

Repository Index¹

File Name	Where to find	Description	Uploaded
1) Designing, developing and reviewing patient information			
Facilitating-lay-review-of-patient-information	Guidance doc	Short doc on how to facilitate a lay review of patient information	Aug 2017
Template-Guide-Lay-Reviewers-2015	Handout	Customisable you could give to reviewers to guide them on how to review patient information sheet	Aug 2017
LayReview-Questions-You-Might-Ask-2016	Checklist	Use to check lay reviewer's understanding of a patient information sheet (very detailed)	Aug 2017
2a) Planning and evaluating PPI: Evaluating/measuring impact			
Brett-PPI-Impact-on-People-Involved-SystematicReview-2014	Peer-reviewed article	Systematic review of the impact of PPI on the people involved – 66 included studies	Aug 2017
Brett-PPI-Impact-on-Research-SystematicReview-2014	Peer-reviewed article	Systematic review of the impact of PPI on the research – 66 included studies	Aug 2017
PiiAF Assessment Framework (2014)	Guidance doc	Part 1 explores a range of factors that might shape public involvement impact and part 2 focuses on developing an impact assessment plan	Aug 2017
Staley-measuring-PPI-impact-2015	Peer-reviewed article	Review of quantitative evidence of impact of PPI	Aug 2017
Young-including-patients-in-COS-development-2016	Peer-reviewed article	Reports on 3 workshops that explored how patients can contribute to decisions on core outcome sets in clinical trials and identifies challenges	Aug 2017
Morris-Understanding-role-PPI-2017	Peer-reviewed article	Paper analysing motivation of people who are involved in PPI; a PPI group help design a recruitment campaign to recruit others to a PPI group	Nov 2017
2b) Planning and evaluating PPI: Planning PPI			
Bagley-PPI-DevelopingAToolki-2016	Peer-reviewed article	Describes the process used to develop a PPI toolkit at the Clinical Trials Unit, Liverpool. This paper reports on phase 1 (where can PPI happen in a clinical trial)	Aug 2017

¹ Links provided to resources that are publically available.

		and phase 2 (what resources exist already and where are the gaps?) of the toolkit development. Appendixes at the end point to tools developed so far.	
Buck-PPI-in-clinical-trials-2014	Peer-reviewed article	Compares PPI plans documented in trialists' grant applications with what actually happened, based on qualitative data from PIs and patient participants (UK data)	Aug 2017
RCP-for-Doctors-Research-engagement-toolkit- 2015	Guidance doc	A toolkit to support physicians get engaged in research. Information regarding PPI page 20-21	Aug 2017
NHS-PPI-GettingStarted-Handbook-2010	Guidance doc	A general overview of getting started with PPI handbook.	Aug 2017
Ennis—Impact-PPI-mental-health-studies-2013	Peer-reviewed article	Investigates over if PPI is associated with study success, defined as hitting recruitment targets, in all mental health studies registered on an MHRN database up to 2011.	Aug 2017
NIHR-Co-Producing-Research-Guidance	Guidance doc	Identifies some key principles and features involved in co-producing research, defines co-production, and written for public, researchers and other professionals. Plain English summary of theory and principles underpinning co-production.	Oct 2017
INVOLVE-PPI-EthicalResearch-2016	Briefing doc	A joint briefing from the Health Research Authority and INVOLVE on how public involvement can help in the ethical design and conduct of research.	Oct 2017
PPI-PlanningDissemination.pdf	Guidance doc	Good advice on involving patients and the public in communicating research findings, based on PPI experience in a flagship NIHR-funded study helping parents understand survival data about children's heart surgery.	Nov 017
TableOfContents-of-Involve-Briefing-Notes	Guidance doc	INVOLVE have 10 PPI Briefing notes on different aspects of PPI on their web site - a great place to start on each aspect of PPI.	Nov 2017
Sally-Crowe-onPPI-INFANTConf-2017	Powerpoint presentation	Conference presentation by Sally Crowe many useful references . Sally's web site is <u>http://www.crowe-associates.co.uk/patient-and-public-involvement-ppi/</u>	Nov 2017
INVOLVE-PPI-SysRev-2012	Guidance doc	General guidance on PPI in the systematic review process.	Feb 2018

3) PPI Tools and Toolkit			
CancerResearchUK-Toolkit-Summary	Guidance doc	Points to the Cancer Research UK toolkit web site - an excellent resource, very easy to navigate, with examples/templates for many of the steps of the PPI process.	Aug 2017
ResearchWithChildren-PPI-Toolkit-2011	Guidance doc	UK-produced toolkit, a how-to guide covering PPI in all steps in research cycle, with a focus on children's research	Aug 2017

4) Training – lay people			
NottinghamBioBank-LayPeopleTrainedfor Consent-2014	Folder	Description of process and all training materials used to train lay people to conduct the consent process in a bio-bank study	Aug 2017
Community-Groups-Interact-Researchers.pdf	Guidance doc	A guide for community groups working with universities on research projects: advice on how to get started and how to manage interactions	Oct 2017
DurhamUniversity-doing-research-together-easyread-2013	Guidance doc	Easy read explanation of PPI – doing research together	Feb 2018
NCRI-toolkit-for-laypeople-2014	Guidance doc	Guide to new lay people getting involved with the National Cancer Research Institute studies	Feb 2018

5) Training – researchers			
Involve- Developing training and support for public involvement in research - 2012	Involve report	Everything to think about when developing training and supports for both researchers and Lay people	Aug 2017
Graphic-Public-Participation-Spectrum	Graphic	International Association for Public Participation, developed a spectrum to help define the public's role in the public participation process (1 page)	Aug 2017
Geissler-Roadmap-PPI-Opportunities-2016	Graphic	Graphic that could be included in training slides on where PPI could be included across research cycle.	Oct 2017
Research Engagement Toolkit - 2015	Guidance doc	Page 20, PPI Section – UK based how to involve patients in research	Aug 2017
OxfordUniversity-working-with-PPI contributors-2017	Guidance doc	A detailed PPI go-to guide for researchers; covers all phases of PPI process; includes templates of many different documents required to run PPI activities	Aug 2017
Useful-links	Guidance doc	Pointers to miscellaneous PPI web sites	Aug 2017
UKCRF-Induction-Framework-PPI-section– 2016	Guidance doc	General Induction Booklet for NHS Clinical Research Staff – extracted Section B Theme 12 PPI section – how to define role, responsibilities and include in staff action plan.	Aug 2017
Low-Patient-Involvement-in-Drug-Development-2016	Peer-reviewed article	Article on the current level of PPI by pharmaceutical companies, based on qualitative interviews.	Oct 2017

EMA-Patient's-Voice-Included - 2014	Slide presentation	Presentation from Drug Information Association conference San Diego 2014 outlining how EMEA involve patients in regulatory processes	Oct 2017
INVOLVE-Guidance on co-producing a research project	Guidance doc	Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end the including the generation of knowledge.	Mar 2018
National Standards for Public Involvement in Research	National PPI Standards	The standards are the work of a Public Involvement Standards Development Partnership.	Mar 2018
Centre for research in Public Health and Community Care	Guidance Document	A guidance document for researchers on how to give feedback to PPI research contributors. Public and Patient Involvement (PPI): Feedback from Researchers to PPI Contributors.	2018