



Patient, Carer, Public Involvement (PCPI) Strategy 2015 - 2018

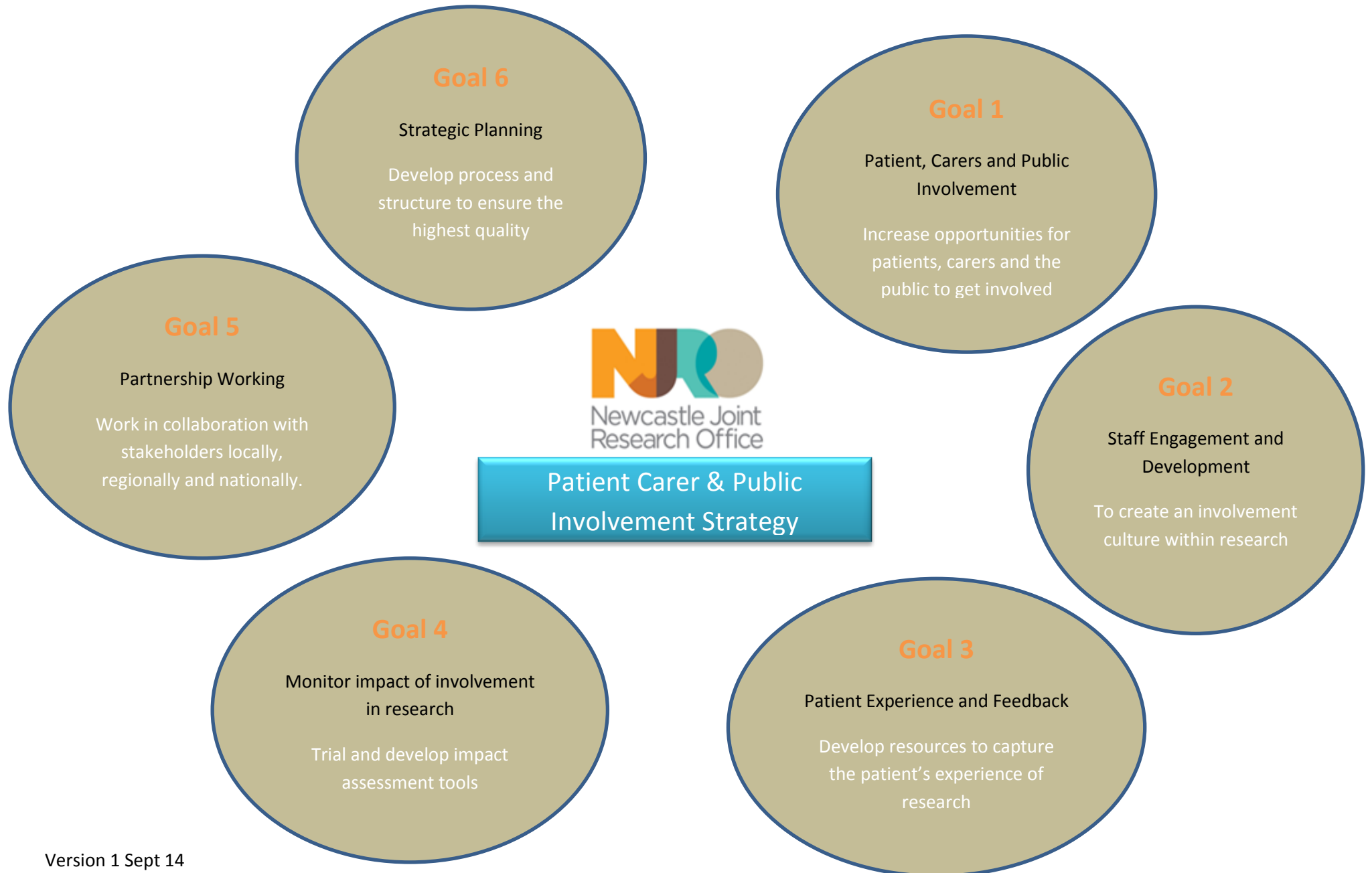
Summary

Patient carer and public involvement is a means of improving research rather than an end in itself. There are many ways that members of the public can be involved in research. Most often this is in partnership with others (such as researchers, academics, clinicians, methodologists, statisticians etc) and can include:

- Setting research priorities and identifying research questions
- Influencing the development and design of research
- Assessing research protocols and participating in making funding decisions
- Being active partners with researchers in the research process itself
- Ensuring the results of research are publicised and used
- Speaking up about the value of research

Patients, carers and the public need to be recognised as our research partners and we will continue to ensure that patients play a key part in research and development at The Newcastle Upon Tyne Hospitals. It is the aim of the research and development department to become an exemplar location for PCPI that makes a difference.

This strategy sets out a plan for strengthening patient and public involvement in research. Central to the plan will be the development of resources and guidelines to support staff across all disciplines within The Newcastle Upon Tyne Hospitals.



Goal 1 Patients, Carers and Public Involvement
<p>We are committed to:</p> <ul style="list-style-type: none"> Placing our patients, carers and public at the heart of everything we do.
<p>We currently achieve this by:</p> <ul style="list-style-type: none"> Funders currently ask researchers to demonstrate pcpi models in grant applications PCPI research working groups across speciality areas Promote research opportunities across the Trust Registration Database for patients through the platform
<p>We will develop this by:</p> <ul style="list-style-type: none"> Develop/review database to register patients interested in research Strengthen the diversity of Patient Focus Research Groups across speciality areas and/or patients research council Actively promote and participate annually in the NIHR “It’s okay to ask” campaign Scope opportunity to attend and participate in external events and seminars Develop patient information leaflets Review patient website on R & D pages

Goal 2. Staff Engagement and Development
<p>We are committed to:</p> <ul style="list-style-type: none"> Consistently provide high personal and professional standards in all pcpi activities To have pride in all that we do
<p>We currently achieve this by:</p> <ul style="list-style-type: none"> Provide some opportunity for training Allocated pcpi roles across some speciality areas Provide limited resources for pcpi activity
<p>We will develop this by:</p> <ul style="list-style-type: none"> Develop fit for purpose training opportunities Provide on-going pcpi support across staff domains Develop pcpi research strategy Create pcpi practical guidelines to enhance and share good practice Provide a bank of resources for research staff to enhance the quality of pcpi across the whole research cycle Improve website information for staff

Goal 3. Patient Experience and Feedback

We are committed to:

- Putting patients at the heart of research activity, listening and responding to their needs compassionately and demonstrating respect for their opinions and wishes. The experience of patients, service users and their carers should drive everything we do.

We currently achieve this by:

- Listening and acting upon anecdotal evidence
- Sporadically capture case studies demonstrating patient experience

We will develop this by:

- Develop resources to capture the patient experience of research
- Strengthen pcpi groups relating to research within the Trust
- Create an evidence trail / database of case studies

Goal 4. Monitor impact of involvement in research

We are committed to:

- Moving to a system where quality and outcomes drive everything we do.

We currently achieve this by:

We will develop this by:

- Capturing good quality case studies
- Evidence practice at every opportunity
- Monitor/support pcpi activity through the whole research cycle
- Review Quality Assurance frameworks
- Trial and develop fit for purpose impact assessment tools

Goal 5. Partnership working
<p>We are committed to:</p> <ul style="list-style-type: none"> • In partnership with others to be nationally and internationally respected for our successful clinical research and development programme which leads to benefits in healthcare and for patients
<p>We currently achieve this by:</p> <ul style="list-style-type: none"> • Working in collaboration with stakeholders • Report directly to NIHR
<p>We will develop this by:</p> <ul style="list-style-type: none"> • Work in close collaboration with Newcastle University • Report research pcp activity Trust wide • Seek opportunities to provide seamless signposting the Research Design Service • Actively promote “Involve” policy and framework • Strengthen collaborative systems and process in collaboration with Clinical Research Network • Continue to deliver and respond to NIHR • Provide overview for Newcastle Healthwatch members • Consider the involvement opportunities of other local groups eg: local council, support groups, voluntary groups

Goal 6. Strategic Planning
<p>We are committed to:</p> <ul style="list-style-type: none"> • To focus upon continuous improvement in the pursuit of excellence • To maintain financial viability and stability • Consistently develop high personal and professional standards in all pcp activities
<p>We currently achieve this by:</p> <ul style="list-style-type: none"> • Research and Development Executive Team
<p>We will develop this by:</p> <ul style="list-style-type: none"> • Implementing Operational standards • Develop Strategic planning • Adopt relevant Policy Frameworks • Embed practical reporting mechanisms • Review opportunistic Benchmarking

Work Plan 2015 – 2018

Goal	Action	Responsibility	Timescale	Comments
1 Patients, Carers and Public Involvement	<ul style="list-style-type: none"> Develop a database to register patients interested in research 	TS/ link staff	2015	Patients/public will know more about research, what they can expect and what is expected of them.
	<ul style="list-style-type: none"> Strengthen the diversity of Patient Groups 	Link staff within speciality areas	By 2017	Raising awareness of research and involvement opportunities for patients/public. Researchers can access existing groups rather than create new ones.
	<ul style="list-style-type: none"> Create a patients research council 	NJRO/TS	End 2015	Aim for this group to meet at least 3 times per year for the exchange of ideas and information within the department
	<ul style="list-style-type: none"> Promote and participate annually “It’s okay to ask” campaign 	NJRO PCPI working group TS/uni engagement team	Nov – May Annually	Media coverage, increased public awareness and participation
	<ul style="list-style-type: none"> Scope opportunity to attend and participate in events 	All & NJRO pcpi working group	On-going	Regular attendance at events internally and externally
	<ul style="list-style-type: none"> Develop patient information leaflets 	NJRO Website FG	End of 2016	Fits with R & D’s strategy – “provide written information relating to research in NuTH, and the opportunities arising, to 90% of out-patients and 75%of in-patients in NuTH by the end of 2016
	<ul style="list-style-type: none"> Review patient website on R & D pages 	TS/ communication focus group	2015	Patients/public will be more informed and know where to go for further advice/information.
2 Staff Engagement and Development	<ul style="list-style-type: none"> Develop fit for purpose training opportunities 	Uni engagement team/TS	2016	Researchers will have a better understanding of the need for PPI in research studies. Researchers will have a better understanding of minimum expectations and feel confident

	<ul style="list-style-type: none"> • Provide on-going pcpi support across all staff domains • Develop pcpi research strategy • Create/adopt pcpi guidelines to enhance and share good practice • Provide a bank of resources for research staff • Improve website information for staff • Promote pcpi activity through internal and external events 	<p>TS/NJRO PCPI working group</p> <p>TS/PCPI Trust Group, R & D Executive Board</p> <p>Involve, NIHR, TS</p> <p>NJRO Website FG</p> <p>NJRO website FG</p> <p>TS & uni engagement team</p>	<p>On-going</p> <p>Jan 2015</p> <p>On- going</p> <p>2016</p> <p>2015 - 2016</p> <p>On- going</p>	<p>in approaching research nurses and patient/public and will give a unified approach across the Trust.</p> <p>To be agreed by R & D executive team and Trust PCPI group</p> <p>To be presented and signed off by R & D executive board</p> <p>Accessible information and signposting info for staff</p> <p>Accessible information and signposting info for staff</p> <p>PR role and raising awareness of department</p>
<p>3 Patient Experience and Feedback</p>	<ul style="list-style-type: none"> • Develop resources to capture the patient experience • Strengthen pcpi research groups Trust wide • Create an evidence trail / database of patient case studies 	<p>TS & uni engagement team</p> <p>TS</p> <p>All</p>	<p>2016</p> <p>2015-2018</p> <p>On-going</p>	<p>Considerations FFT, Take 2 mins, mystery shopper</p> <p>Patients/public will be more informed and know where to go for further advice/information.</p> <p>The Trust will have an up to date record of PCPI activities within research.</p>

<p>4 Monitor impact of involvement in research</p>	<ul style="list-style-type: none"> • Capture good quality case studies • Evidence practice at every opportunity • Monitor/support pcpi activity through the research cycle • Review Quality Assurance frameworks • Trial and develop impact assessment tools 	<p>All</p> <p>All</p> <p>TS</p> <p>TS</p> <p>TS/uni engagement team</p>	<p>On-going</p> <p>On-going</p> <p>On-going</p> <p>On-going</p> <p>2015 - 2017</p>	<p>The Trust will have an up to date record of PCPI activities within research.</p> <p>This may inform future applications and report to NIHR on our activity.</p> <p>Inform R & D Exec Board</p> <p>Work in partnership with? New role? in engagement team to measure/evaluate impact</p>
<p>5 Partnership working</p>	<ul style="list-style-type: none"> • Work in close collaboration with Newcastle University engagement team • Report research pcpi activity Trust wide • Promote signposting to the Research Design Service • Actively promote “Involve” policy and framework • Strengthen systems and processes with CRN 	<p>NJRO & TS</p> <p>TS & Executive board</p> <p>NJRO</p> <p>TS</p> <p>TS</p>	<p>On-going</p> <p>Quarterly</p> <p>On-going</p> <p>On-going</p> <p>2016</p>	<p>Signposting will act as a trigger to good collaborative working and has a shared resource purpose and support mechanism. Attend joint meetings where possible</p> <p>Quarterly report of activity and strategy implementation</p> <p>Signposting will act as a trigger to good collaborative working and has a shared resource purpose and support mechanism.</p> <p>To be embedded within practice and evidenced accordingly</p> <p>Opportunistic and systematic</p>

	<ul style="list-style-type: none"> Continue to deliver and respond to NIHR requirements 	TS & Executive Board	On-going	
	<ul style="list-style-type: none"> Provide overview for Newcastle Health watch members 	TS	Annually	May support capacity issues for involvement in short term
	<ul style="list-style-type: none"> Consider the involvement opportunities of other local groups 	TS/uni engagement team	2016	Will support capacity issues for department, will ensure diversity
6 Strategic Planning	<ul style="list-style-type: none"> Implement Operational standards 	TS & Executive board	2015-2017	Standards to be presented reviewed and agreed by Executive board.
	<ul style="list-style-type: none"> Develop Strategic planning 	TS & Executive Board	2015	Plans to be presented reviewed and agreed by Executive board.
	<ul style="list-style-type: none"> Adopt Policy Frameworks 	TS	2015-2018	
	<ul style="list-style-type: none"> Embed practical reporting mechanisms 	TS & PCPI working group	2015-2016	Report mechanisms to be presented, reviewed and agreed by Executive board.
	<ul style="list-style-type: none"> Review opportunistic Benchmarking 	TS	2015	.
	<ul style="list-style-type: none"> Plan review of strategy 	TS & Executive board	2018	Review plans to be presented, reviewed and agreed by Executive board.
	<ul style="list-style-type: none"> To align and support BRC/BRC initiatives and activities 	TS, Uni engagement team, BRU BRC	On - going	.

Challenges

Budget

There is no easily accessible budget currently allocated within NJRO to support pcpi activities within the action plan. Costs may be incurred in relation to reimbursement of patient/public costs, staffing, catering, events and resource materials.

(Separate paper to be drafted for consideration)

Staffing

A PCPI Manager is employed within the research department. There are some research nurses within various speciality areas who have PCPI embedded within their job descriptions however this is not consistent across the Trust. There is no administrative support for PCPI.

(Separate paper to be drafted for consideration)