NHS
Research and Development Forum

http://www.rdforum.nhs.uk
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September 1st 2017

Dear Public Involvement Standards Development Team,

Re: Public involvement standards consultation

Thank you for providing an opportunity for feedback on the draft public involvement standards for research, dated 15th June 2017
https://drive.google.com/file/d/0BwA_7XPlWvrgNFFoWkZpYldlOG8/view

- We submit these comments on behalf of the NHS R&D Forum, which is a professional network and community of practice representing the health and care research management, support and leadership workforce. We are a non-profit organisation.

- We submit in addition to a completed survey, in order to fully communicate thoughts, which were not easily translated into the survey questions. We hope this is helpful and can be used.

- Please be aware that this response has been drafted by a very small number of the Forum Research Management Working Group and as such has not been through a wider review from the Forum membership.

Summary Forum Response:

- We welcome any work that aims to support and develop better practice for health and care research. We therefore broadly support this project in its intention to improve research, involvement in research and the processes around it.

- We welcome the objective to shine a light on good practice and showcase examples of existing excellence in order to inspire improvement and aid organisational strategies that might otherwise be starting from scratch. We are mindful that the case study examples were missing from the draft document and feel these would be the most valuable addition.

- We remain unconvinced that the draft format fully serves this objective or that it would be utilised by organisations. We have some concerns that if not re-framed or further developed there may also be some unintended more negative effects on all the good progress made in NHS organisations across the UK.

- It is because we value the intention of this work for good involvement and improvement in practice that we provide the detailed comments below and as such hope they are taken to be both supportive and facilitative.

Our response

1. Use of language

- We suggest the document links each high level standard (or principle) to its purpose i.e. how it achieves a standard both for research and health care improvement. This would convey meaning and help to prevent tick-box mentality.

- We felt the language could be improved. The document is long and, in parts, difficult to easily ascertain what to do. Plain language should be used throughout and it feels a little '*them and us*'. Some specific language changes are provided on p6 of this response.

- Given there is suggestion of measurement it is important to be absolutely clear on this expectation. The purpose for use could be articulated more explicitly. Perhaps bring the diagram from p16 up to the front (see further comment on this below). We are concerned that an industry is not created in adhering to a standard meaninglessly because it is measured.

- The members responding were clear that PI (public involvement) could be confused with Principal Investigator for which the acronym PI is very well used internationally in research. We prefer PPI as an acronym that is already well established within the research community.

- We recognise that the public makes a valuable contribution to all aspects of research and that this should be appropriately supported. The photographs of funding used throughout the leaflet infer an expectation of payment and raised some concerns that different organisations will have different funding available to support involvement. We would advocate that wherever possible all out of pocket expenses should be covered for members of the public and the standards should help to leverage more executive support from the organisation. However in the current financial climate this needs to be balanced with pragmatism and must not create reasons for withdrawing support for research or to take our involvement progress backwards.

2. Involvement for research with links to organisational purpose needs to happen before research has happened

- The documents create a sense that at an organisational level involvement begins once research has already been decided or is in someway in existence. This may be semantics around the definition of PPI *for research* (and might make better sense for research organisations that are perhaps funders) however for NHS sites and other healthcare organisations, it can be interpreted that a level of research exists in which involvement can occur and involvement opportunities are created. If this is then to be measured it sets a bar for some that may not be easily achieved (*see 3. below).*

- The challenge for enabling and growing good impactful research in an NHS organisation requires involvement much earlier, before specific research and research areas might exist at all. If involvement were better embedded in an organisation and with the research strategy of that organisation then the links to research purpose, i.e. improvement for health, might be clearer for all from the outset.

- In the accessibility leaflet references are made to projects rather than research development and it feels insular to the research project process missing important links with organisational purpose. Many organisations will be making good progress towards improving involvement opportunities in research development and research involvement activities and it would be good to be able to chart this progress.

3. What is to be measured?

- It is not clear to us what should be measured. Is it that an organisation has involvement throughout its development programme for research? Or is it the nature of the involvement itself i.e., where involvement in research happens (its development at organisational level or in a project or programme) that it has happened well?

- If the purpose is to set standards for both of these things then it might be wise to split them up for clarity. Some suggestions are given below by way of illustration of the different angles:

  (a) These are the standards of good involvement where research activity exists**.**
  For e.g.
    - That involvement it is open & fair
    - That it is ethical
    - That it is transparent
    - That it can be measured

- Translatable actions/indicators might include good communication plans, clear roles and responsibilities, thank you at the end and feedback etc.

NB*:* *Making research accessible and fair through involvement is not necessarily the same thing as making involvement accessible and fair and we can often confuse the two. Research involvement in itself is not the aim but research for health improvement is. If the research that we conduct does not answer questions for all groups in society it is not fair. This is not the same thing as creating all involvement opportunities fairly.*

(b) These are the standards of good research project development for all those who undertake it, *for e.g.*

- Opportunities for PPI are as broad and relevant as possible to enable research to answer meaningful questions for the breadth of society.

(c) These are the standards of good research practice for all those who undertake it for *e.g.,*

- That there is involvement at every point in the journey to ensure the real world impact for health care is achievable.

(d) These are the levels of involvement as a standard in all organisations *of x size and of x type etc., for e.g.*

- That patients and the public are involved in our all of our organisational research committees, structures and help to shape them
- That our research strategy development team includes representation from the public in areas we serve clinically.
- That all our research projects and programmes we lead involve patients or the public
- That all our research projects and programmes involve the patient and public well (i.e. to high standards of good involvement practice)

4. **The standards are too broad to be measured in context and the indicators are too specific to be applied to all types of organisation.**

- There are many different types of organisation taking part in health & care research (NHS, University, charity, non-profit, commercial etc), with many different roles (Sponsor, funder, host, collaborator) therefore in order for standards to be measurable, and for meaningful benchmarking between organisations to occur, the standards need to reflect the many roles and types of research organisation which would be a much bigger job. It would be very much more difficult for a small organisation to meet the standard 1.0 for example (“ we provide clear, meaningful and accessible opportunities for involvement across a range of people across the all research ”) when they don’t yet provide a wide range of research opportunities at all. However if it were re-worded to read “*where a wide range of research exists a wide range of opportunities for involvement is provided*” it might be more achievable.

5. **Best practice, principles and standards. Re-frame to avoid tokenism and a tick-box industry?**

   - If a meaningful measurement cannot be achieved (and we don’t believe this document currently enables fair assessment for comparison) then might more achievable indicators be provided or the standards reframed as principles? (Our definition of ‘Principle’ being a fundamental assumption, and ‘Standard’ being a measure that can be compared).

   - The standards must help leverage support from executive teams for research and involvement, and not create an industry around reporting on targets by research departments for organisational standards that they alone cannot attain.

   - We therefore suggest the document might be reframed to create more aspiration and inspiration for PPI, with clarity about where a standard level is expected. This will allow benchmarking where appropriate. The current document gives a mix of general standards and indicators as well as some that are extremely specific and we are not clear if they are all to be met or whether they are just illustrations and examples of practice

   - This re-framing to aspiration with examples of operational practice creates the bar and will remove the sense of ‘stick’. Examples would help to showcase suggestions for good practice in place of expectations. However if the indicators are intended to be expectations of standard practice then we believe more context specific indicators would be required and some would need to be removed.

Specific examples of language to be simplified provided by members feedback:

- It still feels a bit ‘them and us’. Should we change our language from ‘*did you involve patients’* to ‘*were patients involved*?’
- Page 2 Introduction is not very clear and doesn’t provide a good succinct explanation. For example “Public Involvement (PI) in research as research being carried out…”
- The standards appear to cross over somewhat as 5 and the second part of 6 (reporting) is similar.
- Indicator 2.3: should this not read activities rather than activity?
- Indicator 3.1: use of term “Signers”. Sign language translator would be more appropriate
- Page 3, point 6 uses the term “power sharing”
- Indicator: 3.5: use of Americanism “Learned”

- Indicator 4.1: would read better as “expect to be put in contact (*or even in touch*) with…” rather than “expect to be put into contact with…”

Please do not hesitate to contact us should you need any further information or wish for further input. The Forum working groups would be keen to support additional development.

Please note this response will be published on our website at www.rdforum.org.uk

With kind regards

Forum Research Management Working Group Members
On behalf of the NHS R&D Forum