

# Patient and Public Involvement (PPI) in Research at UHBristol NHS Foundation Trust:

## Current state and future strategy

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### 1. Summary

This strategy sets out a plan for strengthening patient and public involvement (PPI) in research at UHBristol, through all stages of research project design, grant submission, conduct and dissemination of findings and ultimately into improving treatment and clinical service delivery. Central to the plan will be development of resources and guidelines for clinicians at UHBristol.

This strategy has been developed by UHBristol R&I department in consultation with UHBristol researchers, patient representatives, People and Research West of England, and Bristol Health Partners.

**Approved by:** Trust Research Group 31<sup>st</sup> January 2014

**Delivery:** Research and Innovation.

**Reports to:** UHBristol Trust Research Group

### 2. Background

Many of our researchers already consult with patients in the design and running of clinical research. However, the involvement varies greatly, from patient partners as co-applicants on grants in some groups, to other studies where there has been no patient carer or public input. In the latter case this is because researchers either aren't convinced by evidence of benefit to date, or don't know how to go about, involving patients and members of the public in their research.

PPI in research is beneficial for many reasons. However, it is now a mandatory element of all grant applications, and the welcome result is that PPI is gaining a higher profile across the Trust and amongst the research workforce. This year (2012) we were required to feed back to the NIHR via the WCLRN what strategy UHBristol had for PPI in research. In order to do this we need to capture current activities, and develop resources for sharing best practice, guidelines and FAQs in order to help both researchers and patients/public who would like to be involved.

*"Involving patients and members of the public in research can lead to better research, clearer outcomes, and faster uptake of new evidence"* <http://www.nihr.ac.uk/awareness/>

For reviews on the impact of PPI in research see:

i) *Exploring impact: public involvement in NHS, public health and social care research.*

Available at: <http://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research/>

ii) The PIRICOM study: a systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research. Available at: [www.ukcrc.org/index.aspx?o=3239](http://www.ukcrc.org/index.aspx?o=3239)

### 3. Current state

#### 3.1 Current activities & guidelines

##### PPI at UHBristol - patient experience strategy

- UHBristol has a “Patient Experience” Team for public and patient involvement generally within the Trust. Members of R&I have worked with the team to incorporate some milestones for PPI in Research into the Trust’s PPI strategy (details below). A copy of the 2012-2015 strategy is available here: <http://www.uhbristol.nhs.uk/patients-and-visitors/patient-experience-and-involvement/>

##### PPI and Research - guidelines

- We encourage researchers to follow guidelines of INVOLVE and People and Research West of England (PRWE) for involving patients in research; these groups give advice on best practice to researchers.  
INVOLVE: <http://www.invo.org.uk/>  
People and Research West of England: <http://www.weahsn.net/prwe/>

##### PPI in research – current activities and events:

- Our research groups have different levels of involvement; including patients as research partners (on an equal basis as researchers), representation on research steering groups, and events for people who have taken part in a research trial.
- PRWE have held networking meetings and training courses for researchers and patients/public across Bristol.  
<http://www.weahsn.net/prwe/events-prwe>
- Significant research focussed PPI groups exist as stand-alone entities across the Trust, related mainly, but not exclusively, to research units, centres or networks. We do not know the scale of involvement.

#### 3.2. Incorporation of PPI in Research into current strategies:

##### UHBristol Research & Innovation Strategy 2014-19

PPI is embedded within the Trust’s Research and Innovation Strategy 2014-2019; the table below summarises relevant key actions and indicators. However, there has previously been no clear plan on how to implement these objectives and this will be addressed in section 4. The full R&I strategy can be downloaded at: <http://www.uhbristol.nhs.uk/research-innovation/our-research/>

<b>Aim 2</b> Train, mentor and support research-active staff to deliver high quality translational and applied health services research of direct patient benefit in our priority research areas.	
<b>Objective 2.4</b>	<b>Promote and develop patient/public involvement (PPI) for all clinical studies</b>
	<i>Ensure that the trust-approved PPI strategy dovetails and integrates with the PPI strategies and activities of our regional partners</i>
	<i>Work with our regional partners to maximise available resources to support research PPI through existing Trust and regional partner information systems</i>
	<i>Coordinate access to existing support across the region for researchers and monitor use and usefulness of these</i>

	<i>Work with existing PPI leads (Trust and regional partners) to develop sustainable support infrastructure for PPI – cost reimbursement, training, access</i>
	<i>Ensure researchers engage PPI at earliest stages of research study development through education and monitoring.</i>

### Trust's "Patient Experience Strategy 2012-2015"

In 2012 we asked the Trust Patient Experience group to embed PPI in Research in the overall strategy, and agreed the following objectives with them. However, there was no clear plan on how to implement these objectives and original deadlines were missed. This is addressed and new deadlines proposed in section 4 of this document. The full strategy can be downloaded from: <http://www.uhbristol.nhs.uk/patients-and-visitors/patient-experience-and-involvement/>

Objective	Action	Lead	Timescale	Measure of success
2. Share feedback and use this to drive change	2.2 Develop a record log that will include PPI activities conducted by the Research and Innovation team	Tony Watkin / Paul Lewis	1st September 2012	The Trust will have an up to date record of PPI activities that includes PPI work undertaken by the Research and and innovation team
4. Embed patient and public involvement at all levels of the organisation	4.4 We will develop links between the corporate PPI Team and the Research and Innovation (R&I) Team. This will include: - links across respective webpages - where appropriate, corporate PPI contribution to the R&I team's new PPI strategy	Debbie Postlethwaite / Elinor Griffiths / Paul Lewis / Tony Watkin	Cross-links between the PPI and Research websites put in place by September 2012; A formal PPI Strategy for Research will be developed by the R&I Team by April 2013; The R&I Team will produce a guide to PPI in Research by December 2012	Evidence of effective collaboration in the development of the areas described here.

## 4. Future strategy

**Aim: To increase patient and public participation in research design, implementation and dissemination in order to improve the quality of research and patient care**

The following tables list objectives, plus expected benefits and times for implementation

<b>Objective 1. To create a database of the PPI written on grant applications, whether the grant was awarded, and what PPI activity currently takes place in UHBristol, in order to monitor current studies, inform future applications, and share best practice</b>			
	Enabler	Benefit	Deadline
1.1	Collect examples of case studies throughout UHBristol in the form of practical steps and impact	Researchers and patients know what activities have worked well for different types of studies and in different groups;	30/06/14 – then ongoing
1.2	Record PPI in grant applications: type, whether grant was awarded, whether PPI was sustained throughout the project	We will be able to keep a record of this in order to inform future applications and report to NIHR etc. on our activity;	30/06/14 – then ongoing

		May show correlation between PPI input and likelihood of grant awarded	
1.3	Collate and maintain a list of existing patient/public groups, internally and externally, that input into research at UHBristol	Researchers can access existing groups rather than create new ones. Peer-support essential for patient involvement	30/06/14 – then ongoing

<b>Objective 2. To develop resources (promote access to and use of existing resources) for PPI in research and so increase the quality of research studies – applications, delivery and dissemination</b>			
	<b>Enabler</b>	<b>Benefit</b>	<b>Timeline</b>
2.1	Use existing systems and additional signposting to promote and support PPI at all stages in the research	PPI visibly an essential component of UHBristol research, signposting acts as trigger and leads to support	Ongoing
2.2	Share database of PPI activities and case studies (from Objective 1)	Researchers and public/patients are better informed about PPI & know where to go for further info/advice.	30/06/14 – then ongoing
2.3	Create web-based leaflets about engagement in PPI from a practical perspective for researchers and public (adapt from those already written but relevant to UHBristol).	Researchers and public/patients are better informed about PPI & know where to go for further info/advice.	30/06/14
2.4	Create UHBristol good practice guide for researchers, and disseminate. This will indicate appropriate level of input expected for different studies and signposts to appropriate support	To advise researchers on how to get started and the minimum expected; researchers will feel confident approaching patients & will give a unified approach across the Trust.	30/06/14
2.5	Raising awareness of PPI to researchers by regular updates using all appropriate media, examples of case studies, training events and workshops (to be done collaboratively with PRWE to avoid duplication of efforts)	Earlier involvement of PPI in grant applications. Researchers better understand the need for PPI in research studies	30/06/14 – then ongoing
2.6	Events and training for researchers and patients/public in collaboration with PRWE.	Researchers know what to put on grants; how to approach and involve patients. Patients/public know more about research (inc. methods); what they can expect and what is expected of them.	Ongoing
2.7	Linking with Trust PPI group & UoB/UWE public engagement groups.	Access to dissemination of info to patients, trustees, public. Raising awareness of research within Trust, and to local public. Access to patient groups in Divisions	31/10/12 then ongoing