion of research ideas, interests on a 'national level'.
- A role in induction/training programmes for fellow members, and clinicians/researchers/ healthcare professionals.
- A supportive environment for members.

Key targets:
- Recruit to, and establish TCRN/PCRN PPI Forums, identify a suitable Chair for each Forum, and define Terms of Reference within each TCRN and the PCRN by June 2007.
- Establish necessary supporting paperwork including 'Roles & Responsibilities', transparent payment guidance, and an induction/training plan by June 2007.

- Establish a template for the development of suitable databases to allow the collection and storage of data about those interested in becoming actively involved e.g. contacts/personal details/areas of interest and expertise. Template by April 2007 and then ongoing.
- Allocate patients/members of the public (minimum of two people) to each Clinical Studies Group, and each TCRN/PCRN Operational Steering Group in the first instance, with a view to expanding membership to other structures (e.g. UKCRN OSG) as soon as possible once recruitment has started.
- Identify and involve professional mentors as appropriate to the needs of the TCRN/PCRN and its involved patients/public. Clarity on the role of a mentor to be agreed and supported by the production of guidance by May 2007, followed in June 2007 by a 'needs analysis' to identify areas of support for mentors.

To meet the above targets, the actions required to achieve these should be generic where possible across the TCRNs and PCRN, ensuring best practice is shared, and duplication of effort is avoided. UKCRN will liaise with TCRN PPI posts individually and via the UKCRN PPI Working Group, to discuss who may lead on individual pieces of work.

The establishment of a joint PPI Forum across topics should also be considered, for a number of reasons: to join up PPI activities across Local Research Networks in the same geographical area; to support those Networks that are not disease-specific e.g. MCRN and PCRN; to support PPI across the NIHR CRN. Prior to the establishment of such a Forum, a mapping exercise of PPI existing groups and resources should be considered, to allow a clearer understanding of the 'PPI gaps' (both geographical in terms of structures/resource, and PPI experience (disease/topic) in terms of expertise), ensuring a partnership effort with those identified structures/areas of expertise already in place.

6.3 Support for Clinicians, Researchers, and Healthcare Professionals

It is essential that those professionals who will be expected to actively involve patients and members of the public in their clinical research activities are offered appropriate support from the onset. For this reason, as an initial project, the views of a sample of professionals across the Research Networks have been collected, in relation to the value of PPI in clinical research, allowing opportunity for barriers/concerns to be identified, in order for appropriate support to be defined.

Key targets:

- Interviews of up to ten professionals in each TCRN/PCRN for their views and expectations of PPI were completed in November 2006.
- Collate all comments, for further discussion amongst UKCRN PPI Working Group members, and the UKCRN Coordinating Centre, to inform next steps by March 2007.
- Develop action plan to support clinicians, researchers and healthcare professionals to actively involve patients/the public in their activities by May 2007.

6.4 Information Resources

Preparation of information resources (written, telephone-based, web-based) for patients/members of the public about clinical trials in general, and topic-specific clinical research is necessary. Such information should also consider the needs of trial participants. A suite of information is being developed in partnership with a range of organisations including the Association for Medical Research Charities (AMRC) and the James Lind Alliance (JLA), targeting patients/the public. Initial examples are a leaflet 'Understanding Clinical Trials – What they are and what they're not', and a booklet 'Understanding Clinical Trials'. The majority of such resources will be piloted initially across the Networks. Expansion of generic information for patients/the public will also be necessary e.g. 'Getting Involved in Clinical Research'; 'What is a Clinical Studies Group/LRN/Adoption Panel?'. In addition to the production of generic

information about clinical research and PPI, some topic-specific information will need to be developed, working with relevant partner organisation such as AMRC members.

Key targets:
- Leaflet: 'Getting Involved in Clinical Research' - launched at INVOLVE national conference on September 6/7 2006.
- Booklet: 'Understanding Clinical Trials' - launched in December 2006.
- Leaflet: 'Clinical Trials – What they are and what they're not' – launch by May 2007.

6.5 UKCRN Payment Guidance
Development of best practice, ensuring transparency and clarity, in relation to the principle of offering payment for PPI in clinical research. Ongoing consideration of resources to support PPI in clinical research.

Key targets:
- Clarify resourcing implications of this guidance – March 2007.
- Agree and produce initial UKCRN guidance on payment by March/April 2007.
- Seek additional resources if required, and/or implement guidance by June 2007.

6.6 Training and Education
Provision of appropriate courses for patients/the public and professionals, including the importance and benefits of PPI in research, as well as information to ensure a better understanding of clinical research.

Key targets:
- Agreement of a number of key courses (e.g. Introduction to Clinical Research; Developing Best Practice for PPI in Clinical Research; Research Methodology) which were launched in November 2006.
- Preparation of a plan (ongoing) for training and education needs for patients/public and professionals, ensuring the provision of both generic (UKCRN) and topic-specific (TCRN/PCRN) information and courses by April 2007.

6.7 Joined-up PPI
Establish a PPI Think-Tank, working with key UKCRC partners and the devolved administrations with some experience and/or expertise of PPI in research, to assist with the ongoing development of the UKCRN's PPI Strategy. This may be based on bringing together the PPI Working Group for ad hoc one-day events with additional input from professionals, involved patients and external advisers.

Key target:
- Agree and invite membership by April 2007, for the event to take place in May/June 2007.

7. Future Challenges and Long Term Developments

The UKCRN recognises that PPI is developmental, with the integration of PPI into the activities of the newer Research Networks just beginning to take place. Even in the well-established Networks (cancer and mental health) involvement is still developing so new experiences are being brought to bear all the time. UKCRN intends to build on existing PPI work, and develop new opportunities for all Networks, supporting PPI activities in the following ways:

Demonstrating the benefits of PPI across the Networks

- Raise awareness of the benefits of PPI to achieve understanding, agreement and co-operation amongst all involved in the work of UKCRN, and all relevant stakeholders/partners.

Information and Best Practice

- Achieve greater consistency and continual improvement in relation to the extent to which patients and the public are involved in activities.
- Offer guidance, and appropriate levels of ongoing support (e.g. mentoring).
- Provision and dissemination of lay summaries of studies in the UKCRN portfolio, and of research results.
- Preparation of guidelines for PPI in clinical research, building on/adapting existing guidelines, for patients/members of the public, and researchers.
- Share best practice and lessons learned from involving patients/the public across the different parts of UKCRN's workstreams.

Feedback

- Seek feedback on, and review the format and content of support, inductions, training opportunities, and information provided, to ensure these meet the needs of patients/the public.
- Develop methods for collecting patient/public views and experiences about being actively involved in the work of the Networks, and as actual participants of clinical trials, to inform all processes.

Representation

- Focus recruitment of patients/the public to ensure involvement of under-represented geographical areas, and groups, including people from minority ethnic backgrounds, carers, younger patients, and consider carefully how to fully take account of the views of a diverse group of people.

Future PPI practice

- Consider the ongoing resource implications in establishing a fully effective PPI programme.
- Establish appropriate PPI in the collaborative work being developed between UKCRN and the healthcare industry.
- Develop processes and methods to evaluate the successes and limitations of PPI at the TCRN, PCRN and CRN level, in relation to both process of PPI (for example performance indicators, to provide incentives for Network staff as well as making PPI a core part of the work of the Networks), and impact on clinical research, to inform ongoing and future practice.

In addition to supporting PPI in both the more established, and the newer Networks, plans to establish generic PPI best practice in clinical research across the NIHR CRN are being considered. There is a need to ensure that the learning and the value of TCRN/PCRN involvement also benefits all the other diseases with a clinical research need that the NIHR CRN will be supporting. More information will be available as these plans evolve.

Appendix 1

The Partner organisations of the UK Clinical Research Collaboration (UKCRC) illustrate a variety of different approaches to patient and public involvement but there are many core issues of common interest where a joint approach to tackling challenges is being taken.

Four initial projects have been identified and agreed by the UKCRC PPI Project Group:

1. 'People in Research'

The original idea behind this project came from 2 frequently asked questions. Members of the public asking 'How can I get involved?' and research organisations or projects asking 'How do we find people who want to get involved? INVOLVE is leading on the development of 'People in Research' (www.peopleinresearch.org), a UKCRC web based project that aims to help members of the public make contact with organisations that want to actively involve people in clinical research.

2. Developing standard criteria for assessing patient and public involvement in research applications

This project aims to address the question – how can research funders effectively judge the quality of patient and public involvement in research proposals? It intends to develop, pilot and evaluate some 'patient and public involvement judgment criteria' as well as developing associated guidance for research funders. The Association of Medical Research Charities is leading on this project for the UKCRC.

3. Including patient and public involvement in research contracts

This project will focus on looking at research contracts, both those that are issued by research project funders and those that are issued to individual researchers. The Project Group is working with the UK Health Departments to ensure that the contracts they issue encourage appropriate patient and public involvement as a prerequisite of funding. This project could lead to a UK wide adoption of such an approach by other research funders.

4. Developing the evidence base

There is a growing body of literature that describes different models of good practice in patient and public involvement in research projects, programmes and organisations. However, as yet there is little research that has been done to systematically evaluate the impact of patient and public involvement in research. The Project Group is developing a log of information about work that is going on in this area so that a more coherent approach can be taken towards developing the evidence base.

Appendix 2

UKCRN Patient & Public Involvement Team

UKCRN CC

Co Director responsible for PPI: **Janet Darbyshire**
UKCRN Assistant Director for Clinical Trials: **Maxine Stead**
UKCRN Associate Director: **Roger Wilson**
UKCRN PPI Lead: **Marianne Miles**

TCRN PPI Leads

National Cancer Research Network (NCRN)

- Consumer Lead: Karen Inns

Medicines for Children Research Network (MCRN)

- Consumer Liaison Officer: Jenny Preston

Diabetes Research Network (DRN)

- Consumer Liaison Officer: Martin Lodemore

Mental Health Research Network (MHRN)

- Service User Research Group England (SURGE) Manager: Jan Wallcraft

Dementias & Neurodegenerative Diseases Research Network (DeNDRoN)

- PPI Coordinator: Terry McGrath

Stroke Research Network (SRN)

- PPI Manager: Zena Lethbridge

Primary Care Research Network (PCRN)

- PPI Lead: Marianne Miles
- PC Research Manager: Patricia Ellis

Devolved Administrations

- CRC Cymru: Roger Duncan
- NI R&D: Michael Neely
- Scottish Executive Health Dept: Moria Nolan

Other stakeholders

UKCRC

- Programme Manager: Philippa Yeeles
- Communications Programme Manager: Matthew Hallsworth

INVOLVE

- Public Involvement Adviser: Maryrose Tarpey

Appendix 3

Terms of Reference

UKCRN Patient and Public Involvement Working Group

Reports to:

- UKCRC PPI Project Group
- UKCRN Management Group

Membership:

- UKCRN Co-Director
- UKCRN Associate Director for PPI (Chair)
- UKCRN PPI Lead
- DeNDRoN PPI Coordinator
- DRN Consumer Liaison Officer
- MCRN Consumer Liaison Officer
- SURGE (MHRN) representation
- NCRN Consumer Lead
- PCRN representation
- SRN Patient & Carer Involvement Manager
- TCRN PPI Forum/CLG Chairs
- UKCRC PPI Programme Manager
- CRC Cymru (Wales) representation
- Northern Ireland CRN representation
- Scotland CRN representation
- INVOLVE Director or Public Involvement Adviser

Terms of Reference:

1. To contribute to the development, implementation and review of the UKCRN PPI Annual and Strategic plans
2. To oversee the effective operational delivery of UKCRN PPI activities and develop common systems of best practice which ensure transparency and consistency, yet provide flexibility to respond to topic requirements
3. To discuss, monitor and review issues related to the implementation, development and evaluation of UKCRN PPI
4. To consider ways of improving, supporting and sustaining effective PPI activities across UKCRN
5. To work closely with the UKCRC PPI Project Group, ensuring a working knowledge of the Group's activities, and a joined up approach to ensure compatibility
6. To review TCRN/PCRN PPI documentation to be disseminated, to ensure consistency in content, quality and appearance
7. To discuss and advance new PPI initiatives that complement the UKCRN study portfolio, ensuring a knowledge of other PPI activities occurring outside the UKCRN
8. To develop a peer support network, share experiences and offer advice between UKCRN PPI Working Group members
9. To recommend actions (prioritised) to the UKCRC PPI Project Group and the UKCRN Management Group
10. To consider any other matters considered relevant

Frequency of Meetings:

Three/four times a year
Substitutes may be sent

Member	Position	Email
*****Sarah Buckland	INVOLVE Director	sbuckland@invo.org.uk
Janet Darbyshire	UKCRN Co-Director	jhd@mrc.ctu.ac.uk
*Roger Duncan	Involving Peoples Officer, CRC Cymru (Wales)	rduncan@wcva.org.uk
**Patricia Ellis	UKCRN Primary Care Research Manager	p.ellis@ukcrn.org.uk
*Lesley Griffiths	Associate Director (Involving People in Research) of CRC Cymru (Wales)	L.J.Griffiths@swansea.ac.uk
*****Matthew Hallsworth	UKCRC Programme Manager	matthew.hallsworth@ukcrc.org
Karen Inns	NCRN Consumer Lead	k.inns@ncrn.org.uk
Zena Lethbridge	SRN Patient and Carer Involvement Manager	Zena.Lethbridge@newcastle.ac.uk
Martin Lodemere	DRN PPI Officer	m.lodemore@imperial.ac.uk
Terry McGrath	DeNDRoN PPI Coordinator	Terry.McGrath@dendron.org.uk
Marianne Miles	UKCRN PPI Lead	m.miles@ukcrn.org.uk
***Michael Neely	Operational Director R&D Office, Northern Ireland	mneely@rdo.n-i.nhs.uk
***Moira Nolan	Chief Scientist Office, Scottish Executive Health Dept	Moira.Nolan@scotland.gsi.gov.uk
Karen Robinson	Research Worker, SURGE, MHRN	Karen.Robinson@surge.scmh.org.uk
*****Mary Rose Tarpey	INVOLVE; Public Involvement Adviser	mtarpey@invo.org.uk
Jenny Preston	MCRN Consumer Liaison Officer	Jennifer.Preston@liverpool.ac.uk
Jan Wallcraft	Operational Manager, SURGE, MHRN	j.wallcraft@surge.scmh.org.uk
Roger Wilson	UKCRN PPI Associate Director, Chair	roger@dflair.demon.co.uk
*****Philippa Yeeles	UKCRC Programme Manager	philippa.yeeles@ukcrc.org

*****Attendance from UKCRC, INVOLVE and CRC Cymru will be confirmed prior to each meeting, depending on the agenda. However at all meetings, at least one named member will be present.
** The UKCRN Primary Care Research Manager will represent PCRN, and will liaise directly with colleagues from this Network. In time, a colleague working within the PCRN may be identified and invited to join the Group.
*** Attendance from the R&D Office (NI) and the CSO (Scotland) will be confirmed shortly. In the meantime, the above named colleagues will represent each devolved administration.