

**Horizon Scanning Research
& Intelligence Centre**
Patient and Public Involvement &
Engagement Strategy
2015 – 2016

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INTRODUCTION

The National Institute for Health Research (NIHR) is funded through the Department of Health to improve the health and wealth of the nation through research. In May 2014 the NIHR set out a new five year strategic programme, *Promoting a research active nation*¹, to encourage public engagement and participation in health, social care and public health research. It is clear that patients, carers and the public are integral to the NIHR achieving its ambition to improve the health and wealth of the nation.

The NIHR Horizon Scanning Research and Intelligence Centre (HSRIC) supplies timely information to key health policy and decision-makers and research funders about emerging health technologies that may have a significant impact on patients or the provision of health services in the near future.

The NIHR HSRIC cemented its commitment to explore and investigate patient and public involvement and engagement with the publication of its first patient and public involvement (PPI) Strategy document in June 2013². The progress made against the objectives set out within the strategy, and reflections from those involved, can be found in detail in the activity report on our [website](#).

The NIHR HSRIC have made a solid start to PPI with successful involvement in our horizon scanning reviews, increased engagement via target Tweets to patient groups and charities, and a review of our website via a patient focus group. We have disseminated our experiences in 2014 through oral presentations both nationally and internationally. Areas that need continued exploration include; gathering patient comment on individual drugs in our technology briefings, and assistance with prioritisation in our medical technologies work stream.

Challenges faced by the HSRIC include gaining access to patients, obtaining representative input, the time taken to add a PPI element into our work programmes, new skills required by team members to ensure engagement is successful, logistical issues regarding the tight turnaround required for certain outputs, and the lack of familiarity of the public with the often technical nature of early awareness and alert systems such as the HSRIC.

The NIHR HSRIC's commitment to involving and engaging patients, carers and the public remains resolute and our plans for 2015-2016 are outlined in this strategy document.

AIMS OF PPI IN THE WORK OF THE HSRIC

Our core aims are:

1. To identify areas of work where the HSRIC can build and strengthen mutually beneficial relationships with patients and the public, and professionals working within the PPI arena.
2. To add value to HSRIC work and outputs through patient and public involvement.
3. To ensure accessibility and effective dissemination of the work and outputs of the HSRIC through patient and public engagement.
4. To ensure PPI is strategic, meaningful and appropriate.

BENEFITS OF INCREASING PPI IN THE WORK OF THE HSRIC

We believe that our work to sustain current levels of PPI within the HSRIC - and to develop new areas - will:

1. Increase the accessibility of information on emerging health technologies for patients and carers,
2. Support our identification of emerging technologies of relevance to patients and carers,
3. Increase the validity of HSRIC outputs by considering patient and carer views, and
4. Facilitate sharing of patient and carer views on identified health technologies with the HSRIC's customers and information users.

PPI PRINCIPLES WITHIN THE HSRIC

Values	Summary principles
Respect	Researchers and the public should show mutual respect for each other's roles and perspectives <i>e.g. at the HSRIC hear and consider all comments made by patients/public with respect and patience</i>
Support	Researchers and the public should have access to the support necessary to enable them to involve and be involved <i>e.g. at the HSRIC offering reimbursement for expenses incurred if group is convened within Public Health e.g. website review</i>
Transparency	Researchers should provide accessible information, and show clarity and openness around the aims and scope for involvement in the research <i>e.g. at the HSRIC being honest and open about why we are involving them and what is our organisational responsibility</i>
Responsiveness	Researchers should show a commitment to act on involvement and make changes to decisions and policies <i>e.g. at the HSRIC to include, where appropriate, comments made by patients/public in outputs</i>
Diversity	Involvement should be offered to relevant groups with equal opportunity, and effort should be made to ensure involvement is inclusive and seldom heard voices are represented <i>e.g. at the HSRIC involve patients/public regardless of the burden of their disease</i>
Accountability	There should be accountability to communities and groups that are affected, and involvement should be assessed with feedback provided to those involved <i>e.g. at the HSRIC letting patients/public know how their comments on a briefing/review were incorporated</i>
From 'Values, principles and standards for public involvement in research', NIHR INVOLVE. Oct 2013. Examples have been added <i>in italics</i> to show how it may apply to the HSRIC.	

ACTION PLAN 2015-2016

1 - BUILDING AND SUSTAINING PARTNERSHIPS

- 1.1 Investigate the appropriateness and usefulness of participation in the Health Technology Assessment International (HTAi) Interest Sub-Group on Patient & Citizen Involvement in Health Technology Assessment (HTA). Consider encouraging the group to broaden their remit to include horizon scanning, enabling the HSRIC to share learning and PPI experiences internationally. HSRIC will email international contacts to judge interest and possible plans for PPI, to be fed back in to the HTAi Sub-Group.

- 1.2 Investigate new relationships with patient groups. This will allow the HSRIC to continue to build on our knowledge, and appreciation of the wider context of PPI, and to investigate additional routes to gain access to patients and carers.
- 1.3 Liaise with appropriate teams within the NIHR such as INVOLVE and the Central Commissioning Facility (CCF), enabling the HSRIC to tap in to a wealth of expertise in PPI and support the Centre in involving patients.
- 1.4 Prepare, as appropriate, publications and conference presentations of the PPI activity within the HSRIC to ensure the broader dissemination of our work.

2. ADDING VALUE TO HSRIC OUTPUTS - PATIENT AND PUBLIC INVOLVEMENT

- 2.1 Continue to develop the processes and investigate the methods that can be used to ensure representative views of patients and carers are included in horizon scanning reviews where appropriate and practicable. This would apply for both internally generated reviews and those externally requested from collaborators.
- 2.2 Finish the pilot of the feasibility and practicality of gaining patient comment on individual health technologies, particularly when quality of life is highlighted as key to the technology. This pilot will determine whether the input from patients and carers substantively adds to the briefing content or MedTech prioritisation decision.

3. DISSEMINATION AND ACCESSIBILITY TO THE WORK AND OUTPUTS OF THE HSRIC – PATIENT AND PUBLIC ENGAGEMENT

- 3.1 Write a 'for the public' page for the new HSRIC website. This will contain a lay summary of the HSRIC purpose, methods and processes; detail how they can get involved in our work and signpost them to key relevant sections on our website and provide details of named staff who lead on PPI within the Centre.
- 3.2 Conduct a focus group with patients and carers to determine the usefulness of the new for the public page on the HSRIC website, and of the improved suggest a topic and search facilities, and identify any further improvements.
- 3.3 Ensure that when the new HSRIC website is launched in 2015, that any dissemination activity includes PPI partners and patient groups to raise awareness of new and improved features e.g. suggest a topic page, new 'for the public' page.

3.4 Pilot the introduction of lay summaries for drug briefings and medtech alerts to improve the accessibility of the intelligence on new and emerging technologies. Conduct a focus group with patients and carers to determine if these summaries are useful and meet their needs.

3.5 Continue to target relevant outputs to patient groups via Twitter to increase awareness of the technology in particular and the HSRIC in general.

3.6 To work with relevant patient groups to disseminate the findings of horizon scanning reviews so as to maximise the usefulness and reach of these outputs.

DELIVERY

PPI within the HSRIC is led by a Senior Analyst and an Associate Director ('core PPI leads') who will, with the support of the Senior Management Team (SMT), ensure that the Strategy is delivered. Potentially all staff within the HSRIC could become involved in the PPI work outlined in this Strategy as the Action Plan proceeds, with the appropriate support of their Team Lead and the core PPI leads.

REPORTING AND GOVERNANCE

At HSRIC'S bi-monthly SMT meetings the core PPI leads will update on progress with the Action Plan that underpins this Strategy. On an annual basis the HSRIC will update and report to the NIHR CCF as required on PPI activity.

REFERENCES

¹ http://www.nihr.ac.uk/documents/get-involved/Promoting%20A%20Research%20Active%20Nation_NIHR%20Strategic%20Plan_May%202014.pdf

² <http://www.hsc.nihr.ac.uk/files/downloads/2233/54.6088b52c.HSCPPIstrategyDec13.pdf>