PenCLAHRCThe NIHR CLAHRC for the South West Peninsula



Patient and Public Involvement Readings and Resources



Readings:

Barnes and Cotterell (eds) (2012) Critical perspectives on user involvement Bristol: Policy Press

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Brett, J. Staniszewska, S. Mockford, C. Seers, K. Herron-Marx, S. and Bayliss, H. (2010) The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research. UKCRC http://www.ukcrc.org/wp-content/uploads/2014/03/Piricom+Review+Final+2010.pdf

Brett J, Staniszewska S et al (2012). Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expectations.19 JUL 2012.

Britten, N. Denford, S. Harris, J. Harris-Golesworthy, F. Jibson, S. Pyart, N. Tatnell, L. Stein K. (accepted for publication). Patient involvement in drug licensing: a case study. Social Science and Medicine

Cartwright, J. Crowe, S (2011) Patient and Public Involvement Toolkit, Chichester: Wiley-Blackwell

Faulkner, A. (2004) The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors. Bristol: The Policy Press

Gibson A, Britten N, Lynch J. (2012) Theoretical Directions for an Emancipatory Concept of Patient and Public Involvement. Health, 16(5) 531-547

Harrison, S. and Mort, M (1998) Which Champions, Which People? Public and User Involvement in Health Care as a Technology of Legitimation Social Policy and Administration. 32:1, pp60-70

Ives, J. Damery, S. Redwod, S. (2012) PPI, paradoxes and Plato: who's sailing the ship? Journal of Medical Ethics. 39:3, pp181-185

Kennedy, I (2001) The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary1984–1995 Learning from Bristol. Norwich: The Stationary Office Ltd http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.bristolinquiry.org.uk/final_report/the_report.pdf

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Martin, G.P. (2008) "Ordinary people only": knowledge, representativeness, and the publics of public participation in healthcare. Sociology of Health & Illness. 30:1 pp35-54

Mockford C, Staniszewska S. Griffiths F, and Herron-Marx S (2011). The impact of patient and public involvement (PPI) on UK NHS healthcare: a systematic review. International Journal for Quality in Health Care, (1353-4505)

Morrow, E. Boraz, A. Brearley, S. Ross, F. (2012) The Handbook of Service User Involvement in Nursing and Healthcare Research. Chichester: Wiley-Blackwell

NICE (2008) Quick Reference Guide: Community Engagement http://www.nice.org.uk/nicemedia/live/11929/39565/39565.pdf

Oliver, M (1992) Changing the Social Relations of Research Production, Disability Handicap and Society, 7:2, pp101-115

Oliver, S., Rees, R., Clarke-Jones, L., Milne, R., Oakley, A., Gabbay, J., Stein, K., Buchanan, P. and Gyte, G. (2008) A multidimensional conceptual framework for analysing public involvement in health services research. Health Expectations, 11:1, pp72-84.

Popay, J. Williams G. (1996) Public health research and lay knowledge. Social Science & Medicine. 42: 5, pp759–768

Popay, J., Williams, G., Thomas, C. and Gatrell, T. (1998), Theorising Inequalities in Health: The Place of Lay Knowledge. Sociology of Health & Illness. 20, pp619–644

Prior, L. (2003) Belief, knowledge and expertise: the emergence of the lay expert in medical sociology. Sociology of Health & Illness. 25:3, pp41–57

Purtell, R. Gibson, A. (2012) How to Make Health and Social Care Research Really Really Useful. in Lloyd and Heller (eds) Long Term Conditions, Challenges in Health and Social Care. London: Sage

Richards, T. and Godlee, F. (2014) The BMJ's own patient journey: Seeks to promote patient partnership by walking the talk. British Medical Journal 2014; 348: g3726

Snape D, Kirkham J, Preston J, Popay J, Britten N, Collins M, Froggatt K, Gibson A, Lobban F, Wyatt K, Jacoby A. (2014) Exploring areas of consensus and conflict around values underpinning public involvement in health and social care research: a modified Delphi study. BMJ Open 2014;4:e004217

Staley, K. (2009) Exploring Impact: Public involvement in NHS, public health and social care research. Eastleigh: INVOLVE

Staniszewska S, Brett J, Mockford C, Barber R (2011). The GRIPP checklist: Strengthening the quality and transparency of reporting for patient and public involvement in research. International Journal of Technology Assessment for Health Care, 27 (4):391-399.

Tritter J. Q. and McCallum A. (2006) The snakes and ladders of user involvement: Moving beyond Arnstein. Health Policy. 76, pp156–168

Tritter, J.Q. (2009) Revolution or evolution: The challenges of conceptualizing patient and public involvement in a consumerist world. Health Expectations. 12, pp275–287

Tritter, J. Q. and Koivusalo, M. (2013) Undermining patient and public engagement and limiting its impact: The consequences of the Health and Social Care Act 2012 on collective patient and public involvement. Health Expectations. 16:2, June 2013, pp115–118

Ursu, I. Cowl J. (2010) Community membership of NICE groups producing public health guidance - Report of an evaluation study, NICE

Wallerstein, N, (2006) What is the evidence on effectiveness of empowerment to improve health? Copenhagen: WHO Regional Office for Europe

Weinstein (ed) (2010) Mental Health, Service User Involvement and Recovery. London and Philadelphia: Jessica Kingsley Publishers.

Williamson, C. (2010) Towards the emancipation of patients. Bristol: The Policy Press.

Videos:

Documenting patient and public involvement in research:

http://www.youtube.com/watch?v=_St3Mbcekrs

Healthtalkonline: People's Experiences of Patient and public involvement in research from a partnership between a charity (DIPEx) and The Health Experiences Research Group or 'HERG' at The University of Oxford's Nuffield Department of Primary Care. Includes both videos and transcripts. http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics

PenPIG: The Public involvement group for the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South West Peninsula

http://clahrc-peninsula.nihr.ac.uk/patient-public-involvement-in-research.php

http://clahrc-peninsula.nihr.ac.uk/meet-the-penpigs.php

Severe Pressure Ulcer Project Patient and Public Involvement

http://www.youtube.com/watch?v=bgg6zkblLrg

Webs:

Gripp 2: Developing Guidance for Reporting Involvement of Patients and Public http://www2.warwick.ac.uk/fac/med/research/hscience/rcn/research/themea/

INVOLVE: Funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research www.invo.org.uk

National Institute for Health Research:

Resources for researchers: http://www.nihr.ac.uk/get-involved/Resources-for-researchers.htm Resources for patients and the public: http://www.nihr.ac.uk/get-involved/Resources-for-patients-and-the-public.htm

PenCLAHRC: The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South West Peninsula http://clahrc-peninsula.nihr.ac.uk/patient-public-involvement-in-research.php http://clahrc-peninsula.nihr.ac.uk/ppi-conference.php

Public Involvement Impact Assessment Framework (PiiAF): http://piiaf.org.uk

Simon Denegri's Lay Review: The Public and Health Research: http://simondenegri.com/