

Patient & Public Involvement, Engagement and Experience references and resources

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This set of resources is intended to help people to develop person centred improvement, innovation, research and care.

Please use, share, add to and send any feedback to:

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Person centred care

General

- Coulter A. Engaging patients' in Healthcare. (2011) Open University Press. Eng. <http://sgh.org.sa/Portals/0/Articles/Engaging%20Patients%20in%20Healthcare.pdf>
- National Voices. (2014). Prioritising person-centred care - the evidence <http://www.nationalvoices.org.uk/evidence>

Person-centred organisations – improvement methodologies

- **Schwartz Rounds** Goodrich J. (2012). Supporting hospital staff to provide compassionate care: Do Schwartz Center Rounds work in English hospitals? J R Soc Med, 105, 117–122. <http://www.pointofcarefoundation.org.uk/What-We-Do/>
- **Patient shadowing** http://www.kingsfund.org.uk/sites/files/kf/field/field_pdf/pfcc-patient-and-family-shadowing-guide.pdf
- **Experience-based co-design** Locock L et al. (2014). Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. Health service Deliver Res, 2(4). http://www.journalslibrary.nihr.ac.uk/data/assets/pdf_file/0013/112090/FullReport-hsdr02040.pdf

Person-centred organisations

- Dr Chih Hoong Sin, Dr Heather Heathfield, Kate Fitzpatrick, Leah Benson. Closing the gap through changing relationships. (2014). The Health Foundation. England <http://www.health.org.uk/publications/closing-the-gap-through-changing-relationships-evaluation/>
- Luxford K, Safran DG, Delbanco T. (2011). **Promoting patient-centred care: a qualitative study of facilitators and barriers in healthcare organisations** with a reputation for improving the patient experience. International Journal for Quality in Healthcare, May 16, pp1–6.
- Coulter A. (2012). **Leadership for patient engagement**. Kings Fund, London. <http://www.kingsfund.org.uk/sites/files/kf/leadership-patient-engagement-angela-coulter-leadership-review2012-paper.pdf>
- Doyle C, [Lennox](#) L, [Bell](#) D (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open. <http://bmjopen.bmj.com/content/3/1/e001570.abstract>
- The Picker Institute. (2011). **Always Events: creating an optimal patient experience**. Picker Institute. <http://alwaysevents.pickerinstitute.org/>
- Goodrich J, Cornwall J. The Point of Care Review: **Seeing the person in the patient** (2008). The Kings Fund. London

- DeSilva D. **Helping measure person-centred care.** A review of evidence about commonly used approaches and tools used to help measure person-centred care. (2014). Health Foundation. England.

<http://www.health.org.uk/public/cms/75/76/313/4697/Helping%20measure%20person-centred%20care.pdf?realName=lnet6X.pdf>

Patient and public involvement

General/Toolkits

- [Cartwright C](#), [Crowe S](#). (2011). **Patient and Public Involvement Toolkit.** Wiley Blackwell. BMJ Books.
- Scottish Health Council Participation Toolkit
http://www.scottishhealthcouncil.org/patient_public_participation/participation_toolkit/the_participation_toolkit.aspx
- <http://www.bhlink.org/res/media/pdf/ppitoolkitBMA.pdf>
- GP Patient Participation Groups Toolkit http://healthwatchreading.org.uk/wp-content/uploads/Healthwatch_PPG_Toolkit.pdf
- Public Involvement in Health Services Reading List: Kings Fund, 2014
http://www.kingsfund.org.uk/sites/files/kf/field/field_pdf/Library-reading-list-public-involvement-Aug2014.pdf
- http://www.evidenceintopractice.scot.nhs.uk/media/135286/involving_patients_and_carers_guide.pdf DH (2005)
- Working with people using services, carers and local citizens Think Local Act Personal [TLAP] http://www.thinklocalactpersonal.org.uk/Browse/Co-production/Working_with_people_using_services/

Research

- INVOLVE <http://www.invo.org.uk/resource-centre/putting-it-into-practice-database/>

Social media/digital

- Using social media. (2014). HSJ
<http://www.hsj.co.uk/Journals/2014/05/28/p/d/x/Social-Media-Pioneers-supplement.pdf>
- Digital Engagement <http://www.digitalengagement.info/2012/03/14/nhs-local/>
- Tweets about Hospital Quality: a mixed method study
<http://qualitysafety.bmj.com/content/early/2014/04/19/bmjqs-2014-002875.full.pdf+html>

Techniques/methods

- Experience Based Co-design (EBCD) <http://www.kingsfund.org.uk/projects/ebcd>

- Accelerated EBCD - <http://www.healthtalk.org/peoples-experiences/improving-health-care/trigger-films-service-improvement>
- Co-production <http://www.thinklocalactpersonal.org.uk/Browse/Co-production/>
- Co-production <http://coproductionnetwork.com/page/about-coproduction>
- Whose Shoes? Boardgame involvement tool <http://nutshellcomms.co.uk/>
- Making community engagement interactive and fun <http://www.involve.org.uk/blog/2011/03/13/not-another-consultation-making-community-engagement-informal-and-fun>
- National Co-ordinating Centre for public engagement <http://www.publicengagement.ac.uk/do-it/techniquesapproaches>
- Participation Compass <http://participationcompass.org/article/index/method>

Commissioning

- Transforming Participation in Healthcare, Guidance for Commissioners, 2013 <https://www.england.nhs.uk/2013/09/25/trans-part/>
- Royal College of General Practitioners Centre for Commissioning Guide http://www.rcgp.org.uk/policy/~/_media/Files/CIRC/Effective_PPI.ashx

Making the case/Evaluating the impact of involvement

- Making a Difference: A guide to evaluating public participation in central government <http://www.involve.org.uk/evaluation-guide/>
- <http://www.involve.org.uk/wp-content/uploads/2011/07/Making-the-Case-for-Public-Engagement.pdf>

Other publications

- [Patient and Public Engagement](#) - NHS Evidence library
- Participation Cymru (Wales) <http://www.participationcymru.org.uk/resources/other-publications>
- Child & Youth Participation Guide http://www.unicef.org/ceecis/Child_Youth_Resource_Guide.pdf

Patient engagement

People in control/People power

- [People in control of their own health and care](#) Kings Fund, blog around this subject called [Power to the people](#)
- <http://www.nesta.org.uk/project/people-powered-health>
- Mulley A, Trimble C, Elwyn G. (2012). Patients' Preferences Matter. Stop the silent misdiagnosis. The Kings Fund. London.

http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/patients-preferences-matter-may-2012.pdf

Co-production

- Co-production and people at the centre <http://www.nesta.org.uk/what-we-have-learnt-people-powered-health>

Self-management

- <http://selfmanagementuk.org/>

Personal Health Budgets

- <http://www.personalhealthbudgets.england.nhs.uk/Topics/latest/tags/?tag=co-production>

Shared Decision Making

- Coulter A, Collins A. (2011). Making Shared Decision-making (SDM) a Reality. No decision about me, without me. Kings Fund. England.

http://www.kingsfund.org.uk/sites/files/kf/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf

- The Health Foundation <http://personcentredcare.health.org.uk/person-centred-care/shared-decision-making/>
- Healthtalk <http://www.healthtalk.org/peoples-experiences/improving-health-care/shared-decision-making/topics>
- NHS Right Care <http://sdm.rightcare.nhs.uk/>

Patient Decision Aids

- The International **Patient Decision Aids** Standards (IPDAS) Collaboration's Quality Dimensions: Theoretical Rationales, Current Evidence, and Emerging Issues. (2013). Medical informatics and Decision Making, 13 (2).
- NHS England patient decision aids <http://www.england.nhs.uk/ourwork/pe/sdm/tools-sdm/pda/>
- [Sepucha KR](#). (2008). Developing instruments to measure the quality of decisions: early results for a set of symptom-driven decisions. Patient Educ Couns, 73(3):504-10. <http://www.pec-journal.com/article/S0738-3991%2808%2900340-6/abstract>

Patient experience

- Measuring patient experience. (2013). The Health Foundation. England <http://www.health.org.uk/public/cms/75/76/313/4300/Measuring%20patient%20experience.pdf?realName=7qM8Wm.pdf>
- Understanding and Using Health Experiences Improving Patient Care. Ed Ziebland S, Coulter A, Calabrese JD, Locock L. (2013). Oxford University Press. England.

- Robert G et al. (2011). What matters to patients'? Developing the evidence base for measuring and improving patient experience. Kings Fund. England.
http://www.institute.nhs.uk/images/Patient_Experience/Final%20Project%20Report%20pdf%20doc%20january%202012.pdf
- Kings Fund Patient Experience <http://www.kingsfund.org.uk/topics/patient-experience>
- http://www.experienceledcare.co.uk/docs/Rowlands_Pharmacy_Co-Designing_Services_with_Customers_and_Staff.pdf
- Healthtalk - Thousands of people have shared their experiences on film about what it's really like to have a health condition <http://www.healthtalk.org/>