Annex 10

Patient and Public Involvement

This annex describes the structures and activities that have been put in place to improve Patient and Public Involvement in clinical research in the Health Service and research networks across the UK.

	England	Northern Ireland	Scotland	Wales
Strategy document for PPI in research	INVOLVE Strategic Plan 2007-11 http://www.invo.org.uk/wp-content/uploads/2011/11/INVOLVE-Strategic-Plan-2007-081107.pdf UKCRC PPI Strategic Plan 2008-11 http://www.ukcrc.org/patientsandpublic/ppi/ppistratplan/	Strategy for personal and public involvement in Health and Social Care research www.publichealth.hscni.net/publications/strategy-personal-and-public-involvement-health-and-social-care-research UKCRC PPI Strategic Plan 2008-11 www.ukcrc.org/patientsandpublic/currentppiprojects/ppistrategy.aspx	UKCRC PPI Strategic Plan 2008-11 www.ukcrc.org/patientsandpublic/currentppiprojects/ppistrategy.aspx	UKCRC PPI Strategic Plan 2008-11 www.ukcrc.org/patientsandpublic/currentppiprojects/ppistrategy.aspx Commitment to develop PPI strategy
Health Department funded support for PPI in research	INVOLVE www.invo.org.uk NIHR Central Commissioning Facility (CCF) http://www.ccf.nihr.ac.uk/PPI/Pages/default.aspx NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) http://www.netscc.ac.		Chief Scientist Office Public Involvement Group www.sehd.scot.nhs.uk/cso/AboutCSO/PublicInvolv.htm	Involving People: Cynnwys Pobl funded within NISCHR CRC http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=14773

	England	Northern Ireland	Scotland	Wales
	uk/getting_involved/			
Network staff with remit to support PPI	NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC) has a PPI Lead & a PPI Manager. Also an Assistant Director with PPI responsibilities and a Director of Planning and Programmes with overall responsibility for PPI. All TCRNs have PPI Lead & Associate Director with responsibility for PPI	Northern Ireland PPI Lead within HSC R&D	Networks are all encouraged to involve patients and the public in their work.	PPI lead within NISCHR CRC and Involving People Officer

	England	Northern Ireland	Scotland	Wales
Web resources with information about opportunities for PPI in the Networks	People in Research www.peopleinresearch.org NIHR CRN CC http://www.crncc.nihr.ac.uk/ppi DeNDRoN http://www.dendron.org.uk/ppi/index.html DRN www.ukdrn.org/patients.html MCRN – Children & Families http://www.mcrn.org.uk/children MHRN – SURGE (Service User Research Group England) http://www.mhrn.info/pages/people-with-experience-of-mental-health-problems.html MHRN – FACTOR (Friends and Families Together in Research) http://www.mhrn.info/pages/family-members-friends-or-carers.html Stroke Research Network www.uksrn.ac.uk/index.php?option=com_content&task=view&id=86&Itemid=120	People in Research www.peopleinresearch.org	People in Research www.peopleinresearch.org	People in Research www.peopleinresearch.org Involving People www.involvingpeople.org.uk/

	England	Northern Ireland	Scotland	Wales
Guidance available for patients/ public about PPI in research	People in Research www.peopleinresearch.org INVOLVE http://www.invo.org.uk/ UKCTG – UK Clinical Trials Gateway http://www.ukctg.nihr.ac.uk/default.aspx NIHR CRN CC – Getting Involved in Clinical Research http://www.crncc.nihr.ac.uk/ppi Healthtalkonline – people's experiences of clinical trials http://www.healthtalkonline.org/medical_research/ Youthhealthtalk – young peoples and parents real life experiences of clinical trials http://www.youthhealthtalk.org/Clinical_trials_in_children_and_young_people/	People in Research www.peopleinresearch.org	People in Research www.peopleinresearch.org	People in Research www.peopleinresearch.org Involving People – Flyer for patients, carers, service users www.involvingpeople.org.uk/
Guidance available for research professionals about PPI in research	INVOLVE http://www.invo.org.uk/	www.publichealth.hscni.net/sites/default/files/directorates/files/Personal%20and%20Public%20Involvement_PPI.		Involving People – Flyer for researchers www.involvingpeople.org.uk/

	England	Northern Ireland	Scotland	Wales
		pdf		
PPI training for patients/ public and research professionals	NIHR CRN CC 1 day course - Developing Best Practice Through Patient and Public Involvement NIHR CRN CC 1 day course -Introduction to Clinical Research Training courses provided by some of the TCRNs Training provided by RDSUs	NIHR CRN CC courses open to Devolved Nations	NIHR CRN CC courses open to Devolved Nations	NIHR CRN CC courses open to Devolved Nations Training courses provided by Cynnwys Pobl/ Involving People
Gathering evidence of the nature, processes and impact of PPI	INVOLVE Projects Database - research projects involving patients/public as partners in the research process http://www.invo.org.uk/resource-centre/research-project-database/	Able to use and contribute to INVOLVE Project database	Able to use and contribute to INVOLVE Project database	Able to use and contribute to INVOLVE Project database
	INVOLVE – invoNET Library http://www.conres.co.uk/Resources_Results.asp?val1=all	Able to use and contribute invoNET library	Able to use and contribute invoNET library	Able to use and contribute invoNET library
	- project reports reflecting on the impact, nature and extent of PPI in research	Able to use and contribute to UKCRC PPI Activities Log	Able to use and contribute to UKCRC PPI Activities Log	Able to use and contribute to UKCRC PPI Activities Log