

Patient-Oriented Research Competencies for patients, healthcare providers, decision-makers and researchers

Listing of Included and Excluded Academic Studies

137 papers total went through full text review, of which 35 yielded data on competencies

- 35 Included studies - page 2
- 102 excluded studies – page 7

Published Literature - 35 Included Papers

Search #1 (9 papers)

28 (D28)

Shaywitz D.A., Martin J.B., Ausiello DA. Patient-oriented research: Principles and new approaches to training. *Am J Med* 2000 01 Aug 2000;109(2):136-140.

29 (D29)

Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, Wang Z, Elraiayah TA, Nabhan M, et al. Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expect* 2015 Oct;18(5):1151-1166.

38 (G38)

Dudley L, Gamble C, Allam A, Bell P, Buck D, Goodare H, et al. A little more conversation please? Qualitative study of researchers' and patients' accounts of training for patient and public involvement in clinical trials. *Trials* 2015;16

42 (GS42)

Bayliss K, Starling B, Raza K, Johansson EC, Zabalan C, Moore S, et al. Patient involvement in a qualitative meta-synthesis: lessons learnt. *Research Involvement and Engagement* 2016;2(1):18

44 (GS44)

Coon JT, Gwernan-Jones R, Moore D, Richardson M, Shotton C, Pritchard W, et al. End-user involvement in a systematic review of quantitative and qualitative research of non-pharmacological interventions for attention deficit hyperactivity disorder delivered in school settings: reflections on the impacts and challenges. *Health Expect* 2016 Oct;19(5):1084-1097.

88 (R88)

Brett J., Staniszewska S., Mockford C., Seers K., Herron-Marx S., Bayliss H. The PIRICOM Study: a systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research. 2010.

92 (R92)

Duffett L. Patient engagement: What partnering with patient in research is all about. *Thromb Res* 2017 Feb;150:113-120.

94 (R94)

Kirwan JR, de Wit M, Frank L, Haywood KL, Salek S, Brace-McDonnell S, et al. Emerging Guidelines for Patient Engagement in Research. *Value Health* 2017 Mar;20(3):481-486.

108 (SR_E108)

De Wit M.P.T., Berlo S.E., Aanerud G.J., Aletaha D., Bijlsma J.W., Croucher L., et al. European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. *Ann Rheum Dis* 2011 May 2011;70(5):722-726.

Search #2 – Searches of databases and new papers:

(MEDLINE 10 papers)

163 (M7Rev-19)

Arkind J, Likumahuwa-Ackman S, Warren N, Dickerson K, Robbins L, Norman K, et al. Lessons Learned from Developing a Patient Engagement Panel: An OCHIN Report. *J Am Board Fam Med*. 2015 Sep-Oct;28(5):632-8.

173 (M7Rev-29)

Backhouse T, Kenkmann A, Lane K, Penhale B, Poland F, Killett A. Older care-home residents as collaborators or advisors in research: a systematic review. *Age Ageing*. 2016 May;45(3):337-45.

174 (M7Rev-30)

Bailey S, Boddy K, Briscoe S, Morris C. Involving disabled children and young people as partners in research: a systematic review. *Child Care Health Dev*. 2015 Jul;41(4):505-14. 197

197 (M7Rev-53)

Blair T, Minkler M. Participatory action research with older adults: key principles in practice. *Gerontologist*. 2009 Oct;49(5):651-62.

233 (M7 Rev-89)

Chalmers JD, Timothy A, Polverino E, Almagro M, Ruddy T, Powell P, et al. Patient participation in ERS guidelines and research projects: the EMBARC experience. *Breathe*. 2017 Sep;13(3):194-207.

393 (M7 Rev-249)

Horowitz CR, Robinson M, Seifer S. Community-based participatory research from the margin to the mainstream: are researchers prepared? *Circulation*. 2009 May 19;119(19):2633-42.

397 (M7 Rev-253)

Hubbard G, Kidd L, Donaghy E. Involving people affected by cancer in research: a review of literature. *Eur J Cancer Care (Engl)*. 2008 May;17(3):233-44.

429 (M7 Rev-285)

Katigbak C, Foley M, Robert L, Hutchinson MK. Experiences and Lessons Learned in Using Community-Based Participatory Research to Recruit Asian American Immigrant Research Participants. *J Nurs Scholarsh*. 2016 Mar;48(2):210-8.

432 (M7 Rev-288)

Kelly PJ. Practical suggestions for community interventions using participatory action research. *Public Health Nurs*. 2005 Jan-Feb;22(1):65-73.

580 (M7 Rev-436)

Reed J, Weiner R, Cook G. Partnership research with older people - moving towards making the rhetoric a reality. *J Clin Nurs*. 2004 Mar;13(3a):3-10.

Additional Articles (1 paper)

143 (N-5)

Robbins M, Tuftte J, Hsu C. Learning to "Swim" with the Experts: Experiences of Two Patient Co-Investigators for a Project Funded by the Patient-Centered Outcomes Research Institute. *Perm J*. 2016 spring;20(2):85-8.

Review Articles (12 papers)

29_21

Nierse CJ, Schipper K, van Zadelhoff E, van de Griendt J, Abma TA. Collaboration and co-ownership in research: dynamics and dialogues between patient research partners and professional researchers in a research team. *Health Expect*. 2012 Sep;15(3):242-54. doi: 10.1111/j.1369-7625.2011.00661.x. Epub 2011 Feb 17.

29_38

May M, Law J. CBPR as community health intervention: institutionalizing CBPR within community based organizations. *Prog Community Health Partnersh*. 2008 Summer;2(2):145-55. doi: 10.1353/cpr.0.0019.

29_51

Ahmed SM, Palermo AG. Community engagement in research: frameworks for education and peer review. *Am J Public Health*. 2010 Aug;100(8):1380-7. doi: 10.2105/AJPH.2009.178137. Epub 2010 Jun 17.

137 (88_39)

Hubbard G, Kidd L, Donaghy E, McDonald C, Kearney N. A review of literature about involving people affected by cancer in research, policy and planning and practice. *Patient Educ Couns*. 2007 Jan;65(1):21-33.

138 (88_71)

Staniszewska S, Jones N, Newburn M, Marshall S. User involvement in the development of a research bid: barriers, enablers and impacts. *Health Expect*. 2007 Jun;10(2):173-83.

139 (88_75)

Telford R, Boote JD, Cooper CL. What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expect*. 2004 Sep;7(3):209-20.

88_39_39

McCormick S., Brody J., Brown P. & Polk R. (2004) Public involvement in breast cancer research: an analysis and model for future research. *International Journal of Health Services* 34, 625–646

88_39_44

Parboosingh J, Stachenko S, Inhaber S. A Model of Consumer Participation: The Canadian Breast Cancer Initiative. *Canadian Public Policy / Analyse de Politiques*. 1997 Spring;23:Special Joint Issue: Aging / Vieillesse:177-186.

92_15

Fleurence R, Selby JV, Odom-Walker K, Hunt G, Meltzer D, Slutsky JR, Yancy C. How the Patient-Centered Outcomes Research Institute is engaging patients and others in shaping its research agenda. *Health Aff (Millwood)*. 2013 Feb;32(2):393-400. doi: 10.1377/hlthaff.2012.1176.

92_48

Morrow E, Ross F, Grocott P, Bennett J..A model and measure for quality service user involvement in health research. *International Journal of Consumer Studies*. 2010 Sept;34(5):532-39.

136 (108_9)

Abma TA, Nierse CJ, Widdershoven GAM. Patients as partners in responsive research: methodological notions for collaborations in mixed research teams. *Qual Health Res*. 2009 Mar;19(3):401-15.

135 (108_21)

Abma TA, Broerse JEW. Patient participation as dialogue: setting research agendas. *Health Expect*. 2010 Jun;13(2):160-73.

UK Paper (3 papers)

UK-65

Braye S, Preston-Shoot M. Emerging from out of the shadows? Service user and carer involvement in systematic reviews. *Evidence and Policy*. 2005;1(2):173-94.

UK-74

Cornes M, Peardon J, Manthorpe J, 3YO Project Team. Wise owls and professors: the role of older researchers in the review of the National Service Framework for Older People. *Health Expect*. 2008 Dec;11(4):409-17.

UK-100

Meyer MC, Torres S, Cermeno N, MacLean L, Monzon R. Immigrant women implementing participatory research in health promotion. *West J Nurs Res*. 2003 Nov;25(7):815-34.

Published Literature 102 Excluded Papers – Final List

Search #1 (33 papers)

33 (G33)

INVOLVE: Involving the public in systematic reviews: What does the evidence tell us? Conference 2012. <http://www.invo.org.uk/posttypeconference/involving-the-public-in-systematic-reviews-what-does-the-evidence-tell-us/>.

4 Boote

Boote J.; Baird W.; Sutton, A. Public involvement in the design and conduct of clinical trials: A narrative review of case examples. *Trials* 2011 8()

14 Boote

Boote, Baird & Sutton Public involvement in the systematic review process in health and social care: a narrative review of case examples. *Health Policy* 2011 102; 105.

8. Boote

Boote, J. Telford R & Cooper C. Consumer involvement in health research: A review and research agenda. *Health Policy* 2002 61(2) 213.

10 Collins

Collins K.; Boote J.; Ardron D.; Gath J.; Green T.; Ahmedzai, S. H. Making patient and public involvement in cancer and palliative research a reality: academic support is vital for success. *BMJ Supportive & Palliative Care* 2015 5(2) 203.

15 Domecq

Domecq, Pablo; Prutsky, G; Elraiyyah, T et al. Patient engagement in research: a systematic review. *BMJ Health Services* 2014 24(14) 89.

16 Esmail

Esmail, L; Moore, E; Rein, A Evaluating patient and stakeholder engagement in research: moving from theory to practice, *Journal of Comparative Effectiveness Research* 2015 4(2) 133.

22 Miller

Miller, C.L.; Mott, K; Cousins, M; Miller, S; et al. Integrating consumer engagement in health and medical research - an Australian framework. *Health Research Policy and Systems* 2017 15(1) 9

24 Rubio

Rubio D.M.; Schoenbaum E.E.; Lee L.S.; Schteingart D.E et al. Defining translational research: implications for training. *Academic Medicine* 2010 83(3) 470

25 Sacristan

Sacristan J. Patient-centered medicine and patient-oriented research: improving health outcomes for individual patients. *BMJ Medical Informatics and Decision Making* 2013 13:6

26 Sarrami

Sarrami-Foroushani,P; Travaglia,J; Debono,D; Braithwaite,J. Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review. *BMJ Health Services* 2014 14:42

27 Sarrami

Sarrami-Foroushani,P; Travaglia,J; Debono,D; Braithwaite,J. Key concepts in consumer and community engagement: a scoping meta-review *BMJ Health Services* 2014 14:250.

35 PiiAF

PiiAF Study Group. The Public Involvement Impact Assessment Framework: executive summary. <http://piiاف.org.uk/documents/exec-summary-0114.pdf>

48 Evans

Evans,B. A.;Porter ,A.M.;Snooks, H.A.; Burholt,V. Developing a model to enhance patient involvement in designing and conducting research: views of patients, academics and health service staff. *Emergency Medicine Journal* 2016 33(9) e6.

49 Minogue

Minogue,V; Boness,J; Brown,A; Girdlestone,J, The impact of service user involvement in research. *International journal of health care quality assurance* 2005 18: 103.

56 Crossing

Crossing A.M.S.;Whelan,B. Cancer consumer involvement in research in Australia celebrating ten years (2005-2015) of cancer voices' cir program. *Asia-Pacific Journal of Clinical Oncology* 2015 11: 107

71 Oliver

Oliver S.; Liabo K.; Stewart R.; Rees,R. Public involvement in research: Making sense of the diversity. *Journal of Health Service Research and Policy* 2015 20(1) 45.

72 Paterson

Paterson, C. Take small steps to go a long way' consumer involvement in research into complementary and alternative therapies. *Complementary Therapies in Nursing and Midwifery* 2004 10(3) 150.

75 Saunders

Saunders C.;Girgis A.;Butow P.;Crossing S.;Penman,A. Beyond scientific rigour: Funding cancer research of public value. *Health Policy* 2007 84:234.

76 Stevens

Stevens T.;Wilde D.;Hunt J.;Ahmedzai,S. H. Overcoming the challenges to consumer involvement in cancer research. *Health Expectations* 2003 6(1) 81.

78 Thornton

Thornton, H. Patient perspectives on involvement in cancer research in the UK. *European Journal of Cancer Care* 2002 11(3) 205.

79 Wyatt

Wyatt K.;Carter M.;Mahtani V.;Barnard A.;Hawton A.;Britten,N. The impact of consumer involvement in research: An evaluation of consumer involvement in the London Primary Care Studies Programme. *Family Practice* 2008 25(3) 154.

81 Nordhoek

Noordhoek,J; Gulmans,V; van der Ent,K; Beekman,M. Intestinal organoids and personalized medicine in cystic fibrosis: a successful patient-oriented research collaboration. *Current Opinion in Pulmonary Medicine* 2016 22(6) 610.

82 Pelletier

Pelletier,J-F; Lesage,A; Boisvert,C; Denis,F; Bonin,J-P; Kisely,S. Feasibility and acceptability of patient partnership to improve access to primary care for the physical health of patients with severe mental illnesses: an interactive guide. *International Journal for Equity in Health* 2015 14:78

83 Snyder

Snyder,H; Engstrom,J The antecedents, forms and consequences of patient involvement: A narrative review of the literature. *International journal of nursing studies* 2016 53:351.

84 Thornton

Thornton,H; Edwards,A; Elwyn,G. Evolving the multiple roles of 'patients' in health-care research: reflections after involvement in a trial of shared decision-making. *Health Expectations* 2003 6(3)189.

85 Attree

Attree,P; French,B; Milton,B; Povall,S; Whitehead,M. Popay,J. The experience of community engagement for individuals: a rapid review of evidence. *Health & Social Care in the Community* 2011 19(3) 250

89 Cancer Australia

Cancer Australia and Cancer Voices Australia. National Framework for Consumer Involvement in Cancer Control. 2011.

90 Concannon

Concannon,TW.; Fuster,M; Saunders,T; Patel,K; Wong,JB.; Leslie,LK.; Lau,J A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research Journal of General Internal Medicine 2014 29(12) 1692

99 Sarrami

Sarrami-Foroushani,P; Travaglia,J; Debono,D; Braithwaite,J. Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review. BMC Health Services Research, 2014 13:402

101 Shen

Shen,S.; Doyle-Thomas,K. .; Beesley,L.; Karmali,A.; Williams,L.; Tanel,N.; McPherson,A. C. A scoping review of current practices Health Expectations 2016

126 Forsythe

Forsythe,L.P.; Ellis,L.E.; Edmundson,L.; Sabharwal,R.; Rein,A; Konopka,K; Frank,L. Patient and Stakeholder Engagement in the PCORI Pilot Projects: Description and Lessons Learned Journal of General Internal Medicine 2016 31(1) 13.

Search #2 (22 papers)

150 (M7 Rev-6)

Adams A, Miller-Korth N, Brown D. Learning to work together: developing academic and community research partnerships. *WMJ*. 2004;103(2):15-9.

155 (M7Rev-11)

Allen J, Mohatt GV, Beehler S, Rowe HL. People awakening: collaborative research to develop cultural strategies for prevention in community intervention. *Am J Community Psychol*. 2014 Sep;54(1-2):100-11.

160 (M7Rev-16)

Anderson EE, Solomon S, Heitman E, DuBois JM, Fisher CB, Kost RG, et al. Research ethics education for community-engaged research: a review and research agenda. *J Empir Res Hum Res Ethics*. 2012 Apr;7(2):3-19.

170 (M7 Rev-26)

Austrom MG, Bachman J, Altmeyer L, Gao S, Farlow M. A collaborative Alzheimer disease research exchange using a community-based Helpline as a recruitment tool. *Alzheimer Dis Assoc Disord*. 2010 Jul-Sep;24(Suppl):S49-53.

171 (M7Rev-27)

Averill JB. An Ethnographic Meta-Synthesis of Three Southwestern Rural Studies. *Public Health Nurs*. 2016 Jan-Feb;33(1):32-41.

180 (M7Rev-36)

Barber R, Boote JD, Cooper CL. Involving consumers successfully in NHS research: a national survey. *Health Expect*. 2007 Dec;10(4):380-91.

181 (M7Rev-37)

Barnidge EK, Baker EA, Estlund A, Motton F, Hipp PR, Brownson RC. A Participatory Regional Partnership Approach to Promote Nutrition and Physical Activity Through Environmental and Policy Change in Rural Missouri. *Prev Chronic Dis*. 2015 Jun 11;12:E92.

182 (M7Rev-38)

Barnieh L, Jun M, Laupacis A, Manns B, Hemmelgarn B. Determining research priorities through partnership with patients: an overview. *Semin Dial*. 2015 Mar-Apr;28(2):141-6.

198 (M7 REV-54)

Blevins D, Morton B, McGovern R. Evaluating a community-based participatory research project for elderly mental healthcare in rural America. *Clin Interv Aging*. 2008;3(3):535-45.

211 (M7 REV-67)

Bronstein MG, Kakkis ED. Patients as key partners in rare disease drug development. *Nat Rev Drug Discov*. 2016 11;15(11):731-2.

220 (M7 REV-76)

Buckley B. There's a will...but is there a way? Patient perspectives in healthcare research, development, and decision making. *J Wound Ostomy Continence Nurs*. 2005 discussion 56-7; Jan-Feb;32(1):53-6.

221 (M7 REV-77)

Burns KEA, Devlin JW, Hill NS. Patient and Family Engagement in Designing and Implementing a Weaning Trial: A Novel Research Paradigm in Critical Care. *Chest*. 2017 Oct;152(4):707-11.

234 (M7 REV-90)

Chen Y, Chalmers I, Tti Editorial Alliance. Testing treatments interactive (Tti): helping to equip the public to promote better research for better health care. *J Evid Based Med*. 2015 May;8(2):98-102.

246 (M7 REV-102)

Commodore A, Wilson S, Muhammad O, Svendsen E, Pearce J. Community-based participatory research for the study of air pollution: a review of motivations, approaches, and outcomes. *Environ Monit Assess*. 2017 Aug;189(8):378.

262 (M7 REV-118)

Cunningham-Burley S. Public knowledge and public trust. *Community Genet*. 2006;9(3):204-10.

274 (M7 REV-130)

Demian MN, Lam NN, Mac-Way F, Sapir-Pichhadze R, Fernandez N. Opportunities for Engaging Patients in Kidney Research. *Can j kidney health dis*. 2017;4: doi.org/10.1177/2054358117703070

276 (M7 REV-132)

Dent M, Pahor M. Patient involvement in Europe—a comparative framework. *J Health Organ Manag*. 2015;29(5):546-55.

326 (M7 REV-182)

Fudge N, Wolfe CDA, McKeivitt C. Involving older people in health research. *Age Ageing*. 2007 Sep;36(5):492-500.

347 (M7 REV-203)

Gore JL. Incorporating the Patient into Urologic Cancer Research. *Urol Oncol*. 2017 Sep;35(9):546-7.

486 (M7 REV-342)

Macaulay AC. Promoting participatory research by family physicians. *Ann Fam Med*. 2007 Nov-Dec;5(6):557-60.

500 (M7 REV-356)

Mayan MJ, Daum CH. Worth the Risk? Muddled Relationships in Community-Based Participatory Research. *Qual Health Res*. 2016 Jan;26(1):69-76.

566 (M7 REV-422)

Ponic P, Reid C, Frisby W. Cultivating the power of partnerships in feminist participatory action research in women's health. *Nurs Inq*. 2010 Dec;17(4):324-35.

Embase (4 papers)

790 (E2 Rev-51)

Crocker J., HughesMorley A., PetitZeman S., Rees S. Assessing the impact of patient and public involvement on recruitment and retention in clinical trials: A systematic review. Netherlands: 3rd International Clinical Trials Methodology Conference. United Kingdom. 16 (no pagination); BioMed Central Ltd.; 2015. *Trials*. 2015;16(Suppl 2):O91.

814 (E2Rev-75)

Frankena T.K., Naaldenberg J., Cardol M., Linehan C., van Schrojenstein Lantmande Valk H. Active involvement of people with intellectual disabilities in health research - A structured literature review. *Res Dev Disabil*. 2015 Oct-Nov;45-46:271-83.

836 (E2 Rev-97)

Haijes H.A., Van Thiel GJM.W. Participatory methods in pediatric participatory research: A systematic review. *Pediatr Res*. 2016 01 May 2016;79(5):676-83.

838 (E2Rev-99)

Hamilton C., Tran B.C., Yoo J.Y., Leese J., Li L. Development of a taxonomy of patient engagement in health research. Netherlands: American College of Rheumatology/Association of Rheumatology Health Professionals Annual Scientific Meeting, ACR/ARHP 2016. United States. 68 (pp 1485-1488); John Wiley and Sons Inc.; 2016.

CINAHL (2 papers)

1033 (CIN-13)

Camden C, Shikako-Thomas K, Nguyen T, Graham E, Thomas A, Sprung J, et al. Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts. *Disabil Rehabil.* 2015 07/15;37(15):1390-400.

1064 (CIN-44)

Kara H. "Mental health service user involvement in research: where have we come from, where are we going?", *Journal of Public Mental Health.* 2013;12(3):122-35.

Other (4 papers)

140 (N-2)

Evans BA, Porter AM, Snooks HA, Burholt V. Developing a model to enhance patient involvement in designing and conducting research: views of patients, academics and health service staff. *Emerg Med J.* 2016 BMJ Publishing Group Ltd and the British Association for Accident & Emergency Medicine;33(9):e6-.

141 (N-3)

Horobin A, Brown G, Higton F, Vanhegan S, Wragg A, Wray P, et al. Co-producing public involvement training with members of the public and research organisations in the East Midlands: creating, delivering and evaluating the lay assessor training programme. *Research Involvement and Engagement.* 2017 04/05;3(1):7.

142 (N-4)

Leese J, Kerr S, McKinnon A, Carruthers E, Backman C, Li L, et al. Evolving patient-researcher collaboration: an illustrative case study of a patient-led knowledge translation event. *J Participat Med.* 2017 2017, Aug 4;9:e13.

144 (N-6)

Shimmin C, Wittmeier KDM, Lavoie JG, Wicklund ED, Sibley KM. Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma-informed intersectional analysis. *BMC Health Serv Res.* 2017 Aug 7;17(1):539,017-2463-

Review Papers (10 papers)

29_32

Faridi Z, Grunbaum JA, Sajor Grey B, Franks A, Simoes E. Community-based participatory research: necessary next steps. *Prev Chronic Dis.* 2007 Jul;4(3):A70.

92-47

Staley K. 'Is it worth doing?' Measuring the impact of patient and public involvement in research. *Res Involv Engagem*. 2015 Jul 31;1:6.

756-1 (M7 REV 30_1)

Beresford, B. Working on Well-Being: Researchers' Experiences of a Participative Approach to Understanding the Subjective Well-Being of Disabled Young People. *Children & Society*. 2012;26(3):234-40.

756-2 (M7 REV 30_2)

Mogensen LL. 'I want to be me': Learning from teenagers diagnosed with autism using collaborative, participatory research. [dissertation]. Sydney (NSW): University of Western Sydney (Australia), ProQuest Dissertations Publishing, 2010. 10308811.

756-3 (M7 REV 30_3)

Street C, Herts B. Putting participation into practice: a guide for practitioners working in services to promote the mental health and well-being of children and young people. UK:YoungMinds;2005 Jun. Available from: <https://www.bl.uk/collection-items/putting-participation-into-practice-a-guide-for-practitioners-working-in-services-to-promote-the-mental-health-and-wellbeing-of-children-and-young-people>

756-4 (M7 REV 30_4)

Delman J. Participatory action research and young adults with psychiatric disabilities. *Psychiatr Rehabil J*. 2012 Winter;35(3):231-4.

756-5 (M7 REV 30_5)

Sloper P, Lightfoot J. Involving disabled and chronically ill children and young people in health service development. *Child Care Health Dev*. 2003 Jan;29(1):15-20.

756-6 (M7 REV 30_6)

Lightfoot J, Sloper P. Having a say in health: involving young people with a chronic illness or physical disability in local health services development. *Children & Society*. 2003 Sept;17(4):277-90.

756-7 (M7 REV 30_7)

Kembhavi G, Wirz S. Engaging adolescents with disabilities in research. L'implication des adolescents en situation de handicap dans les recherches participatives. *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap*. 2009 Jul-Sep;3(3):286-96.

756-10 (M7 REV 30_10)

Allsop MJ, Holt RJ, Levesley MC, Bhakta B. The engagement of children with disabilities in health-related technology design processes: identifying methodology. *Disabil Rehabil Assist Technol*. 2010 Jan;5(1):1-13.

UK Study (7 papers)

UK-6

Boote J. Patient and Public Involvement in Health and Social Care Research: A Bibliography. NIHR Research Design Service for Yorkshire and the Humber. White Rose university consortium. University of Leeds, Sheffield & York and National Institute for Health Research. July 2011. DOI: 10.13140/2.1.4084.4322

UK-17

Boote J, Baird W, Sutton A. Public Involvement in the Design and Conduct of Clinical Trials: A Review. *International Journal of Interdisciplinary Social Sciences*. 2011;5(11):91-111.

UK-32

Gilbert T. Involving people with learning disabilities in research: issues and possibilities. *Health Soc Care Community*. 2004 Jul;12(4):298-308.

UK-93

Howe A, MacDonald H, Barrett B, Little B. Ensuring public and patient participation in research: a case study in infrastructure development in one UK Research and Development consortium. *Primary Health Care Research & Development*. 2006;7(1):60-7.

UK-97

McCaffery KJ, Smith SK, Wolf M. The challenge of shared decision making among patients with lower literacy: a framework for research and development. *Med Decis Making*. 2010 Jan-Feb;30(1):35-44.

UK-118

Rowe A. The effect of involvement in participatory research on parent researchers in a Sure Start programme. *Health Soc Care Community*. 2006 Nov;14(6):465-73.

UK-132

Wright DN, Hopkinson JB, Corner JL, Foster CL. How to involve cancer patients at the end of life as co-researchers. *Palliat Med*. 2006 Dec;20(8):821-7.

Family Practice Journal (20 papers)

FP-1

Goodyear-Smith F. Collective enquiry and reflective action in research: towards a clarification of the terminology. *Fam Pract* 2017 Jun 01;34(3):268-271.

<https://academic.oup.com/fampra/issue/34/3>

FP-2

Macaulay AC. Participatory research: What is the history? Has the purpose changed?. Fam Pract 2017 Jun 01;34(3):256-258.

FP-2

Macaulay AC. Participatory research: What is the history? Has the purpose changed?. Fam Pract 2017 Jun 01;34(3):256-258.

FP-3

Ramsden VR, Rabbitskin N, Westfall JM, Felzien M, Braden J, Sand J. Is knowledge translation without patient or community engagement flawed?. Fam Pract 2017 Jun 01;34(3):259-261

FP-4

Westfall JM, Zittleman LK. Quandaries in patient and community engagement in research. Fam Pract 2017 Jun 01;34(3):253-255.

FP-5

Salsberg J, Macridis S, Garcia Bengoechea E, Macaulay AC, Moore S, KSDPP School Travel Planning Committee. The shifting dynamics of social roles and project ownership over the lifecycle of a community-based participatory research project. Fam Pract 2017 Jun 01;34(3):305-312.

FP-6

Chung JS, Young HN, Moreno MA, Kliems H, Cox ED. Patient-centred outcomes research: brave new world meets old institutional policies. Fam Pract 2017 Jun 01;34(3):296-300.

FP-7

Hahn DL, Hoffmann AE, Felzien M, LeMaster JW, Xu J, Fagnan LJ. Tokenism in patient engagement. Fam Pract 2017 Jun 01;34(3):290-295.

FP-8

MacFarlane A, Galvin R, O'Sullivan M, McInerney C, Meagher E, Burke D, et al. Participatory methods for research prioritization in primary care: an analysis of the World Cafe approach in Ireland and the USA. Fam Pract 2017 Jun 01;34(3):278-284.

FP-9

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