

Meaningful or tokenistic?

An approach to assess the quality and impact of public involvement in research proposals

Duncan Barron, Research Design Service (RDS) South East

Ruth Chandler, Sussex Partnership NHS Foundation Trust (SPT)

Jim Elliott, Drakesyard Consultancy Ltd

Helen Ashdown, Lived Experience Advisory Forum (LEAF) member

Outline of workshop

- Introduction to approach – Jim
- Pilot work with lay reviewers – Duncan
- Evaluation of work to date:
 - LEAF feedback – Helen
 - RDS & R&D Dir Feedback - Duncan
- Trying out the approach – Ruth & you!
- Feedback and conclusions – Jim and all

Health Expectations paper

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Critical appraisal guidelines for assessing the quality and impact of user involvement in research

David Wright PhD,* Claire Foster PhD,† Ziv Amir PhD,‡ Jim Elliott PhD,§ and Roger Wilson¶

Abstract

Background The involvement of service users in the design and conduct of health research has developed significantly in the UK in recent years. Involving service users is now seen as a core component of good research practice for all forms of health research. Given the important role that users have in health research, it is necessary to develop guidelines for their effective involvement. Whilst guidelines are currently being formulated, there remain no criteria with which to assess user involvement in published studies and funding applications.

Objective This study offers guidelines for appraising the quality and impact of user involvement in published papers and grant applications.

Methods Appraisal guidelines for user involvement have been developed on the basis of available literature and experiences from studies involving cancer patients and carers in the design and conduct of research.

Findings Nine appraisal criteria have been developed. Criteria include issues such as 'Is the rationale for involving users clearly demonstrated?', 'Is the level of user involvement appropriate?', 'Is the recruitment strategy appropriate?', and 'Is the nature of training appropriate?'

Conclusion Generating and applying guidelines is vital if the impact of user involvement agenda in health research is to be understood.

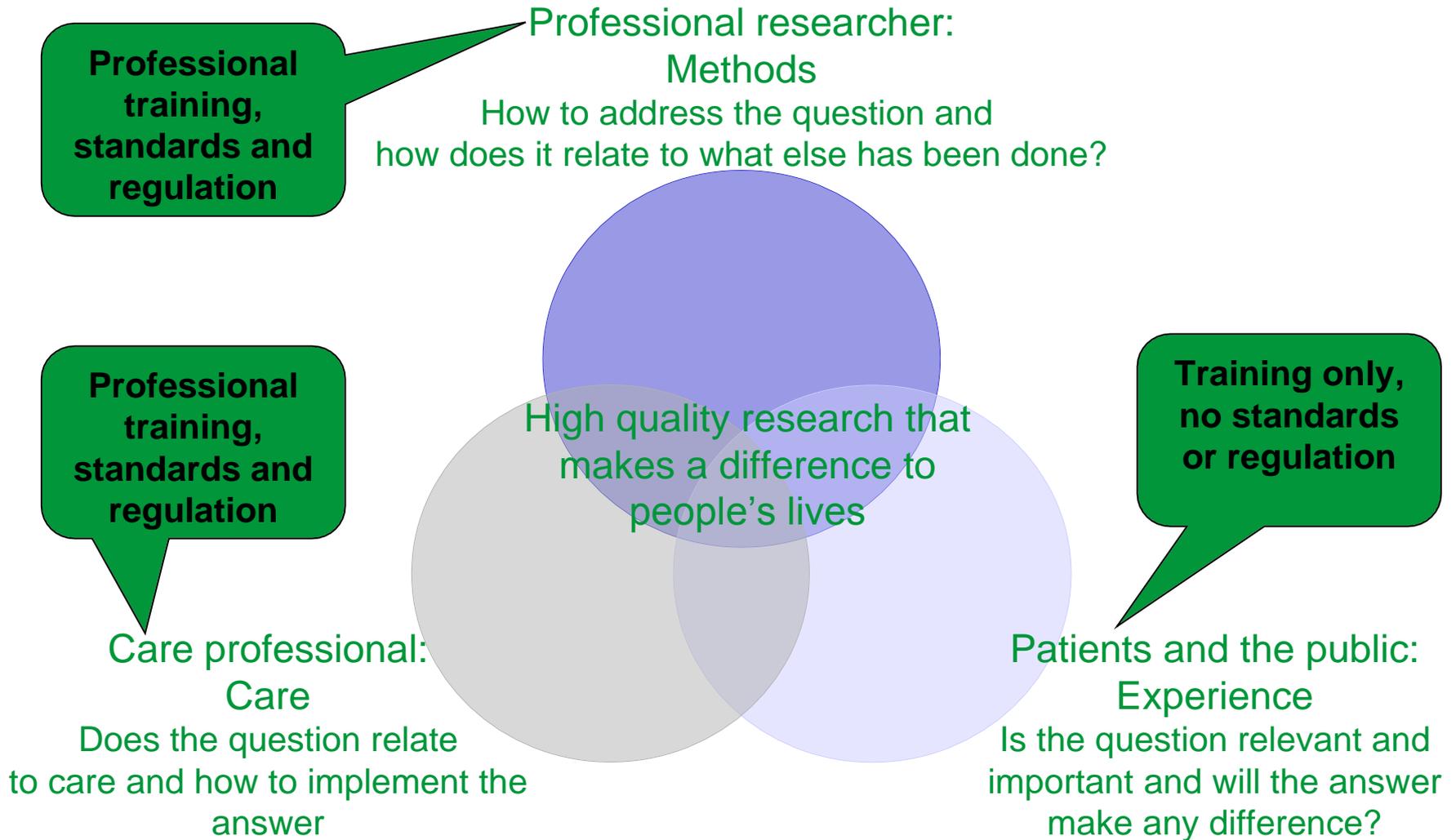
Definitions

- Which term to use?
 - User involvement / consumer involvement / Patient and Public Involvement (PPI) / public involvement / involving people
- Quality – how well the activity is planned and carried out
- Impact – what difference does it make?

Why do it?

- Guidelines exist for how to involve patients and the public
- No guidelines exist for how to assess the quality and impact of what patients and the public do when they get involved
- Without an evidence base for its effectiveness patient and public involvement risks stagnating rather than spreading

The case for assessing quality and impact



The case for assessing quality and impact

- To assure the quality of research
- To demonstrate the real value public involvement can bring
- To spread good practice of enquiring about the quality and impact of PPI
- To help make public involvement the norm not the exception

Developing and using guidelines

The approach in the Health Expectations paper is:

- For all elements of the research cycle, i.e. both the funders' and researchers' jobs
- To ensure that research is of the highest quality
- For:
 - Readers of published studies
 - Researchers
 - Funding bodies
- Informed by the CASP framework

Training Service Users: What we did

- Part of research methods training for Lived Experience Advisory Panel members (SPT) which included:
 - Introduction to research design
 - Introduction to Critical Appraisal (CA)
 - What is CA?
 - Strategies to help summarise a paper
 - Different CA tools
 - Hamer & Collinson (1999)
 - CASP
 - Greenhalgh

Critical Appraisal Skills Programme (CASP) Tools for Appraising Different Research Designs:

CASP Appraisal Tools for:

- Systematic reviews
- RCTs*
- Qualitative research*
- Cohort studies
- Case control studies
- Diagnostic test studies
- Economic evaluations

<http://www.casp-uk.net/>

Appraising PPI in Research Funding Bids:

What we did in our service user / lay training:

- Ways patients and the public can be involved in research: A brief reminder
- Over-view of how PPI in funding bids is currently appraised

How is PPI in research proposals currently appraised?

3 Examples:

- The NIHR Peer Review Form (section 6; 4 questions)
- The RDS-SE Peer Review Form (13 in-depth questions)
- New CASP approach to appraising PPI in articles and funding applications (9 questions)

Wright et al (2008): Critical Appraisal Guidelines for User Involvement

How is PPI in research proposals assessed? The NIHR Review Form (Section 6)



*National Institute for
Health Research*

6. INVOLVEMENT of patients and the public

Where applicable (N.B. if there is no patient and public involvement, please address question d below)

- a) What is your assessment of the patient and public involvement (if any) in the development of the application including involvement in: identifying the research topic; prioritising the research questions; preparing the application (e.g. contributing to the research design)?
 - b) What is your assessment of any proposed plans for patient and public involvement throughout the duration of the research? Can you identify particular strengths, weaknesses and/or areas for improvement?
 - c) Are the resources set aside for patient and public involvement appropriate - including plans for a training and support budget?
 - d) If there is no patient and public involvement in the application, what is your assessment of the reasons given for this?
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How is PPI in research proposals assessed? The RDS-SE Peer Review Form

13 questions including:

1. Is the purpose of the research clear to you and understandable?
2. Is the plain English summary clear and understandable? Could it be improved?
3. Are the research questions of relevance to the public/NHS and of importance?
4. For this question please try to put yourself in the place of a patient who has been approached to take part in this study as a participant. How will people be recruited as participants in the study and will this strategy work? Do you think people will agree to be a participant in this study? Do you have any suggestions to encourage participant recruitment into the study?

The New PPI CASP Approach: Developments

- Developed by a team at Uni of Southampton:
Wright et al (2008): Critical Appraisal Guidelines for User Involvement
- Duncan Barron; Ruth Chandler (SPT); Jim Elliott (co-author), RDS lay panel and LEAF members have worked on piloting PPI CASP to help review bids
- RDS peer review panel and LEAF users have compared CASP with other PPI review tools and commented
- INVOLVE conference Nov. 2012: your opportunity to feedback
- NIHR to adopt PPI CASP? Pilot for RfPB panel in SE?

The New CASP PPI Approach:

Research Activity	Appraisal Criteria
Planning and project design	<p>1. Is the rationale for involving users clearly demonstrated? <i>Consider the following:</i></p> <p>a) Have the researchers explained the rationale for user involvement?</p>
	<p>2. Is the level of user involvement appropriate? <i>Consider the following:</i></p> <p>a) Have the researchers explained and justified the level of user involvement? (E.g. have they discussed whether the study involves user consultation, user collaboration or user control?)</p> <p>b) Have the researchers discussed the nature of tasks users were asked to perform (e.g. identifying the research question, selecting the research method, commenting on information sheets, data collection, data analysis, dissemination?)</p>
Recruitment and training	<p>3. Is the recruitment strategy appropriate? <i>Consider the following:</i></p> <p>a) Have the researchers explained how users have been identified?</p> <p>b) Have attempts been made to involve a wide cross-section of interests where appropriate (e.g. ethnic minorities, age, gender)?</p> <p>c) Have the researchers discussed the 'credentials' of the users involved? (E.g. Do the researchers discuss why the users involved are appropriate to meeting the aims of the involvement activity?)</p>
	<p>4. Is the nature of training appropriate? <i>Consider the following:</i></p> <p>a) Have the researchers discussed the nature of the training provided?</p> <p>b) Is the nature and extent of the training justified by the researchers? (E.g. Do the researchers discuss how the training meets the needs of the users during the course of the study?)</p> <p>c) Has an account been given of user involvement training for professional researchers, where necessary?</p>

The New CASP PPI Approach (contd):

Data collection and analysis	<p>professional researchers, where necessary:</p> <p>5. Has sufficient attention been given to the ethical considerations of user involvement and how these were managed? <i>Consider the following:</i></p> <ul style="list-style-type: none"> a) Do the researchers discuss ethical issues relating to the involvement of users in research (e.g. fatigue, the emotional demands of data collection)? b) Are there any discussions about the management of ethical issues (e.g. provision of adequate information about research tasks, peer supervision)? <p>6. Has sufficient attention been given to the methodological considerations of user involvement and how these were managed? <i>Consider the following:</i></p> <ul style="list-style-type: none"> a) Have the researchers discussed methodological issues relating to user involvement in research (e.g. potential impact on the quality of the data)? b) Do the researchers discuss how methodological issues are managed (e.g. how differences in interpretations of qualitative data are negotiated?) 	
Dissemination	<p>7. Have there been any attempts to involve users in the dissemination of findings? <i>Consider the following:</i></p> <ul style="list-style-type: none"> a) Have users been involved in the writing of the publication / funding application? b) Have the researchers described how the findings have been disseminated to participants and service users? c) Are findings disseminated appropriately where necessary (e.g. translation of findings into different languages, provision of interim findings to participants in receipt of palliative care)? 	<p>interim findings to participants in receipt of palliative care):</p> <p>8. Has the 'added-value' of user involvement been clearly demonstrated? <i>Consider the following:</i></p> <ul style="list-style-type: none"> a) Do the researchers discuss what difference involving users in the design and conduct of the research has made to the research process? (i.e. Have the researchers considered whether the study and findings would look any different if users were not involved?) b) Do the researchers support the claims for the benefits of user involvement with examples from the research project? <p>9. Have there been any attempts to evaluate the user involvement component of the research? <i>Consider the following:</i></p> <ul style="list-style-type: none"> a) Have the researchers discussed the evaluation of the impact of user involvement on the research project (e.g. impact on the length of the study, the financial cost of involvement activities, cost – benefit analyses)? b) Do the researchers support claims about the impact of user involvement with examples from the evaluation?

The New PPI CASP Approach: Exercise

We asked LEAF members to:

- Read an RfPB outline proposal
- Compare the NIHR form with the new CASP PPI tool to assess the PPI in this proposal.
 - Advantages/disadvantages to the CASP approach?
 - Are there any over-sights / changes you can suggest?

The New PPI CASP Approach: Feedback (CASP cf. NIHR Form)

LEAF Feedback:

- CASP are sensible Qs. Good to have 'considerations'
- CASP Better language Subheadings are a gd feature of CASP; gives a guided framework for asking Qs.
- CASP form needs to be condensed
- CASP is more in-depth, gives a better assessment
- NIHR form easier and quicker to complete but a bit vague

Limitations:

- payment for PPI is missing
- CASP does not ask if there is no PPI in the study. This should be incorporated.
- 'Recruitment' rather than 'involvement' is used

The New PPI CASP Approach: Feedback

In addition to piloting the new PPI CASP tool with a group of service users (LEAF), we also invited feedback from:

- RDS-SE lay peer review panel members
- RDS Research Advisors
- A NHS R&D Director

They were asked to compare the new CASP tool with the NIHR form & the RDS-SE form

The New PPI CASP Approach: Feedback

RDS SE Lay Panel Feedback:

- No mention of: PPI budget; The quality and accessibility of the writing style
 - Poss include Qs 11 (writing style) and Q.14 (PPI budget) from the existing RDS-SE form
- No space for lay reviewers to add further comments
- Presumption that PPI has taken place.
- RfPB form seems too brief but stresses a personal opinion is being sought.
- *“I’d like a question on whether proposal suggests service users will be valued for their contribution” (cf. RDS form Q.10)*
- *“I like the CASP format, but language could be more lay friendly”*
- *“CASP form is not clear or straightforward as the RDS SE form”.*

The New PPI CASP Approach: Feedback

RDS SE Advisor Feedback; Eg:

- CASP: too much detail and too long; intimidating; layout could be condensed to one page
- The CASP tool would be an excellent checklist for researchers when considering PPI / when writing the proposal
- The CASP form readership appears to be the researcher?

NHS R&D Director Feedback:

- What is “added value” of CASP?
- CASP may be better suited for CIs to the design of their proposals
- CASP to generate a score threshold cf. NIHR form
- There is a lot of work needed for external reviewers who have limited time

The New PPI CASP Approach: Workshop Exercise

Handouts:

- CASP tool
- NIHR Form
- RfPB proposal to read through (Engaging Young People in Early Intervention project)
- **Questions to consider:**
 - 1) What works and what does not work?
 - 2) What are the essential features for assessing the quality and impact of involvement?
 - 3) What are the desirable features?

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Contact:

For further information please contact:

Jim Elliott

Drakesyard Consultancy Ltd

Research strategy, management, governance and analysis

M: 07867 538182

[E:jim@drakesyard.co.uk](mailto:jim@drakesyard.co.uk)