



**The Views and Experiences of Research Network Professionals on  
Patient & Public Involvement in Clinical Research**

**Project Report**

**March 2007**

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## **1. Executive Summary**

### ***Background***

The UK Clinical Research Network (UKCRN) exists to facilitate the conduct of clinical trials and other well-designed studies, aiming to improve patient care and allow people across the country access to the best treatment. It believes that patient and public involvement (PPI) is needed if it is to deliver a programme of research which directly benefits, and reflects the needs and views of, patients and the public.

### ***Aim***

The aim of this project was to collate the views of a range of professionals involved in the work of the UKCRN, on PPI in clinical research. The information collected will be used to inform this activity, and will help UKCRN to address any concerns/challenges that are identified as a result of this piece of work.

### ***Methodology***

Following a request by email for volunteers to be interviewed, 41 interviews (telephone-based) took place across the Research Networks: 3 from cancer, 6 from dementias and neurodegenerative diseases, 5 from diabetes, 6 from medicines for children, 10 from mental health, 6 from primary care and 5 from stroke. Interviews were carried out by the UKCRN PPI Lead, and three PPI postholders within the Topic-Specific Clinical Research Networks (TCRNs). Interviewees comprised 2 colleagues from the TCRN Coordinating Centres, 13 Clinical Leads, 8 Clinical Study Group (CSG) members, 8 Local Research Network (LRN) Managers, 3 researchers working within a LRN and 7 nurses. All responses have been anonymised.

### ***Outcomes***

Of those interviewed, 85% said they were aware that patient/public representatives and patient organisations are encouraged to become involved in the work of UKCRN.

The majority of respondents (90%) do have direct experience of PPI in research, and a vast range of activities were described, from peer review and funding committee work, to involvement in study design and dissemination of information. Both positive and negative accounts were described. Positive experiences included improved recruitment to trials as a result of PPI, and more focused research. Negative examples included unrealistic expectations, and the concern that PPI had not led to an improvement.

Detailed comments were collected in relation to PPI in the following research areas: identifying priorities and prioritising specific questions; systematic reviews; study design; research outcomes; study oversight; disseminating results; producing research information. The majority of respondents felt there was a role for PPI in all of these areas, as well as in other areas, including raising awareness of clinical research and the Research Networks; acting as advocates for recruitment to trials; service development; ethics; working with Industry; training researchers.

Concerns raised in relation to PPI in the work of UKCRN included representation – how to achieve this; tokenism – how to avoid this; time; resources; cost; finding the right people.

A range of priority areas were identified in relation to provision of suitable information and support by UKCRN. These included training opportunities; generic guidelines and resources – to support a joined up way of working; systems to identify patients/members of the public; evidence of the impact of PPI; clarity and consistency around payment – demonstrating commitment; a need for UKCRN to improve the culture of research to support PPI.

### ***Conclusion***

This piece of work has enabled UKCRN to understand better the breadth of experience of PPI in research already present in the Research Networks, and the challenges that exist. It should be noted that all of those interviewed volunteered to take part, and therefore they are not necessarily representative of all Research Network staff. Several priority areas have been highlighted, and as a result, those with responsibility for supporting PPI across the Research Networks strategically and operationally, will use these findings to ensure best practice of PPI in clinical research.

## **2. Background**

The UK Clinical Research Network (UKCRN) forms 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 if it is to deliver a programme of research which directly benefits, and reflects the needs and views of, patients and the public. Therefore a key theme that runs throughout its work is PPI.

## **3. Aim**

The aim of this project was to collate the views of a range of professionals involved in the work of the UKCRN on PPI in clinical research. The information collected will be used to inform this activity, and will help UKCRN to address any concerns/challenges that are identified as a result of this research. The questions covered a number of areas including current/previous experience of PPI, the impact of PPI has on research, the benefits and challenges of PPI, and any barriers/concerns related to this activity.

## **4. Methodology**

A request was made by email for volunteers to be interviewed across the Research Networks, with an aim to interview up to ten individuals within each Topic-Specific Clinical Research Network (TCRN) and the Primary Care Research Network (PCRN). Following a successful response, a background paper was sent to each individual, and a time and date arranged for the interview. This short paper introduced the UKCRN and its various activities, with a focus on the area of PPI, to provide the individual with an understanding of potential plans for PPI across the Research Networks in clinical research. To summarise, key objectives described included:

- UKCRN processes of PPI should be open and transparent.
- The views and perspectives of patient/public representatives should inform the work of UKCRN.
- Information about PPI should be accessible to all patients/the public, and researchers/healthcare professionals.
- PPI roles and responsibilities should be clearly defined.
- Training, mentoring and support should be provided for all patient/public representatives and researchers/healthcare professionals involved.
- The impact of PPI should be evaluated, and the evidence collated and disseminated.

All interviews took place by telephone, and were carried out by the UKCRN PPI Lead (17 interviews) and four PPI postholders within the TCRNs (DRN: 5; MCRN: 6; MHRN: 10; SRN: 3). Responses have been anonymised and collated in the following outcomes section of this report.

## 5. Outcomes

### 5.1 Interviewees: Network and Role

Across the Research Networks, a total of 41 interviews took place. A breakdown of these interviews according to topic is provided in Table 1, and a description of the roles of the interviewees within the Networks is shown in Table 2.

**Table 1: Interviews across the Networks**

Research Network	No. of Interviews
Cancer	3
Dementias & Neurodegenerative Diseases	6
Diabetes	5
Medicines for Children	6
Mental Health	10
Primary Care	6
Stroke	5
<b>Total</b>	<b>41</b>

**Table 2: Role within the Network**

Role	No.
Clinical Studies Group Chair/member	8
LRN Clinical Lead	13
LRN Manager	8
Nurse	7
Researcher within a LRN	3
TCRN Coordinating Centre staff	2

### 5.2 Experience of PPI in research

Interviewees were asked if they had any direct experience of involving patients and/or the public in the research process:

**YES: 90%**

**NO: 10%**

Of those that indicated they did have some experience, examples were requested. A range of activities from across the TCRNs/PCRNs was provided, examples of which are described below (a full list of experiences is available on request):

- Chair of a consumer group which has been running for two years with a small cohort of 5/6 patients. Patients and carers comment on research proposals and papers. Information is provided in an accessible format, for example large print. They (patients and carers) come with lists of questions. We try and adhere to best practice principals.
- Within funding body committees - sometimes helpful, sometimes more difficult.
- Jointly written paper.

- Involvement in running focus groups.
- Local NHS service user groups - especially on local research groups with PPI which have helped guide and design studies and study questions.
- Production of lay summaries of study findings for lay people. Collected feedback on whether the lay summaries were accessible enough.
- Involved young people who had been involved in trials to increase participation on to new studies.
- Involvement in having patients and the public originating a research idea - off they went and got on with it.
- On project advisory groups and trial steering committees.
- Involving service user researchers in developing protocols.
- Input from parents in the past in reviewing articles, and in submitting their own bits or giving permission to use their stories.
- Clinical Studies Group (CSG) membership – is a mentor for one of the lay members.
- Working with research charities, who have well-established PPI processes.

### **5.3 Impact of PPI**

Interviewees were then asked if they felt that the comments/input received from patient/public representatives and patient organisations add anything to the research process and decision-making:

**OFTEN: 50%**  
**SOMETIMES: 45%**  
**RARELY: 5%**

Additional comments made more than once, by different interviewees included:

- Some people say they don't want to be a participant in research for whatever reason, but do want to contribute to the process of research i.e. active PPI.
- Yes – but often lots of box-ticking and tokenism – UKCRN need to take a stand against this!

Further information was requested to determine where patient/public input/comments had made a difference, either positively or negatively in relation their own experience. Selected responses are described below (a full list of all responses is available on request):

#### *Examples of positive experiences:*

- They are very important in steering group settings, to gain a parent's point of view, especially in regards to outcomes.
- On a positive note by listening to the public about their experiences of being involved in clinical trials increased patient involvement into new trials.
- Necessitated us as professionals to think more clearly and use good, simple English.
- Positively, PPI has enabled us to change the timing of the delivery of the roll-out of the intervention.
- Input from service users changed the training we were delivering to clinical trial staff with a responsibility for recruiting patients to clinical trials - so they helped us with good practice.

- They commented on the respectfulness of the language we used and, in general, how we communicated.
- The service user's insights into analysing data were fantastic offering a completely new insight.
- Makes researchers think in a more focused way about the context of research, reminding us that patients should be at the centre of our work.
- Peer reviewing – very positive – helped reassure the funding decision.
- Involvement in writing and editing a book – a carer wrote a chapter which brought a positive dimension to the book, and the reviewers agreed.

*Examples of negative experiences/barriers:*

- Adds another layer to what we have to do: time, resource, cost.
- Generally positive. One big negative is a lay member who has unrealistic expectations of what research can achieve resulting in destructive comments, can cloud judgements and produce an unhappy atmosphere.
- For patients already involved in the area that have now come on board to be involved in the Network, a real negativity towards the fact that we will be working in partnership with industry.
- Conflict between researchers and patients, due to scientific quality vs. patient priorities.
- Disappointing experience of PPI on funding bodies and review committees due to sheer volume of work, complexity of information and lay summaries which were still daunting to grasp – therefore negative, but due to process rather than the patients involved.
- In general, when services users/lay people have been involved in meetings to do with research, they have found it a frustrating process: the meetings can be dull and are quite big, so nobody individually makes much of a contribution. Service users particularly can wonder if it's a waste of their time – what is their legitimate expectation?
- Experience of disruption – embarrassing – causes damage and is counter-productive.

*Examples of indifferent experiences:*

- No negative experiences but no really positive 'eureka' moments either.
- Service users have made interesting comments but I wouldn't say this has altered the design or conduct of the study. Maybe it's good to know we're heading in the right direction, but it has made no difference.

**5.4 Awareness of PPI in the UKCRN**

Interviewees were asked if they were aware that patient/public representatives and patient organisations are encouraged to become involved in the work of UKCRN.

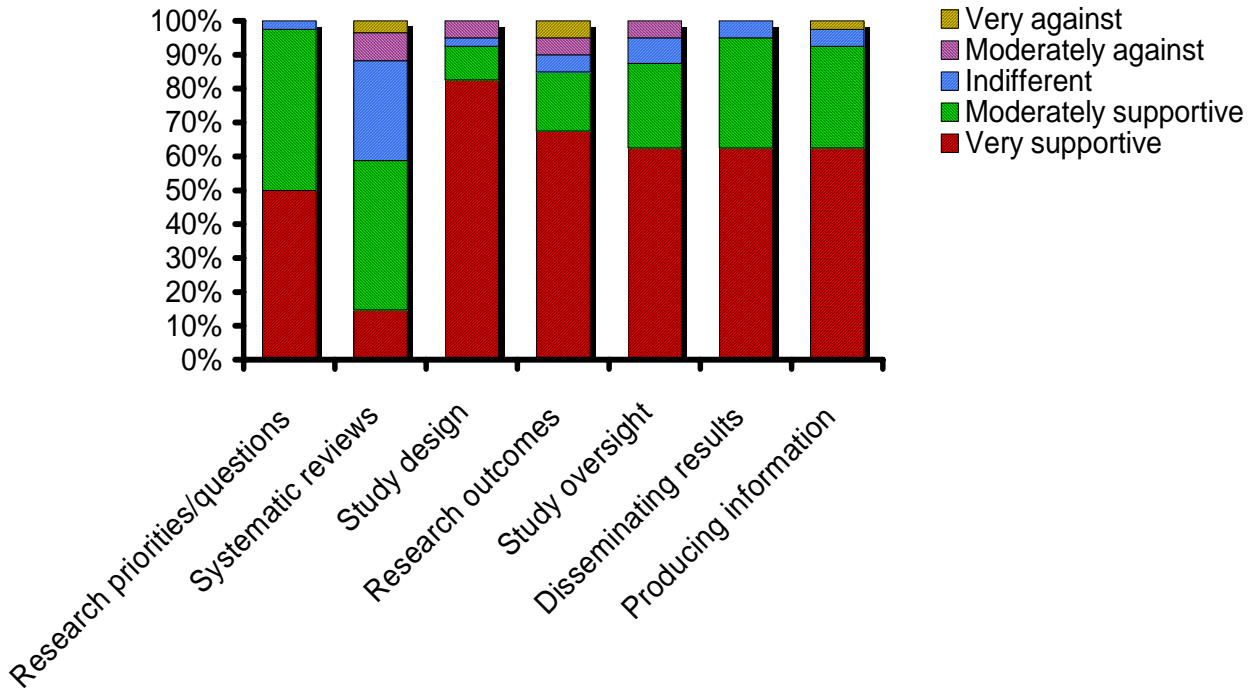
**YES: 85%**  
**NO: 15%\***

\*All interviewees who responded 'no' said that they were familiar with their own Research Network (although not with their PPI practices), but not with UKCRN and its work. One respondent viewed UKCRN as another layer of bureaucracy, in relation to PPI activities. Two respondents requested information about UKCRN and PPI plans.

### 5.5 PPI in the research cycle

Interviewees were asked if they were supportive (or not) of PPI in the following research areas in the work of UKCRN. The collated responses are shown in Figure 1 below.

Figure 1: Views on PPI in different research areas



With the focus still on PPI in the research areas described in Figure 1, interviewees were asked if they had any specific comments or advice about involving and gaining the views of patient and/or the public in these areas. Of those that did (75%), a selection is described below (a full list of responses is available on request):

#### 5.5.1 Research priorities/questions

- It's a re-framing of the agenda. It's a shifting of the power over who decides what's of importance.
- Support the contribution to identifying priorities, but very against prioritising specific questions.
- Really helpful and can sometimes be a reality check for clinicians.
- With caveats – patients are just like clinicians and will push for their own view, whether sensible or not!

#### 5.5.2 Systematic reviews

- Provisionally supportive, especially to help inform patient-led research - with appropriate training as a proviso to equip patients with the skills required to review evidence.
- Need to understand the perceptions of all stakeholders, including patients. Need to work out what the outcomes of a systematic review should be.
- Difficult for all parties unless familiar with jargon. Can't see it working very well for a rigorous review.

- People need to learn skills and have clinical knowledge for effective reviewing and this takes time.
- Can't see how they can draft question - not sure what their role would be?

#### 5.5.3 *Study design*

- There's nothing like real life translation of jargon. It's very easy in the academic world to assume everyone understands the language we are using.
- Service user input to patient information sheets is particularly relevant.
- It takes time to grasp research methodology, but it's the different perspective which is important.
- It can be invaluable in terms of getting the language right.
- Yes in design of material, but not design of study!
- Against PPI in designing whole studies, but in favour of contribution to e.g. Patient Information Sheets.
- Need to make Patient Information Sheets part of the funding process - a requirement for funding. Will help lay members understand the more complex issues, and give researchers an opportunity to explain better - often the Lay Summary is not sufficient to allow a complete understanding of subject.

#### 5.5.4 *Research outcomes*

- It would be better to have lay groups/bodies rather than individuals. A representative balance is very important.
- Determining what's relevant and meaningful, rather than abstract science, is important – professionals can forget this. Too much research serves the researchers.
- Those outcomes which are used aren't always the most useful, but often just the easiest to measure.
- Research outcomes should not just be about journal articles, but more about how this might affect NICE decisions, appraisals and policy decisions – this is where PPI could be invaluable.

#### 5.5.5 *Study Oversight*

- Can't see any harm in this, but thinks it's not necessarily a good use of a lay person's time.
- Different perspectives and multi-disciplinary expertise would add value to monitoring, especially around areas of governance, ethics and relevance.
- Involvement should be used strategically, for national and local steering groups, and especially on study steering groups.
- They (patients, the public) have insufficient understanding for clinical trials.
- Always have patients on Trial Steering Committees for trials.

#### 5.5.6 *Disseminating results*

- In terms of understanding the impact and relevance of the research, and the ways this might need to be communicated and to which groups.
- If someone's comfortable with doing it and has the relevant support.
- People offer unique (and sometime better) ways of feeding back - can help to change practice.
- This does not happen as well as it should at present.

- Researchers often don't have the time or skills to disseminate research results/information – pressure to move on to next study. So use the patients!
- Enthusiasm may be there, but dangerous if results are over-inflated by patients.

#### *5.5.7 Producing information*

- May result in miscommunication – production of the wrong messages.
- Absolutely. Vitally important. To be involved in communicating to every stakeholder (i.e. not only to lay groups).
- If this is about turning research results into lay language, this would be marvellous; however, Service Users should not be producing the research information from scratch – this would be far too stressful for someone not qualified in the right way.
- What kind of information? No to writing papers, yes to producing lay summaries.

### **5.6 Advice from experience**

Interviewees were asked if they had any specific comments or advice about any of the described areas of research, in relation to involving and gaining the views of patients/the public. A sample of comments/advice offered is provided below (a full list of experiences is available on request):

- For all domains that patients are asked to contribute they must be briefed and brought up to speed - the research world is alien so to get the best they have to be genuinely supported.
- Each Network should focus on raising public awareness about research and the work of the UKCRN and other Networks involved. Also raise awareness of how patients and the public can get involved, why and how? It has to be done meaningfully, not just to tick a box.
- We should be clear about the process of involvement, and people's expectations: academics' expectations and expectations of patients/public.
- Influencing decisions that they could see the result of quickly.
- Because of the pressure (to involve service users), it can be done in a thoughtless way. It is important for researchers to form relationships with service users – not just co-opt them onto existing processes.
- All involved should be sensitive and respectful.
- The structural way a service user is involved doesn't necessarily tell you about the level of openness or the extent of the collaboration.
- Should be prepared to be constructive and flexible in promoting lay input.
- Roles in influence and promotion are good, but are different and this needs to be recognised.
- For some of the named research areas, if input is to be more than tokenistic, patients need training and there's far too little. Having experienced tokenistic involvement before, there is nothing to be gained from it.
- People come and go - don't get disillusioned if you don't always meet their expectations.
- Hard to reach groups ARE difficult to involve - keep trying, but don't focus on them too much.

- Meetings need to be structured, but keep them as informal as possible.
- Need to identify and recruit GOOD patient reps. Poor patient reps, with own agendas, can scupper plans and put everyone off - researchers and the public alike.
- Need to ensure appropriate selection process, remembering that scientists and clinicians are also selected according to their 'track record'!
- Need to change the culture – and UKCRN needs to lead the way.
- Need to ensure that patient organisations are happy with the processes UKCRN and the Networks adopt, since many have established PPI practice.
- Transparency is crucial.
- Rather than PPI on every CSG, suggests a single committee covering all CSGs that lay members could be a part of.
- The Chairman needs to be good in order for PPI to work on committees.

### ***5.7 PPI in other areas related to the research process***

Interviewees were asked if they felt there are any other areas not mentioned in the research cycle (Figure 1) that they feel PPI ought to be brought into:

**YES: 60%**  
**NO: 40%**

Of those that responded 'yes', the additional areas suggested are described below:

- There needs to be more education around the area of PPI, and patients/the public should be a part of the delivery of such education.
- Getting patients to raise the profile of the Networks for staff and service users.
- There is definitely a role for patients/the public to encourage recruitment to trials/studies, especially those who have already had some experience of being in a clinical trial – what it is like to be a trial participant e.g. provision of patient stories – UKCRN should do this.
- Word of mouth can help, directly from patients/the public. They are very good ambassadors for research, which can feed into other Networks and support groups, which again helps dissemination. And they can train researchers.
- Raising awareness – the benefits of research.
- Service development – it goes hand in hand with research.
- Sitting on ethics committees. Sitting on funding bodies. Sitting on governmental strategy bodies – with regard to the direction of research. The latter two are fundamental – that's where the power lies.
- Management of the Networks e.g. Operational Steering Groups.
- Breaking down the barriers with industry.
- Provision of local and national activities for PPI.
- Consent issues.

### **5.8 Concerns about PPI in the Networks**

Interviewees were asked if they have any concerns about PPI in the work of UKCRN:

**YES: 87.5%**  
**NO: 12.5%**

Of those that responded 'yes', details about their concerns are described below:

#### *5.8.1 Tokenism*

- To ensure that it's genuine PPI and we resist any element of tokenism.
- PPI has become something you have to write. Not sure it's possible always to involve service users. Concerned about it becoming tokenistic and a tick box for funders.
- Easy to get PPI on a superficial level – but collaborative PPI is tricky, and needs time, support and commitment. It should also be recognised by all, that to do this well often means a slow process.

#### *5.8.2 Representation*

- Representation is a problem i.e. you have to be cautious about who you involve and that you don't always include the professional lay member who takes centre stage, therefore ignoring the most important people whose views are required equally.
- Need to avoid 'professional' patients – concern that this will cause us to lose sight of what is important.
- A fear that those involved become institutionalised over time - need to keep things fresh with new members, although important to allow those with newly-developed skills to still play a part.
- How to involve minority groups: young people, ethnic minorities. And how to involve people who are unwell (rather than carers) but want to be involved e.g. people with early-phase dementia.
- A lot of people who become involved may have had a bad experience – this can colour their views and means they can't represent the wider voice – can be very unhelpful.
- Roles of carers – are UKCRN/the Networks happy about this due to potential differences? We need to be clear about this.

#### *5.8.3 Support*

- People should be carefully selected and adequately trained. Involving the "wrong" people can ruin the atmosphere for other lay members. Good training gives people necessary skills to be effective.
- Involvement should be adequately costed and appropriately funded.
- What if a patient is unsuitable, or not performing? How should we deal with this? What steps should be taken? The role of the chair needs to be explicit.
- Confidentiality issues – but should be overcome with training.
- It's hard to evaluate PPI – how do we do this? An area that needs support.

#### *5.8.4 Expectation*

- We have to do this, but hope UKCRN doesn't inflict something we then can't deliver.
- Steep learning curve for researchers – many are not skilled to engage.

- Timescales need to be clear for PPI (are often unrealistic), so that it doesn't become another hurdle to performing research. Quick turn around of advice and comments.

#### 5.8.5 *Effect on research*

- What advantages do patients receive from involvement? Opportunities are often limited to "professional patients" who get involved in everything. Can mislead as well as lead research.
- Research could only be focused on patient care, and not more complex but equally important topics, if the patient voice becomes too strong. Needs to be flexible in approach.
- Concern about UKCRN taking a simple research project led by service users and taking it over and formalising it. UKCRN would take ownership of the idea, and it would end up not looking anything like the original idea.
- There is a real bias of diseases with a good survival rate – danger of biasing funds away from those diseases doing badly – need to achieve a balance.

#### **5.9 Requests for additional information**

Interviewees were asked if there is any additional information about PPI in UKCRN that they want or need:

**YES: 35%**  
**NO: 65%**

Many of those that said they did not want additional information added 'not yet', but perhaps in time when the Networks are more established. Of those that responded 'yes', their requests for specific information are described below:

- More information on how to effectively engage with the public/patients.
- What training is available for patients/the public.
- More information about what is going to happen within the UKCRN in the area of PPI, and more about how it will happen.
- The latest guidelines and news of latest programmes of activities. It would be helpful to be e-mailed something about that.
- Hard evidence about PPI – otherwise we are sceptical and cautious – and this will be viewed as another layer of work.
- What is already out there – how can we tap into this?
- Educational information – labelled as UKCRN to provide endorsement and leadership.
- Provision of information/learning packs.
- Aware of some disease-specific information and information from INVOLVE, but would like generic information from UKCRN, specifically relating to PPI in clinical research – this would be helpful.
- There is a danger of information overload – PPI info relevant to a specific disease area would be helpful.
- Frequently Asked Questions.

### **5.10 Support for professionals**

Finally, interviewees were asked how they think UKCRN should be supporting individuals (researchers, clinicians, healthcare professionals) who may work with/alongside patient/public representatives. A range of responses were collated, examples of which are provided below:

#### *5.10.1 Guidance*

- Provision of a good set of guidelines, that are all actively worked on and that there is background information to them – there is so much info out there but what is useful? UKCRN should be a focal point for generic resources and information, supporting a joined-up approach.
- UKCRN could give guidance about the best way to use the time of patients/the public, including examples of where it's worked well which could be applied to their own studies.
- Support and guidance on payment would be welcomed. Payment is an issue for local people. People working for voluntary organisations are not paid to help with publicly funded projects, which isn't fair. We must have consistency – needs to be addressed and would be better coming from UKCRN for all the Networks. If the role of PPI is to be taken seriously, then there has to be a process of reward and recognition – would also help to formalise the role.
- There should be a clear directive that this is the way it's going to be. It's not optional. We need a clear mandate, very clearly stated.
- Guidance on systems for mentoring need to be supported and formalised.

#### *5.10.2 Information*

- Provision of the right information and tools to effectively support PPI.
- More generic material for Networks about PPI.
- It would be good to have someone to call for practical advice, information and support – with a focus on clinical research. Lots of theoretical advice, but not so much practical advice available.
- It would also be useful to share examples of good practice and examples of when/how/why PPI has gone wrong.
- Evaluation of PPI – where we were before PPI, and what changes have occurred – we need concrete examples of how PPI has changed/improved research. Necessary to also prove to us that it is worth the investment.

#### *5.10.3 Support (resources; training)*

- To have adequate resources to ensure effective PPI.
- Financial and resource backing. And some understanding of the tensions/difficulties that can arise. Everybody needs space to talk about what they feel about the work they do. Reflecting time can be very helpful.
- Offer more of the right training for both the public and staff. Professionals need to do a systematic training programme. There is also a desperate need to train patients – we have a mix of different age ranges and backgrounds.
- Suggest patients join research staff at training events - rather than keeping them separate. Not always appropriate, but wherever possible - leads to feeling of being part of the process, not attached to it.
- Maybe service users should be training us – shared training.
- Chairs of groups need to be taught how to involve effectively – people in these positions could be really influential with regards to PPI that works.

- Communication. We need more visible resource and support from UKCRN – at the top – to demonstrate commitment and provide real endorsement.

#### *5.10.4 Contact with patients/the public*

- How to find someone to be involved. A database of contacts of patients with their research interests specified would be helpful.
- Would help to have a system that patients can use to find out what research is going on. Would be beneficial to have a direct approach to the public about clinical research, raising awareness and informing them in the right way.
- It would be useful if UKCRN could help identify a representative cross-section of people who might be involved (so that PPI is not a single individual with a single perspective).
- How to avoid duplication – UKCRN needs to support generic PPI Groups across Networks in geographical areas.

## 6. Conclusion

This piece of work has allowed a breadth of views and experience of PPI in clinical research to be collected and documented in some detail across the Research Networks. Whilst a lot of variation in opinion (related to experience) exists, a number of commonly-held views have also become apparent, allowing some key messages to be identified and prioritised for UKCRN to concentrate on initially. The ‘top-ten’ most repeated comments are listed below:

1. **Raise awareness:** a need to raise awareness of UKCRN, and clinical research, to ensure patients/the public fully understands the benefits and risks, and the general environment – this should lead to more informed patients/public members getting involved, and should also support recruitment to trials.
2. **Training:** appropriate training for all who contribute to, and support, PPI.
3. **Guidelines:** provision of standard guidelines relating to the practical aspects of PPI e.g. roles and responsibilities, to help professionals avoid tokenism.
4. **Information:** generic information and tools describing clinical research, and PPI, for professionals to use effectively when working with patients/the public.
5. **Selection processes:** appropriate processes relating to the selection of patients/members of the public, to ensure representation.
6. **Resource:** clarity and additional support regarding resources for PPI.
7. **Evidence:** evidence of the impact of PPI in research.
8. **Existing PPI:** UKCRN should utilise the good practice that is already out there, and facilitate joined up PPI where possible.
9. **Realistic expectations:** transparency should prevent unrealistic demands and expectations.
10. **Sharing experiences:** a bank of real stories describing PPI in research, with examples of what has and hasn’t worked well, would benefit all.

Staff responsible for achieving effective PPI in the UKCRN, TCRNs, the PCRN, and in the coming months, the Comprehensive Research Network (a structure being established to provide support to clinical research in all diseases and areas of health care across England) will use the information collected as a result of these interviews to share best practice and support colleagues working in the Research Networks to do this in the best way. In order to achieve a clinical research portfolio of the highest quality and relevance in the UK, patients and the public need to be involved in the work of the Research Networks to share their experience, offer their perspective, and help shape the culture of clinical research in the UK.