

# Horizon Scanning Research & Intelligence Centre

Progress Report on Patient and  
Public Involvement & Engagement

April 2015 – March 2016

April 2016



This report presents independent research funded by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

The NIHR Horizon Scanning Centre,  
University of Birmingham, United Kingdom  
[nihrsric@contacts.bham.ac.uk](mailto:nihrsric@contacts.bham.ac.uk)  
[www.hsric.nihr.ac.uk](http://www.hsric.nihr.ac.uk)

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## LAY SUMMARY

The horizon scanning team based at the University of Birmingham looks out for important new treatments and tests (called 'health technologies') being developed to help patients or prevent illness. We will find these technologies by talking to the companies that are developing them and to the groups that are researching them. We need to identify these technologies before they become available for use so that decision-makers have time to decide whether the technology should be used in the NHS, which patients could benefit most, and plan any changes that are needed. This information is also helpful to agencies that fund research. They use horizon scanning to help look for areas that are developing fast and decide which areas need more funding.

Since 2012 we have been involving patients and the public in our work. For example we ask patient groups or charities to tell us what they think about technologies we have found. We also gather groups of the public together and ask them to help make things we do better, like improving our website. This report tells you about what we have achieved in our work with patients and the public in the period April 2015 to March 2016.

## INTRODUCTION

The purpose of this report is to describe the patient and public involvement and engagement (PPIE) work of the National Institute for Health Research (NIHR) Horizon Scanning Research & Intelligence Centre (HSRIC) from April 2015 to March 2016 that was originally proposed in our [second strategy document](#) published April 2015. The progress of implementing this strategy is outlined below under the action plan headings used in the original strategy. As the strategy covers the time period to the end of 2016, it is to be expected that some objectives are still in progress or have yet to be met.

## ACTION PLAN 2015-2016

### 1 - BUILDING AND SUSTAINING PARTNERSHIPS

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

#### Progress

A HSRIC staff member has joined the HTAi Interest Group on Patient and Citizen Involvement in HTA (Methods and Impact Working Group), regularly participating in telephone conferences and face to face meetings. Horizon scanning has been added to the work stream of the working group.

Articles about HSRIC and our PPIE work have appeared in a newsletter with an international audience e.g. the HTAi Interest Group on Patient and Citizen Involvement in HTA E-Bulletin November 2015. HSRIC has presented their experience of PPIE in Horizon scanning at the EuroScan International Network meeting in February 2016. The EuroScan network is now planning to work with HSRIC to prepare a section on PPIE to add to its [methods toolkit](#). An abstract describing our work has also been presented at the HTAi

international conference in 2015 about PPIE in Horizon Scanning reviews (see section 1.4).

**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 PPIE, and to investigate additional routes to gain access to patients and carers.**

Progress

Charity and patient groups involved in HSRIC work in 2015-2016 included: FORT (Fighting Oesophageal Reflux Together); Action against Heartburn; INPUT Diabetes; Action Duchenne; Muscular Dystrophy UK; Dravet Syndrome UK; UK Thalassaemia Society; MPS Society UK and Asthma UK.

A focus group looking at the HSRIC's website used volunteers from the Queen Elizabeth Hospital Birmingham. This group was identified and accessed through their Head of Patient Experience.

**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 PPIE and support the Centre in involving patients.**

Progress

- Teleconferences with the Assistant Directors at INVOLVE and with Director of Involvement & Engagement at NIHR CCF during 2015-2016.
- Article describing our work on PPIE in horizon scanning was published in INVOLVE's Autumn 2015 newsletter:

[www.involve.nihr.ac.uk/posttypenewsletter/autumn-2015/](http://www.involve.nihr.ac.uk/posttypenewsletter/autumn-2015/).

- HSRIC's PPIE work was cited as an example of good practice in INVOLVE's Values and Principles Framework published in October 2015:

[INVOLVE\(2015\) Public involvement in research: values and principles framework, INVOLVE: Eastleigh.](#)

- A HSRIC member participated in ‘NIHR standards for patient and public involvement (PPI): Exploring why and how to develop and use them’ - workshop, March 2016. Organised by NIHR CCF & INVOLVE.

**1.4 Prepare, as appropriate, publications and conference presentations of the PPIE activity within the HSRIC to ensure the broader dissemination of our work.**

Progress

Oral presentation - HTAi 2015

Patient and public involvement in horizon scanning reviews. Sue Simpson, Joanna Smith, Sara Trevitt. Global Efforts in Knowledge Transfer: HTA to Health Policy and Practice, HTAi 2015 12th Annual Meeting, 15-17 June 2015.

Abstract accepted for poster presentation - HTAi 2016

Involving the public in the development of an horizon scanning website: experiences from two focus groups. Kathryn Miles, Ali Cook & Muna Mohamed.

Papers covering the experiences of HSRIC in their PPIE work, and on PPIE within a review on artificial pancreases are currently being drafted.

## 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.**

Progress

The involvement of patients and carers is considered at the outset of each horizon scanning review. HSRIC has produced a process document which sets out points to consider before involving patients and carers in a review and approaches to consider that enable us to collect representative views on emerging technologies. Where possible, patients and carers are accessed through an existing patient organisation.

Reviews conducted from April 2015 to March 2016 involving patients include:

- A review of technologies for the diagnosis and monitoring of [Chronic Obstructive Pulmonary Disease](#) (COPD) where we sought the views of patients with COPD by approaching the existing Birmingham Lung Improvement Study (BLISS) Patient Advisory Group. We asked for their assistance to circulate an invitation to members. Three patients agreed to take part, and were sent tables summarising the identified and filtered technologies. The patients were asked to comment on specific aspects of each individual identified technology. In particular whether they believed the technology was new and/or innovative, whether the technology was likely to have a significant impact on themselves, other patients or health services, and whether they would you be willing to use the technology. Patient comments were incorporated into the final review table alongside those of clinical experts. Comments were used to help identify and highlight the most innovative, impactful and acceptable technologies. This review was posted on our website in July 2015.
- A review of technologies for non-invasive glucose monitoring (NIGM) where we collaborated with INPUT Diabetes to access and involve people with type 1 and/or 2 diabetes who regularly monitor their blood glucose levels at home. INPUT Diabetes is an organisation that aims to help people access diabetes technology and support from the NHS, including insulin pumps, smart glucose meters and continuous glucose monitoring. A list of technologies identified by the HSRIC team was sent to the Chief Executive and Chief Adviser and circulated via email to two people with diabetes and two carers of children with diabetes. The people with diabetes and carers were asked to provide comments on specific aspects of each NIGM technology, including whether they would be willing to use this technology, their opinions on whether the technology would improve quality of life and their personal experiences of using NIGM technology. This review will be posted on our website shortly.

**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.**

## Progress

### *Drug Briefings:*

Since April 2015 the drugs team have successfully contacted patient groups and received comments on:

- [Tadalafil for Duchenne muscular dystrophy](#): ambulatory male adolescents and children – to slow the decline in walking ability. July 2015.
- [LentiGlobin BB305 for beta-thalassaemia major](#) November 2015.
- [Dravet syndrome](#) (severe myoclonic epilepsy of infancy); in children aged 2 to 18 years – first line. November 2015.
- [Intrathecal idursulfase \(Elaprase\) for Hunter syndrome](#) (mucopolysaccharidosis type II). March 2016.

Comments have added:

- Up to date epidemiological data, particularly for rare diseases, where the patient groups maintain or oversee key disease registries e.g. the UK Thalassaemia Society provided epidemiological data for the UK based on their research.
- New information about the disease not found in our searches:
  - Dravet Syndrome UK gave extra information on triggers of seizures in Dravet syndrome
  - The UK Thalassaemia Society noted that the birth heel prick test triggers referral to secondary care before onset of symptoms. This was at odds with literature searches stating diagnosis at 6 to 24 months of age.
- Context for the current impact of disease and the possible impact of the new treatment on patients and their carers e.g. for Dravet syndrome that affects young children, comments provided parent and carer perspectives on the most demanding aspects of the disease.
- Impact of proposed new treatment e.g. for beta-thalassaemia major, the patient group highlighted that for many patients current treatments are inconvenient but can control the disease. Patients may be unwilling to trade this for potentially high-risk procedure.
- A recommendation to remove outdated information or information not suitable for a UK population e.g. delete thalassaemia minor as an out dated term.

- Suggestions for wording to improve the clarity and readability of the report.

From the pilot of patient group comments on drug briefing reports, a HSRIC process note has been developed to capture the experience and develop team best practice. This is now used to guide staff when they request patient group comments on briefing reports.

#### *MedTech prioritisation:*

In May 2015 the HSRIC MedTech team identified a medical device called the Reza band®. This is a wearable technology designed by Somna Therapeutics to reduce acid reflux into the throat and lungs and the associated symptoms of laryngopharyngeal reflux disease. We were uncertain of the potential for impact of this technology and decided to seek patient views on the device's acceptability. Comments were received from five individuals identified through our contact with Action Against Heartburn and Barrett's Wessex organisations. Four of the people who responded expressed their wish to try this device if it became available. The comments received were decisive in our final prioritisation decision and we pursued the technology and completed a MedTech alert: [Reza Band® for laryngopharyngeal reflux](#) - September 2015.

HSRIC utilised comments that the WoundCare Healthcare Technology Co-operative (HTC) had sought from patients on a technology and these were included in our subsequent alert: [MolecuLight i:X for visualisation of bacteria in chronic wounds](#) – November 2015.

### 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 PPIE within the Centre.**

#### Progress

This has been completed and was present when the new HSRIC website was launched in the summer of 2015. Please see <http://www.hsrc.nihr.ac.uk/for-the-public/>

**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.**

Progress

In November 2015 we conducted a focus group with 8 members of the public who volunteer at the Queen Elizabeth Hospital Birmingham. The purpose of the session was to ask for their thoughts and feedback on aspects of the HSRIC's new website including the search facility, 'suggest a topic' and 'for the public' pages. The participants ranged in age from 18 to over 75, and were an equal mix of men and women. The session was interactive with easy access to the website for all, with short exercises followed by facilitator led feedback. The session generated lots of useful comments from the participants for the HSRIC to consider in 2016.

**3.3 Ensure that when the new HSRIC website is launched in 2015, that any dissemination activity includes PPIE partners and patient groups to raise awareness of new and improved features e.g. 'suggest a topic' page, new 'for the public' page.**

Progress

- HSRIC has tweeted about 50 patient organisations/charities in Oct 2015 to raise awareness of the new and improved features on our website. The tweet was: 'Suggest topics, use our improved search facility & check out info for the public at our new website <http://bit.ly/1LPPDJX>'.
- Emailed participants of the focus group held in April 2014 to let them know of launch, October 2015.
- Extensive emailing to contacts made through PPIE activity to alert them to INVOLVE newsletter article (see 1.3) that references our 'suggest a topic' page. November 2015.

**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.**

### Progress

Lay summaries were introduced into HSRIC's drug briefings and MedTech alerts from September 2015. HSRIC plan to review these and possibly include in a routine quality audit later in 2016 or early 2017. An assessment exercise looking at the lay summaries will be held later in 2016.

### **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.**

#### Progress

Drug briefings, MedTech alerts and horizon scanning reviews are target tweeted at relevant patient groups and charities as appropriate. Fifty-eight targeted tweets were sent between April 2015 and the end of March 2016, to 38 unique organisations.

### **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.**

#### Progress

None to date.