

## Horizon Scanning Centre

# Progress Report on Patient and Public Involvement & Engagement 2012–2014

March 2015



**NHS**

*National Institute for  
Health Research*

The National Institute for Health Research Horizon Scanning Centre (NIHR HSC) is based at the University of Birmingham in the UK. The NIHR HSC aims to supply timely information to key health policy and decision-makers and research funders within the NHS about emerging health technologies that may have a significant impact on patients or the provision of health services in the near future. The scope of our activity includes pharmaceuticals, medical devices and equipment, diagnostic tests and procedures, therapeutic interventions, rehabilitation and therapy, and public health activities.

Horizon Scanning Centre reports can be accessed via our website at: [www.hsc.nihr.ac.uk](http://www.hsc.nihr.ac.uk), and the centre can be followed on Twitter at: [@OfficialNHSC](https://twitter.com/OfficialNHSC).

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## 1. INTRODUCTION

The purpose of this report is to describe in detail the patient and public involvement (PPI) and engagement work of the National Institute for Health Research (NIHR) Horizon Scanning Centre (HSC) from summer 2012 to February 2015 that was originally outlined in our first strategy document (<http://www.hsc.nihr.ac.uk/about-us/governance/>) of June 2013. The progress of implementing this strategy is outlined below under the action plan headings used in the original strategy. The process of recording how the HSC has met the strategy has been enhanced by collecting team views from those involved in PPI, this has facilitated the third 'reflective phase' of the strategy.

All 'Actions' are taken directly from the original June 2013 strategy. PPI at the HSC is led by a Senior Analyst and an Associate Director who will be referred to in this report as the core PPI leads.

## 2. PROGRESS MADE AGAINST ACTION PLAN FROM 2013–2014, STRATEGY (PUBLISHED JUNE 2013)

### PHASE 1: INVESTIGATION, PLANNING AND STRATEGY DEVELOPMENT (AUGUST 2012 TO MAY 2013)

#### 2.1 ACTION: UNDERTAKE AN INTERNAL REVIEW OF PPI ACTIVITY AT HSC

##### **Progress**

Back in summer 2012, prompted by discussions with the senior management team, a number of case studies were identified from the previous decade where the HSC had had patient group contact. Searches of the HSC network drive and emails identified relevant documents which provided some detail.

### **Case study 1: Briefing for Lycra garments for cerebral palsy and movement disorders, July 2002**

A comprehensive email response was sent from Scope patient group, detailing conversations with a range of patients. The patient group offered useful insights into the benefits for patients to undergo the assessment process for this technology, regardless of whether they were eligible for the technology. The patient group consultation for this briefing was positive as they offered useful comments on the potential use of the technology.

### **Case study 2: Briefing for Miglustat for type 3 Gaucher disease, October 2004**

Following our briefing report on Miglustat for type 3 Gaucher disease, we sent this to the Gaucher Association and received a comment about a section of the briefing stating *“patients would welcome this oral treatment”*. The commenter was concerned about the withdrawal of funding for the then current intravenous treatment as the new oral treatment was cheaper.

### **Case study 3: Engagement with the professional arm of Diabetes UK, 2007**

An advert was placed in the Diabetes UK newsletter, following a presentation to the group, to encourage suggestions of new technologies for the HSC to investigate. Unfortunately there were none made.

### **Case study 4: News brief for Argus II retinal prosthesis for outer peripheral retinal degeneration, July 2011**

Following the upload of the Argus II retinal prosthesis news brief for outer peripheral retinal degeneration to the HSC website, we were tweeted by Retinitis Pigmentosa Fighting Blindness patient group with positive comments:

*“@OfficialNHSC #retinitispigmentosa #blind td for this good summary of situation. Other co's also working on concept. Here's to technology.”*

### **Case study 5: Developing a new medtech ‘news brief’ report output, October 2011**

Two lay / patient representatives on the Medical Technologies Advisory Committee (MTAC) at NICE were consulted via email regarding the content, format and pitch of the proposed news brief. They felt the pitch of the report was correct. It was however, difficult to ascertain whether responders were ‘expert patients’, ‘patient group representatives’ or ‘patients’; this may have a bearing on their view of the report. Involving these individuals was positive; they offered useful comments on the format and content of this new HSC output.

### **Case study 6: News brief for bronchial thermoplasty for asthma, Asthma UK December 2011**

A completed news brief for bronchial thermoplasty for asthma was disseminated to Asthma UK patient group via email. They were pleased to receive the document that *“looked very helpful”* and were happy to circulate to relevant colleagues. Engaging this patient group was positive and mutually beneficial.

### **Case study 7: Specialty reviews**

The HSC periodically reviews the majority of medical specialties in a process known as ‘specialty review’. Up until 2014 clinical experts at key national organisations were approached to assist in (a) prioritisation of technologies already identified by the HSC, and (b) suggestions to the HSC of new topics. Since the start of 2014 only the latter engagement has been employed.

There has been some contact with non-clinicians throughout our specialty review programme, but it has not been standard practice for the HSC to seek these views. Examples have been identified within the past 14 years where patient groups have been approached as part of the specialty review process (Table 1). The most significant attempt to engage patients happened in 2006 in the rehabilitation review.

However the majority of those contacted either felt unable to participate or did not respond (Table 1).

**Table 1: Identified specialty review programme patient group contact**

Specialty	Year	Patient related organisation	Details of contact
Anaesthetics	2010	The Intensive Care Society	Two technologies were suggested by this society, but were not direct patient views.
Rehabilitation	2006	SignHealth	One technology was suggested.
		The British Institute of Learning Disabilities (BILD)	Not able to participate at this time.
		Arthritis research campaign (ARC)	Not able to participate at this time.
		Help the Aged England (now part of Age UK)	No response received.
		Scope	No response received.
		Arthritis Care	No response received.
		Alzheimer's Society	No response received.
Palliative care	2001	Parkinson's Society	No response received.
		The National Council for Palliative Care (NCCPC)	No response received.

## 2.2 ACTION: UNDERTAKE AN INFORMATION GATHERING EXERCISE, SUMMARISING AND DEVELOPING AN UNDERSTANDING OF PPI

### Progress

#### Literature search, August 2012

A search of both Ovid MEDLINE (without revisions 1996 to July week 4 2012) and Embase (1996 to 2012 week 31) was carried out on 6<sup>th</sup> August 2012 using the following criteria: 'Patient involvement' as a keyword, limited to English language, 'review articles', 'humans', '2005 to current'. In MEDLINE there were 116 hits; in Embase no hits. No papers were identified that were directly relevant to patient involvement in Horizon Scanning.

## Conference attendance, 2012 to summer 2013

In November 2012 a core PPI lead attended the NIHR INVOLVE conference, Nottingham University. This proved a useful opportunity to participate in workshops, learn about current research in PPI, and network with experts in the field.

### 2.3 ACTION: ENGAGE WITH AND RECEIVE ADVICE FROM INVOLVE AND OTHER INDIVIDUALS AND ACADEMICS WITH KNOWLEDGE AND EXPERTISE IN PPI

#### Progress

Between 2012 and summer 2013 the core PPI leads made contact with the following key people to seek advice, support and input into the development of the HSC PPI strategy. These links have been made through conference networking, targeted emailing, and telephone conference calls / face to face meetings. Individuals have engaged to varying degrees; key contributions were made by INVOLVE with their commitment to six monthly telephone conferences:

- NIHR INVOLVE – Senior Public Involvement Advisor.
- Department of Health – Research Programmes and Contracts Senior Manager, Research and Development.
- National Institute for Health and Care Excellence (NICE) – Associate Director of the Patient and Public Involvement Programme.
- NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) – NETSCC PPI Manager; Scientific Adviser; Programme Manager – Public and Patient Involvement.
- James Lind Alliance (JLA) – Senior Programme Manager.
- Warwick Medical School – PPI and Patient Experiences Programme Manager, RCN Research Institute.
- Health Services Management Centre (HSMC) University of Birmingham – Lecturer.
- Research Design Service for the West Midlands – PPI lead for Birmingham.
- Collaboration for Leadership in Applied Health Research and Care (CLAHRC) – Researcher & PPI Lead; PPI officer.

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## 2.4 ACTION: DEVELOP HSC PPI STRATEGY

### **Progress**

The foundation work described led to the production in June 2013 of the HSC's first PPI strategy, published on the HSC website (<http://www.hsc.nihr.ac.uk/about-us/governance/>) and circulated to selected key people.

### PHASE 2: STRATEGY IMPLEMENTATION (JUNE 2013 TO MARCH 2014)

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### DEVELOP AND AGREE AN ACTION PLAN FOR STRATEGY IMPLEMENTATION, BY FOLLOWING ACTIONS BELOW

#### **INVOLVEMENT**

- (a) **Action: Working with NETSCC and James Lind Alliance to discuss and pilot HSC involvement in Priority Setting Partnerships (PSP).**

#### **Progress**

In June 2013, at a telephone conference with JLA and NETSCC, it was agreed that the HSC would explore the identified topics from the Sight Loss and Vision Priority Setting Partnership (PSP) to establish if any topics were suitable for a horizon scanning review. In autumn 2013, as a result of this work, the HSC started a review of new and emerging technologies that aim to slow or stop disease progression and/or reverse sight loss in people with inherited retinal diseases in partnership with the charity Fight for Sight. Forty technologies were identified by the HSC using a bespoke search strategy and input from clinical experts. These were subsequently considered for their potential utility and impact by two patient focus groups, arranged and facilitated by Fight for Sight. Fight for Sight made adaptations to the materials prepared for consideration by groups so that they were suitable for those people that were partially sighted. The patients who participated were 'expert patients' with a good knowledge of their disease area. Fight for Sight fed back to the HSC that some people had difficulties with understanding the technical information sent by the HSC, yet they were able to comment on many of the technologies. In addition there was an

opportunity for patients to suggest technologies. However most of the technologies suggested were not relevant to the review e.g. indications outside relevant disease area, not progressed past animal trials. Patients also included more general comments on services, payment and adoption issues of the new technologies; these provided additional insights to the technology area and were incorporated into the final report.

The results of the review were written up in accessible language with further comments incorporated from Fight for Sight. The final publication of the inherited retinal diseases review was uploaded to the HSC website in June 2014. At this time a web news item was disseminated to Fight for Sight with NIHR Communications advice (<http://fightforsight.org.uk/n/new-treatments-on-the-horizon-to-treat-inherited-retinal-diseases-2619>). The NETSCC also produced a press release on the project: (<http://www.southampton.ac.uk/netscc/news/2014/07/16072014.page>).

*“Receiving comments on patient acceptability and impact (from a potential user’s perspective) provided useful insights and often a counterpoint to clinical expert views on technologies highlighted in the review.”*

**Author, Inherited Retinal Disease review**

*“Responses based on their facilitation of a series of focus groups – so direct experience and comments from real patients. Excellent!”*

**Medical Advisor, Inherited Retinal Disease review**

*“The exercise of running the focus groups, expanded our understanding of the experience of inherited retinal diseases and why many have focused on the care and support they can receive rather than believing in the power of research to make a difference. Their input made clear hurdles we, and the research community, will have to dismantle in order to reach patients for the trials of the future as well as the fears inherent for people who still have some precious sight and are afraid to risk it with a new and untried treatment.”*

**Fight for Sight’s Director of Policy and Communications**

- (b) **Action: Involving patients and the public when quality of life is highlighted key to the technology.**

### **Progress**

In autumn 2013 a Public Health Registrar seconded to the HSC carried out a horizon scanning review of new technologies in development for urinary and faecal incontinence. As this topic area was highlighted as having a large impact on patient quality of life, comments were sought from the Bladder and Bowel Foundation (BBF). This UK charity was invited to comment on the report with particular attention to gaps in current care pathways, types of innovation that would have significant impact, and new technologies that they were aware of. At the request of the BBF, it was agreed that the HSC would pay the charity £250 towards their costs; the comments were given by a nurse clinical adviser, not a patient.

In January 2014 the final report for the incontinence review was published on the HSC website (<http://www.hsc.nihr.ac.uk/diseases/new-and-emerging-technologies-for-urinary-and-faec/>). The main reflection internally from this review was it would have been beneficial to start clear discussions with the patient group at the start of the review, deciding if the general voice of the charity or the voice of actual patients/carers would add most value.

*“Patient views provided a valuable counterpoint to those of the nine clinical experts involved in assessing technologies identified.”*

**Author, Incontinence review**

*“The input from the patient representative added a user perspective that was different to the clinical expert’s perspective and highlighted some of the real concerns of patients and practical aspects.”*

**Head of reviews team**

*“Inclusion of the experts’ comments and patients’ views really adds value.”*

**Scientific Advisor (Identification), NIHR Evaluation, Trials and Studies**

**Coordinating Centre**

In August 2014, work started on a horizon scanning review investigating artificial pancreas (AP) technologies. In order to identify some of the key issues about AP technologies from a potential users' perspective we involved members of the public with type 1 diabetes and their carers. To structure the collection of their views on AP technologies, a short questionnaire was used.

The HSC collaborated with two organisations in order to engage with people affected by type 1 diabetes. The type 1 diabetes charity Juvenile Diabetes Research Foundation (JDRF) posted an advertisement on their Facebook page, which invited anyone interested in completing a short questionnaire to contact the project lead at the NIHR HSC. In addition, the NIHR Clinical Research Network (NIHR CRN) Patient and Public Involvement and Engagement (PPIE) team, who work closely with Diabetes UK, invited a group of their existing contacts who are affected by type 1 diabetes to complete the questionnaire. The questionnaire was developed with input from the PPIE team and an experienced patient advocate with type 1 diabetes.

Twenty six questionnaires were completed and returned. Of those who responded, 65% came via the JDRF Facebook page, and 35% came via the PPIE team. The respondents were not a representative sample of people with type 1 diabetes; only one teenager completed the questionnaire, a key sub-group in terms of clinical need for AP. The results were analysed using framework analysis; direct quotes were used to populate a matrix of key themes, and columns were categorised into positive/negative/neutral comments.

The potential users of the technology identified issues of how this new device would interact with their existing devices e.g. insulin pumps. Broader issues of user de-skilling as a result of new technologies, cost to the NHS and overall improvements in health and wellbeing were also identified.

*"The survey found that most respondents were keen and interested in this technology - they were a self-selecting group, so this may not be surprising... Conducting the survey raised public awareness of our work to some extent: the JDRF Facebook advert got 55 'likes' and 22 'shares.'"*

**Author, Artificial Pancreas review.**

People who completed the questionnaire were asked to provide feedback on how to do this type of PPI consultation better in the future. Seventy-five percent of those who completed the initial questionnaire (19/26) provided feedback about the conduct, content and presentation of the questionnaire. There was positive feedback on the questionnaire design, with completers liking the open-ended questions, good question clarity with simple and easy to understand language and clear questionnaire layout. Some of those surveyed would have however preferred an online survey such as SurveyMonkey.

**Action: HSC to explore whether a disease based review could incorporate patient group contact in the next six months.**

### **Progress**

Following the generally positive experience of incorporating patient views in the reviews programme of 2014 with the incontinence, inherited retinal diseases and artificial pancreas reviews, it has been agreed that going forward, PPI will be considered for future reviews.

**Action: Going forward, consider whether PPI involvement can be considered for commenting on appropriate drug briefings or for assisting with prioritisation of medical technologies.**

### **Progress**

In March 2014 the HSC were approached by Genetic Alliance UK, an umbrella patient group for genetic diseases, following the NICE Highly Specialised Programme consultation. HSC met with the Genetic Alliance UK Policy Officer and Director of Policy who offered to work as a conduit between the HSC and an appropriate patient group on any genetic topics on which NICE requested briefings.

In April 2014, a suitable topic was identified: Recombinant human alpha-mannosidase (Lamazym) for alpha-mannosidosis. A briefing draft was produced by the HSC and the Genetic Alliance UK facilitated comments from The Society for Mucopolysaccharide (MPS) diseases. The MPS Society made contact with most of the 14 patients with alpha-mannosidosis in the UK. They provided some replacement paragraphs for the

briefing which were more up to date than the information identified in the web searches, for example in terms of the presentation of the disease. Most of the comments made by the patient group were incorporated into the briefing.

*“(the) patient group were able to provide much more up to date and accurate details for current management options for the (rare) condition.”*

**Briefing author**

*“Hugely detailed responses, which were really helpful in fully understanding the ultra-rare condition and its impact.....the response was written in such a way it could be easily incorporated into our draft.”*

**Medical Advisor to Drugs team**

To date no patient and carer input has been sought in the prioritisation of medical technologies (medtech), as no appropriate technologies have been identified.

**(c) Action: Investigate the development of PPI quality standards for HSC work and create internal processes for HSC staff to use to clarify when and how patient groups should be contacted.**

### **Progress**

The core PPI leads discussed pre-existing quality standards with most of the key individuals listed in phase 1 of this report (page 7). No pre-existing ‘quality standards’ were identified as relevant to the niche role of the HSC. After discussion with INVOLVE, in September 2014, the HSC modified INVOLVE Public Involvement values and principles with the addition of supplementary examples relevant to the HSC (Table 2). These values and principles can be used by the individual HSC teams as they develop their sub-team PPI processes.

**Table 2: Public involvement values and summary principles**

<b>Values</b>	<b>Summary principles</b>
<b>Respect</b>	<p>Researchers and the public should show mutual respect for each other's roles and perspectives  <i>e.g. at the HSC hear and consider all comments made by patients/public with respect and patience</i></p>
<b>Support</b>	<p>Researchers and the public should have access to the support necessary to enable them to involve and be involved  <i>e.g. at the HSC offering reimbursement for expenses incurred if group is convened within Public Health e.g. website review</i></p>
<b>Transparency</b>	<p>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 HSC being honest and open about why we are involving them and what is our organisational responsibility</i></p>
<b>Responsiveness</b>	<p>Researchers should show a commitment to act on involvement and make changes to decisions and policies  <i>e.g. at the HSC to include, where appropriate, comments made by patients/public in outputs</i></p>
<b>Diversity</b>	<p>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 HSC involve patients/public regardless of the burden of their disease</i></p>
<b>Accountability</b>	<p>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 HSC letting patients/public know how their comments on a briefing/review were incorporated</i></p>
<p>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 HSC.</p>	

## **ENGAGEMENT**

**(d) Action: Investigate whether feasible adjustments can be made to the HSC website to increase accessibility standards that support PPI.**

### **Progress**

In January 2014 the HSC decided to review two defined HSC website functions; the 'Suggest a topic' page and the 'Search HSC' facility for HSC reports. After advice from INVOLVE to enlist the help of a pre-existing patient group, an advert for help was put in the college of Medical and Dental Sciences e-newsletter. Three responses were received from individuals involved in CLAHRC Birmingham West Midlands, COPD Breathe Easy patient group and Birmingham Rheumatology Research Patient partnership (R2P2). As the R2P2 group had previous experience of website related activities, a date was arranged with three of their members to carry out this review session.

In April 2014, facilitated by the core PPI leads, this focus group met in the HSC offices at the University of Birmingham. In order for the focus group to be a success, attention was paid to ensure practical details were in place; a map of our location, disabled parking reserved, refreshments provided, provision of a laptop per person, a programme of timings of the one and a half hour session were shared with participants, reimbursement of travel expenses, and a voucher offered for time. Care was taken to introduce the role of the HSC in 'jargon free' language and the session was led ensuring all participants contributed fairly. Flip chart notes were taken throughout the session so the participants could see what was being recorded. After the session, a report was produced and sent to the patients for validation.

For the 'Suggest a topic' page, comments from the group included:

- The first paragraph needs to 'grab you' more with bullet points.
- There needs to be an indication of who gets the form once it is submitted.
- The option to click for a larger font.

Most of these comments have been implemented on the website. Through liaison with INVOLVE, the 'Suggest a topic' page now has a link from the NIHR website:

<http://www.nihr.ac.uk/funding/identifying-a-topic-for-research.htm>

For the 'Search HSC' facility page, comments from the group included:

- A new window for a search so that you can easily close the search and start again.
- Linking lay terms for diseases to medical names; for example 'stomach cancer' linked to 'gastrointestinal cancer'.

These comments will be addressed once the new website developer has implemented changes in 2015.

As an aside from the patient website review and following comments from Genetic Alliance UK, it was suggested that the HSC website needed a diagram of how it linked with other key organisations such as NICE. In August 2014, after consultation with the HSC sub-teams, a 'stakeholder map' was uploaded to the website: <http://www.hsc.nihr.ac.uk/about-us/customers-and-partners/>

**(e) Action: Increasing the targeting of outputs to patient groups via Twitter followers.**

### **Progress**

Since May 2013 the drug, medtech and reviews team reports have all been 'target tweeted' via Twitter at relevant patient groups. By the end of 2014, 108 target tweets had been sent.

## **1. Action: Draw on our identified PPI experts as appropriate**

### **Progress**

Between autumn 2013 and autumn 2014, the following supplemental key contacts were made (in addition to those listed in phase 1, page 7) to advise, support and input into PPI work of the HSC. These links have been made through targeted emailing and telephone conference calls / face to face meetings. During this phase of the strategy, we tried to develop links with others working in the area of horizon scanning / Early Awareness and Alert (EAA) systems finding out if they have PPI elements in their horizon scanning work:

- NIHR INVOLVE – Senior Public Involvement Advisor.
- Queen Elizabeth (QE) Hospital, Birmingham – Associate Director of Patient Affairs. In February 2014 the HSC core PPI leads met with the Associate Director of Patient Affairs at the QE to discuss potential for accessing and using the QE patient groups. These groups are made up of QE hospital users so are generic, i.e. not centred around particular conditions, so would not be appropriate for commenting on specific reports, but could be useful for more general patient input.
- NIHR Central Commissioning Facility (CCF) – Head of Patient and Public Involvement. The core PPI leads held a telephone conference in October 2014 with the Head of Patient and Public Involvement at CCF who offered advice on carrying out a strategy refresh, informing the HSC of new key documents and agreed to comment on our new draft strategy in 2015.
- James Lind Alliance – Senior Programme Manager and Project Co-ordinator.
- All Wales Therapeutics and Toxicology Centre (AWTTC) – Senior Appraisal Scientist and AWTTC Patient Organisation Lead.
- Healthcare Improvement Scotland – Lead Health Economist, Scottish Health Technologies Group.

In order to share learning with other EAA systems, short articles on the PPI work of the HSC were included in the June 2013 and 2014 EuroScan International network newsletters (<http://euroscan.org.uk/>).

## Conference attendance, autumn 2013 to autumn 2014

One core PPI lead attended key conferences to present, participate in workshops, learn about current research in PPI and network with experts in the field.

- New Developments in Public Involvement in Research, organised by the NIHR Collaboration for Leadership in Applied Health Research and Care in the South West Peninsula (NIHR PenCLAHRC) Patient and Public Involvement Team, November 2013.
- Oral presentation at Health Technology Assessment International (HTAi) Putting the Patient and Public in the Centre, Washington USA, June 2014 (see abstract one – appendix).

The core PPI leads attended and presented at the NIHR INVOLVE conference, *Changing Landscapes*, November 2014, NEC Birmingham (see abstract two – appendix).

## 3. CHALLENGES

### 3.1 GENERAL CHALLENGES

The main challenges we have faced are gaining access to patients, obtaining representative input, logistical issues regarding the tight turnaround required by the majority of our outputs, and the lack of familiarity with the often technical nature of EAA systems such as the HSC.

We are not alone in these challenges and a survey conducted in 2010 of members of the International Network of Agencies for Health Technology Assessment (INAHTA) of the involvement of ‘consumers’ in their programmes, found that there was a trend of increased involvement compared to an earlier survey of 2005, but that the level of involvement was relatively limited<sup>1</sup>. A systematic review of the impact of patient and public involvement on NHS healthcare highlighted the need for the significant development of the PPI evidence base, particularly around guidance for the reporting

of user activity and impact<sup>2</sup>. The feasibility of patient engagement in many healthcare research settings was demonstrated recently by a systematic review, but also highlighted the challenges of logistics (extra time and funding needed for engagement) and the concern over tokenism<sup>3</sup>. Indeed *Promoting a research active nation* recognises the increasing trend to fund engagement and participation work in the clinical research arena<sup>4</sup>.

### 3.2 CONDUCTING HORIZON SCANNING REVIEWS

As the inclusion of PPI within the work of the HSC has to date had the greatest impact upon the work of the reviews team, this section is dedicated to the challenges faced by them.

The approach to including a PPI element in a horizon scanning review of new and emerging technologies for specific disease or technology areas will vary. This will depend on the topic to be considered, the availability of patient representatives or organisations that can contribute to the review, and the resources (staff and time) available in the team to facilitate and incorporate patient involvement. As such there is no set method to follow. This challenge is overcome by analysts working closely with the team lead and a medical advisor. Key questions and issues for consideration are:

- What is the topic to be considered (disease area or specific technology)?
- Are there available patient representatives or organisations that could be contacted and asked to participate? What sort of contribution can they make? Can they facilitate patient involvement for the review?
- What resources are available in the team to facilitate and incorporate patient involvement?
- Time – adding a patient involvement element to a review will impact on the time it takes to complete. The amount of time will depend not only on the approach taken

but also on how much extra work needs to be done to adapt technology information for patient involvement so that it is in an appropriate format for patient comment.

- Skills required – depending on the methods used to engage patients, new skills may be required within the HSC team. For example, qualitative methods skills such as facilitating focus groups, questionnaire design and the associated data analysis.
- PPI etiquette – the HSC analysts have well developed skills in liaison with clinical experts and commercial developers. These skills are *not directly* transferable to liaising with individual patients or patient groups; therefore skills and experience need developing in the use of appropriate language and care taken in choosing the mode of communicating (e.g. email, telephone etc.). The HSC has to be careful not to artificially raise expectations for those invited to participate.
- Output – ensuring a balance between an output that is suitable for health professionals and policy makers and one that is accessible to the general public.

## 4. CONCLUSIONS

The last two years have seen a considerable and concerted increase in the PPI activity within the HSC. Generally it has been a positive experience which has added value to the work of HSC with new and important insights included around usability, practicality and accessibility of new health technologies, resulting in an increase in the validity of the final output. Utilising PPI within reviews, when relevant, has added value to the final outputs, and the juxtaposition of clinical and patient viewpoints on technologies has been illuminating. The website review was successful and enlightening with the future incorporation of the majority of comments hopefully leading to a more accessible HSC website. However, the future of incorporating patient and public comments on an individual technology basis, through commenting on drug briefings and assisting with medtech prioritisation, still requires further investigation.

The most successful and productive PPI within the HSC has come from working in partnership with other relevant organisations from the onset of individual projects. The HSC has benefited enormously from their skills, experience and access to networks.

A good deal of time has also been usefully spent liaising with the ever growing field of healthcare researchers and other professionals engaged within the PPI sphere. Our particular thanks are extended to INVOLVE, their support and guidance has been invaluable.

All the lessons learnt over the last two years, and new ideas, will now be taken forward into our PPI plans for 2015-2016 which are outlined in our next PPI strategy on our [website](#). The main methods employed in developing our new strategy were:

- Brief literature search for peer-reviewed relevant articles and policy documents from 2013-2014.
- Questionnaire survey to those team members at the HSC that have recently been involved in PPI, for feedback on experiences and gathering of views. Questions were centred around what impact they thought the inclusion of PPI

made to the activity, what worked particularly well, and what could have been done better.

- Continued support and liaison with INVOLVE.
- Consultation with the HSC's Senior Management Team.

## 5. APPENDIX

### ABSTRACT ONE

Patient and public involvement (PPI) and engagement in early awareness and alert (EAA) activities in England. Miles K, Cook A, Packer C. HTAi 2014, Washington, DC

The NIHR Horizon Scanning Centre (HSC) aims to supply timely information to UK research commissioners and NHS policy makers in England on emerging health technologies that may have a significant impact on patients or the provision of health services.

#### **Aim and objective**

The HSC aimed to investigate the potential benefits of increasing patient and public involvement (PPI) and engagement in early awareness and alert (EAA) activities, and to identify areas of work where we can build and strengthen mutually advantageous relationships.

#### **Methods**

In August 2012 we undertook a search to identify literature documenting PPI in EAA activities. We networked with experts and key academics in England to identify good practice and discuss implementation in a range of organisations.

#### **Results**

We found no literature on the use of PPI in EAA activities. With input from the experts consulted, we developed a PPI strategy and identified areas for initial piloting of methods. We are implementing this strategy and are:

- Involved in the provision of information on key developments in the pipeline in a topic area (inherited eye disorders) identified by a patient-clinician priority setting partnership (PSP),
- Asking for feedback and comments from a patient group on topics identified as potentially of interest in one of our horizon scanning in-depth reviews (urinary and faecal incontinence),
- Increasing the targeting of our outputs to specific patient groups by Twitter. Between 30<sup>th</sup> May 2013 and 8<sup>th</sup> January 2014, 39 patient groups have been targeted with information about our published outputs, with 6 patient groups tweeted more than once, and
- Investigating the practicality of recruiting a patient group to explore and reflect on the accessibility and signposting of our current website.

#### **Conclusions**

We are in the early stages of the implementation of our PPI strategy and will need to reflect on the implementation process and potential benefits.

## ABSTRACT TWO

Involving patients to review a website – positive first experiences. Cook A and Miles K. INVOLVE 2014 – Changing Landscapes.

The NIHR Horizon Scanning Centre (HSC) based at the University of Birmingham aims to supply timely information to UK research commissioners and NHS policy makers in England on emerging health technologies that may have a significant impact on patients or the provision of health services. The HSC is investigating the potential benefits of increasing patient and public involvement (PPI) and engagement in early awareness and alert activities, and to identify areas of work where we can build and strengthen mutually advantageous relationships.

One of our first PPI projects centred around involving three representatives from a local, pre-existing patient group in the review of two defined aspects of our website, namely the 'Suggest a topic' page and general website search facility. This involved a highly interactive session where the representatives had a laptop each and were encouraged to use the two website areas under review individually, followed by group feedback. The session was facilitated by the authors.

Practical issues around planning and running such a session will be discussed, with positive aspects and lessons learnt outlined. Finally the session will end on a discussion around the limitations of such an exercise and the underlying issues around tokenism and the managing of expectations that often challenge those undertaking PPI.

## 6. REFERENCES

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