



**Wales Centre for Public Policy**  
**Canolfan Polisi Cyhoeddus Cymru**

# **Public engagement and 'A Healthier Wales': reshaping the care relationship**

## **Technical Annex: References**

**Paul Worthington, Sarah Quarmby and Dan Bristow**

January 2020



# The Wales Centre for Public Policy

The Wales Centre for Public Policy was established in October 2017. Our mission is to improve policy making and public services by supporting ministers and public services to access rigorous independent evidence about what works.

The Centre collaborates with leading researchers and other policy experts to synthesise and mobilise existing evidence and identify gaps where there is a need to generate new knowledge.

The Centre is independent of government but works closely with policy makers and practitioners to develop fresh thinking about how to address strategic challenges in health and social care, education, housing, the economy and other devolved responsibilities. It:

- Supports Welsh Government Ministers to identify, access and use authoritative evidence and independent expertise that can help inform and improve policy;
- Works with public services to access, generate, evaluate and apply evidence about what works in addressing key economic and societal challenges; and
- Draws on its work with Ministers and public services, to advance understanding of how evidence can inform and improve policy making and public services and contribute to theories of policy making and implementation.

Through secondments, PhD placements and its Research Apprenticeship programme, the Centre also helps to build capacity among researchers to engage in policy relevant research which has impact.

For further information please visit our website at [www.wcpp.org.uk](http://www.wcpp.org.uk)

## Core Funders



**Cardiff University** was founded in 1883. Located in a thriving capital city, Cardiff is an ambitious and innovative university, which is intent on building strong international relationships while demonstrating its commitment to Wales.



**Economic and Social Research Council (ESRC)** is part of UK Research and Innovation, a new organisation that brings together the UK's seven research councils, Innovate UK and Research England to maximise the contribution of each council and create the best environment for research and innovation to flourish.



**Welsh Government** is the devolved government of Wales, responsible for key areas of public life, including health, education, local government, and the environment.

# References

- Abelson, J., Li, K., Wilson, G., Shields, K., Schneider, C. and Boseveld, S. (2015). **Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool.** *Health Expectations*, 19, 817–827. Retrieved from: <https://onlinelibrary.wiley.com/doi/pdf/10.1111/hex.12378>
- Abelson, J., Humphrey, A., Syrowatka, A., Bidonde, J. and Judd, M. (2018). **Evaluating Patient, Family and Public Engagement in Health Services Improvement and System Redesign.** *Healthcare Quarterly*, 2018 Dec;21(SP), 61-67. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/30566406>
- Allender, S. (2018). **Using diagrams to create engaged communities for obesity prevention.** Health Foundation Webinar. Retrieved from: [https://www.health.org.uk/watch-system-mapping-tool-action?dm\\_i=4Y2,60HSX,ULE5VP,NKM6I,1](https://www.health.org.uk/watch-system-mapping-tool-action?dm_i=4Y2,60HSX,ULE5VP,NKM6I,1)
- Baldie, DJ., Guthrie, B., Entwistle, V. and Kroll, T. (2018). **Exploring the impact and use of patients' feedback about their care experiences in general practice settings—a realist synthesis.** *Family Practice*, Volume 35, Issue 1, February 2018, Pages 13–21. Retrieved from: <https://doi.org/10.1093/fampra/cmz067>
- Barratt, H and Raine, R. (2012). **Hospital service reconfiguration: the battle for hearts and minds.** *BMJ*, 2012;344:e953. Retrieved from: <https://www.bmj.com/content/bmj/344/bmj.e953.full.pdf>
- Barratt, H., Harrison, DA., Raine, R. and Fulop, N. (2015). **Factors that influence the way local communities respond to consultation processes about major service change: A qualitative study.** *Health Policy*, 119 (2015), 1210–1217. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4561526/>
- Bauld, L. (2011). **The impact of smoke free legislation in England: Evidence review.** Retrieved from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216319/dh\\_124959.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216319/dh_124959.pdf)
- Ben-Tovim, DI., Dougherty, ML., O'Connell, TJ. and McGrath, KM (2008). **Patient journeys: the process of clinical redesign.** *Medical Journal of Australia*, 2008; 188 (6): S14. Retrieved from: <https://www.mja.com.au/journal/2008/188/6/patient-journeys-process-clinical-redesign>

Board of Community Health Councils (CHCs) in Wales (2016). **National Ophthalmology (eye-care) patient experience review.** Retrieved from: <http://www.wales.nhs.uk/sitesplus/documents/899/FINAL%20NATIONAL%20EYE%2DCARE%20REPORT%20English.pdf>

Board of Community Health Councils (CHCs) in Wales (2016). **Accident & Emergency patient experience review: A view across Wales.** Retrieved from: <http://www.wales.nhs.uk/sitesplus/documents/899/ENGLISH%20REPORT%20IN%20FULL%20Accident%20and%20Emergency%20patient%20experience%20review%20Full%20report%20June%2020181.pdf>

van de Bovenkamp, HM., Trappenburg, MJ. and Grit, KJ. (2010). **Patient participation in collective healthcare decision making: The Dutch model.** Health Expectations Open Access, Volume 13, Issue 1, March 2010, 73-85. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/19719537>

Bull, D., Joy, I., Bagwell, S. and Sheil, F. (2014). **Supporting good health: the role of the charity sector: A discussion paper and topics for future research.** New Philanthropy Capital. Retrieved from: [https://www.thinknpc.org/wp-content/uploads/2018/07/NPC\\_Supporting-good-health.pdf](https://www.thinknpc.org/wp-content/uploads/2018/07/NPC_Supporting-good-health.pdf)

Carman, KL., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C. and Sweeney, J. (2013). **Patient and family engagement: a framework for understanding the elements and developing interventions and policies.** Health Affairs, 2013 Feb;32(2), 223-31. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/23381514>

Chatterjee, S., Davies, MJ., Stribling, B., Farooq, A. and Khunti, K. (2017). **Real-world evaluation of the DESMOND type 2 diabetes education and self-management programme.** Practical Diabetes, Volume 35 Number 1. Retrieved from: <https://wileymicrositebuilder.com/trends/wp-content/uploads/sites/29/2018/01/OA-Chatterjee-lsw.pdf>

Coalition for Collaborative Care (2019). **The Coalition for Collaborative Care website.** Retrieved from: <http://coalitionforcollaborativecare.org.uk/resources/>

Conner, M., Norman, P. (2017). **Health behaviour: current issues and challenges.** Psychology and Health, 32:8, 895-906. Retrieved from: <https://www.tandfonline.com/doi/full/10.1080/08870446.2017.1336240?src=recsys>

Co-production Wales (2019). **Co-production Wales website.** Retrieved from: <https://allinthistogetherwales.wordpress.com/coproduction/resources/>

Coulter, A. (2009). **Engaging communities for health improvement: A scoping study for the Health Foundation.** Retrieved from:  
<https://www.health.org.uk/sites/default/files/EngagingCommunitiesForHealthImprovement.pdf>

Coulter, A, Parsons, S. and Askham, J. (2008). **Where are the patients in decision-making about their own care?** WHO Health Systems and Policy Analysis. Retrieved from:  
<https://www.who.int/management/general/decisionmaking/WhereArePatientsinDecisionMaking.pdf>

Coulter, A., Edwards, A., Elwyn, G. and Thomson, T. (2011). **Implementing shared decision making in the UK.** Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, Volume 105 Issue 4, 2011, 300-304 Retrieved from:  
<https://www.ncbi.nlm.nih.gov/pubmed/21620325>

Coulter, A. (2012). **Patient engagement--what works?** Journal of Ambulatory Care Management, 2012 Apr-Jun;35(2), 80-9. Retrieved from:  
<https://www.ncbi.nlm.nih.gov/pubmed/22415281>

Coulter, A. (2014). **Collecting data on patient experience is not enough: they must be used to improve care.** BMJ, 2014;348:g2225. Retrieved from:  
<https://www.bmj.com/content/bmj/348/bmj.g2225.full.pdf>

Coulter, A. and Mearns, B. (2016). **Developing care for a changing population: Patient engagement and health information technology.** The Nuffield Trust. Retrieved from:  
<https://www.nuffieldtrust.org.uk/files/2017-01/patient-engagement-and-health-information-web-final.pdf>

Coulter, A., Kramer, G., Warren, T. and Salisbury, C. (2016). **Building the House of Care for people with long-term conditions: the foundation of the House of Care framework.** British Journal of General Practice, 2016; 66 (645): e288-e290. Retrieved from:  
<https://bjgp.org/content/66/645/e288>

Crocker, H., Lucas, R. and Wardle, J. (2012). **Cluster-randomised trial to evaluate the 'Change for Life' mass media/ social marketing campaign in the UK.** BMC Public Health, 2012 12:404. Retrieved from:  
<https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-12-404>

Dalton, J., Chambers, D., Harden, M., Street, M., Parker, G. and Eastwood, A. (2016). **Service user engagement in health service reconfiguration: a rapid evidence synthesis.** Journal of Health Services Research and Policy, 2016 Volume 21(3), 195–205. Retrieved from: <https://journals.sagepub.com/doi/abs/10.1177/1355819615623305>

Davis, S., Berkson, S., Gaines, ME., Prajapati, P., Schwab, W., Pandhi, N. and Edgman-Levitan, S (2016). **Implementation Science Workshop: Engaging Patients in Team-Based Practice Redesign—Critical Reflections on Program Design.** Journal of General Internal Medicine, 2016 Jun;31(6), 688-95. Retrieved from:

<https://www.ncbi.nlm.nih.gov/pubmed/26976290>

Diepeveen, S., Ling, T., Suhrcke, M., Roland, M. and Marteau, TM. (2013). **Public acceptability of government intervention to change health-related behaviours: a systematic review and narrative synthesis.** BMC Public Health, 2013 13:756. Retrieved from: <https://doi.org/10.1186/1471-2458-13-756>

DESMOND Project (2019). **DESMOND Programme website.** Retrieved from:

<https://www.desmond-project.org.uk/>

Djellouli, N., Jones, L., Barratt, H., Ramsay, AIG., Rowndrow, S. and Oliver, S. (2019). **Involving the public in decision-making about large-scale changes to health services: A scoping review.** Health Policy 123 (2019) 635–645. Retrieved from:

<https://www.sciencedirect.com/science/article/pii/S0168851019301137>

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P, Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A. and Barry, M. (2012). **Shared Decision Making: A Model for Clinical Practice.** Journal of General Internal Medicine, Oct; 27(10), 1361–1367. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3445676/>

Escobar, MAC., Veerman, JL., Tollman, SM., Bertram, MY. and Hofman, KJ. (2013). **Evidence that a tax on sugar sweetened beverages reduces the obesity rate: a meta-analysis.** BMC Public Health, 2013 13:1072. Retrieved from:

<https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-13-1072>

Filipe, A., Renedo, A. and Marston, C. (2017). **The co-production of what? Knowledge, values and social relations in healthcare.** PLoS Biol, 15(5):e2001403. Retrieved from:

<https://doi.org/10.1371/journal.pbio.2001403>

Foley, C., Drooga, E., Healyb, O., McHugh, S., Buckley, C. and Brown, JP. (2017). **Understanding perspectives on major system change: A comparative case study of public engagement and the implementation of urgent and emergency care system reconfiguration.** Health Policy, Volume 121 Issue 7, July 2017, 800-80. Retrieved from:

<https://www.sciencedirect.com/science/article/pii/S0168851017301471>

Forder, J., Jones, K., Glendenning, C., Caiels, J., Welch, E., Baxter, K., Davidson, J., Windle, K., Irvine, A., King D. and Dolan, P. (2012). **Evaluation of the personal health budget pilot programme.** Commissioned by UK Government Department of Health. Retrieved from:

<https://www.phbe.org.uk/index-phbe.php>

Forbat, L., Caylessa, S., Knightinga, K., Cornwell, J. and Kearney, N. (2009). **Engaging patients in health care: An empirical study of the role of engagement on attitudes and action.** Patient Education and Counseling, 74 (2009), 84–90. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/18790594>

Fulop, N., Walters, R., Perri, G. and Spurgeon, P. (2012). **Implementing changes to hospital services: Factors influencing the process and ‘results’ of reconfiguration.** Health Policy, 104 (2012), 128–135. Retrieved from: <https://www.sciencedirect.com/science/article/pii/S0168851011001096>

Graham, H. (1987). **Women’s smoking and family health.** Social Science and Medicine, 25(1), 47-56. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/3616697>

Greene, J. and Hibbard, J. (2012). **Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes.** Journal of General Internal Medicine, 2012 May;27(5), 520-6. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/22127797>

Greenhagh, P. (2009). **Patient and public involvement in chronic illness: beyond the expert patient.** BMJ, 2009;338:b49. Retrieved from: <https://www.bmj.com/content/338/bmj.b49.extract>

Griffiths, C, Foster, G., Ramsay, J., Eldridge, S. and Taylor, S. (2007). **How effective are expert patient (lay led) education programmes for chronic disease?** BMJ, 2007;334:1254. Retrieved from: <https://www.bmj.com/content/334/7606/1254.full>

Ham, C., Charles, A and Wellings D. (2018). **Shared responsibility for health: the cultural change we need.** The Kings Fund. Retrieved from: <https://www.kingsfund.org.uk/publications/shared-responsibility-health>

The Health Foundation (2012). **Helping people share decision making: A review of evidence considering whether shared decision making is worthwhile.** Retrieved from: <https://www.health.org.uk/sites/default/files/HelpingPeopleShareDecisionMaking.pdf>

The Health Foundation (2014). **Person-centred care: from ideas to action.** Retrieved from: <https://www.health.org.uk/publications/person-centred-care-from-ideas-to-action>

The Health Foundation (2016). **The eight principles of patient-centred care.** Retrieved from: <https://personcentredcare.health.org.uk/resources/eight-principles-of-patient-centred-care>



The Health Foundation (2016a). **Person-centred care made simple: What everyone should know about person-centred care.** Retrieved from: <https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple.pdf>

The Health Foundation (2018). **Are we expecting too much from the NHS?** Retrieved from: <https://www.health.org.uk/sites/default/files/NHS-70-Are-we-expecting-too-much-from-the-NHS.pdf>

The Health Foundation (2019). **Reframing the conversation on the social determinants of health.** Retrieved from: <https://www.health.org.uk/publications/reports/reframing-the-conversation-on-the-social-determinants-of-health>

Heijmans, M., Waverijn, G., Rademakers, J. and van der Vaart, R. (2015). **Functional, communicative and critical health literacy of chronic disease patients and their importance for self-management.** Patient Education and Counselling, 2015 Jan;98(1), 41-8. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/25455794>

Hibbard, J. and Greene, J. (2013). **What the evidence shows about patient activation: better health outcomes and care experiences; few data on costs.** Health Affairs, 32(2), 207-214. Retrieved from: <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2012.1061>

Hoffman, SJ. and Tan, C. (2015). **Overview of systematic reviews on the health-related effects of government tobacco control policies.** BMC Public Health, 15(744). Retrieved from: <https://bmcpublichealth.biomedcentral.com/track/pdf/10.1186/s12889-015-2041-6>

Hughes, TM., Merath, H., Chen, Q., Sun, S., Palmer, E., Idrees, JJ., Okunruntemi, V., Squires, M., Beal, EW. and Pawlik TM. (2018). **Association of shared decision-making on patient-reported health outcomes and healthcare utilization.** The American Journal of Surgery, Volume 216 Issue 1, July 2018, 7-12. Retrieved from: <https://www.sciencedirect.com/science/article/pii/S0002961017317488?via%3Dihub#sc4>

Huygens, MWJ., Vermeulen, J., Swinkels, ICS., Friele, RD., van Schayek, OCP. and de Witte, LC. (2016). **Expectations and needs of patients with a chronic disease toward self-management and eHealth for self-management purposes.** BMC Health Services Research, 2016 Jul 8;16:232. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/27391471>

IAP2 (2014). **IAP2's Public Participation Spectrum.** International Association for Public Participation. Retrieved from: [https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2\\_Public\\_Participation\\_Spectrum.pdf](https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2_Public_Participation_Spectrum.pdf)



Imison, C. (2015). **The reconfiguration of hospital services: is there evidence to guide us?** Future Hospital Journal, 2015 Volume 2 Number 2, 137–41. Retrieved from: <http://futurehospital.rcpjjournal.org/content/2/2/137.full>

Imison, C., Castle-Clarke, S., Watson, R. and Edwards, N. (2016). **Delivering the benefits of digital health care.** The Nuffield Trust. Retrieved from: <https://www.nuffieldtrust.org.uk/files/2017-01/delivering-the-benefits-of-digital-technology-web-final.pdf>

Independent Review Panel (2010). **Learning from reviews: An overview.** Retrieved from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/359402/Learning\\_from\\_Reviews3\\_PDF.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/359402/Learning_from_Reviews3_PDF.pdf)

Involve (2005). **People and Participation: How to put citizens at the heart of decision-making.** Retrieved from: <https://www.involve.org.uk/sites/default/files/field/attachemnt/People-and-Participation.pdf>

Involve (2019). **Deliberative Public Engagement.** Retrieved from: <https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement>

IOM (2002). **Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century.** Institute of Medicine. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/25057539>

Johnson, C., Bell, M. and Bristow, D. (2018). **Behaviour change in the Welsh NHS: insights from three programmes.** Public Policy Institute for Wales. Retrieved from: <https://www.wcpp.org.uk/wp-content/uploads/2018/06/180606-PPIW-Health-and-Behaviour-Change.pdf>

Jones, K., Welch, E., Fox, D., Caiels, J. and Forder, J. (2018). **Personal Health Budgets: Implementation following the national pilot programme; overall project summary.** Commissioned by UK Government Department of Health. Retrieved from: <https://www.pssru.ac.uk/pub/5433.pdf>

Jones, L., Fraser, A. and Stewart, E. (2019). **Exploring the neglected and hidden dimensions of large-scale healthcare change.** Sociology of Health and Illness, Vol. xx No. xx 2019 ISSN 0141-9889, 1–15. Retrieved from: <https://onlinelibrary.wiley.com/doi/pdf/10.1111/1467-9566.12923>

Jonker, L., Fisher, ST. and Dagnan, D. (2019). **Patients admitted to more research-active hospitals have more confidence in staff and are better informed about their condition and medication: Results from a retrospective cross-sectional study.** Journal of

Evaluation in Clinical Practice, 2019, 1–6. Retrieved from:

<https://onlinelibrary.wiley.com/doi/full/10.1111/jep.13118>

Kaehne, A. and Taylor, H. (2016). **Do public consultations work? The case of the Social Services and Well-being (Wales) Bill**. Public Policy and Administration 2016, Vol. 31(1), 80–99. Retrieved from: <https://journals.sagepub.com/doi/pdf/10.1177/0952076715595676>

Keating, NL and Pace, LE. (2018). **Breast Cancer Screening in 2018: Time for Shared Decision Making**. Journal of the American Medical Association, 2018 May 1;319(17), 1814-1815. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/29715344>

Khunti, K., Gray, LJ., Skinner, T., Carey, ME., Realf, K., Dallosso, H., Fisher, H., Campbell, M., Heller, S. and Davies., MJ. (2012). **Effectiveness of a diabetes education and self-management programme (DESMOND) for people with newly diagnosed type 2 diabetes mellitus: three-year follow-up of a cluster randomised controlled trial in primary care**. BMJ, 2012;344:e2333. Retrieved from: <https://www.bmj.com/content/344/bmj.e2333>

The Kings Fund (2011). **Reconfiguring hospital services**. Retrieved from: <https://www.kingsfund.org.uk/sites/default/files/Briefing-on-Reconfiguring-hospital-services-Candace-Imison-Kings-Fund-September-20111.pdf>

The Kings Fund (2012). **Supporting people to manage their health: An introduction to patient activation**. Retrieved from: [https://www.kingsfund.org.uk/sites/default/files/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf)

The Kings Fund (2013). **Delivering better services for people with long term conditions: Building the house of care**. Retrieved from: [https://www.kingsfund.org.uk/sites/default/files/field/field\\_publication\\_file/delivering-better-services-for-people-with-long-term-conditions.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/delivering-better-services-for-people-with-long-term-conditions.pdf)

The Kings Fund (2014). **The reconfiguration of clinical service: What is the evidence?** Retrieved from: <http://www.nhshistory.net/Reconfiguration-of-clinical-services.pdf>

The Kings Fund (2015). **Using patient feedback to drive improvement**. Retrieved from: <https://www.kingsfund.org.uk/blog/2015/12/using-patient-feedback-drive-improvement>

The Kings Fund (2016). **A digital NHS? An introduction to the digital agenda and plans for implementation**. Retrieved from: <https://www.kingsfund.org.uk/publications/digital-nhs>

The King's Fund. (2018). **Shared responsibility for health: the cultural change we need.** Retrieved from: <https://www.kingsfund.org.uk/publications/shared-responsibility-health>

The Kings Fund (2018a). **Shedding light on service design involving patients and the public.** Retrieved from: <https://www.kingsfund.org.uk/blog/2018/11/shedding-light-service-design-involving-patients-and-public>

The Kings Fund (2018b). **How can community involvement reduce health inequalities?** Blog. Retrieved from: <https://www.kingsfund.org.uk/blog/2018/09/how-can-community-involvement-reduce-health-inequalities>

The Kings Fund (2019). **A citizen-led approach to health and care: Lessons from the Wigan Deal.** Retrieved from: <https://www.kingsfund.org.uk/sites/default/files/2019-07/A%20citizen-led%20report%20final%20%2819.6.19%29.pdf>

The Kings Fund (2019a). **A citizen-led approach to health and care: Lessons from the Wigan Deal.** Blog post. Retrieved from: <https://www.kingsfund.org.uk/publications/wigan-deal>

Krist, AH., Tong, ST., Aycock, RA. and Longo, DR. (2017). **Engaging Patients in Decision-Making and Behavior Change to Promote Prevention.** Studies in Health Technology and Informatics, 2017; 240, 284-302. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/28972524>

Kuntsche, E., Sznitman, S. and Kuntsche, S., (2017). **Alcohol and other substance use in a cross-cultural perspective.** Drug and Alcohol Review, 36(6), 717-720. Retrieved from: <https://onlinelibrary.wiley.com/doi/full/10.1111/dar.12625>

Laurance. J., Henderson, S., Howitt, PJ., Matar, M., Al Kuwari, H., Edgman-Levitan, S. and Darzi, A (2014). **Patient Engagement: Four Case Studies that highlight the potential for improved health outcomes and reduced costs.** Health Affairs, 2014 Volume 33(9), 1627–1634. Retrieved from: <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2014.0375>

Lavallee, DC., Chenok, KE., Love, RM., Peterson, C., Holve, E., Segal, CD. and Franklin, PD. (2016). **Incorporating Patient-Reported Outcomes Into Health Care To Engage Patients And Enhance Care.** Health Affairs, 2016 Volume 35(4), 575-82. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/27044954>

Lindblad, S., Ernestam, S., Van Citters, AD., Lind, C., Morgan TS. and Nelson EC. (2017). **Creating a culture of health: evolving healthcare systems and patient engagement.** QJM: An International Journal of Medicine, Volume 110 Issue 3, 1 March 2017. Retrieved from: <https://academic.oup.com/qjmed/article/110/3/125/2681814>

Locock, L. (2003). **Healthcare redesign: meaning, origins and application.** BMJ Quality and Safety, Volume 12 Issue 1. Retrieved from:  
<https://qualitysafety.bmj.com/content/12/1/53>

Lugo-Palacios, DG., Hammond, J., Allen, T., Darley, S., McDonald, R., Blakeman, T. and Bower, P. (2019). **The impact of a combinatorial digital and organisational intervention on the management of long-term conditions in UK primary care: a non-randomised evaluation.** BMC Health Services Research, 2019 19:159. Retrieved from:  
<https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-019-3984-6>

Making Choices Together (Undated). **Making Choices Together website.** Retrieved from:  
<http://www.1000livesplus.wales.nhs.uk/making-choices-together>

Mackey, LM., Doody, C., Werner, EL. and Fullen, B. (2016). **Self-Management Skills in Chronic Disease Management: What Role Does Health Literacy Have?** Medical decision making, 2016 Aug;36(6):741-59. Retrieved from:  
<https://www.ncbi.nlm.nih.gov/pubmed/27053527>

Maher, C., Lewis, L., Ferrar, K., Marshall, S., De Bourdeaudhuji, I. and Vandelanotte, C. (2014). **Are Health Behaviour Change Interventions That Use Online Social Networks Effective? A Systematic Review.** Journal of Medical Internet Research, 2014 Feb 16(2). Retrieved from: **e40.**<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3936265/>

Marmot, M. (2017). **Closing the health gap.** Scandinavian Journal of Public Health, 2017; 45, 723–731. Retrieved from:  
<https://journals.sagepub.com/doi/pdf/10.1177/1403494817717433>

Marteau, T. (2108). **The art of medicine: Changing minds about changing behaviour.** The Lancet, Volume 391, January 13, 2018. Retrieved from:  
<https://www.thelancet.com/action/showPdf?pii=S0140-6736%2817%2933324-X>

Martin, GP (2008). **'Ordinary people only': Knowledge, representativeness, and the publics of public participation in healthcare.** Sociology of Health and Illness, Volume 30 Issue 1, January 2008, 35-54. Retrieved from:  
<https://www.scopus.com/record/display.uri?eid=2-s2.0-38749106971&origin=inward&txGid=4ce83226fd61ab00517fef37addf63e>

Merchant, FM., Dickert, NW. and Howard, DH (2018). **Mandatory Shared Decision Making by the Centers for Medicare & Medicaid Services for Cardiovascular Procedures and Other Tests.** Journal of the American Medical Association, 2018 Aug 21;320(7),641-642. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/29868828>

Michie, S., Atkins, L., West, R. (2014). **The Behaviour Change Wheel: A Guide to Designing Interventions**. London: Silverback Publishing.

Mockford, C., Staniszewska, S., Griffiths, F and Herron-Marx, S. (2012). **The impact of patient and public involvement on UK NHS health care: a systematic review**. International Journal for Quality in Health Care, Volume 24 Issue 1, 1 February 2012, 28–38. Retrieved from: <https://doi.org/10.1093/intqhc/mzr066>

Montori, VM., Kunnemann, M. and Brito, JP (2017). **Shared Decision Making and Improving Health Care: The Answer Is Not In**. Journal of the American Medical Association, August 15 2017, Volume 318 Number 7. Retrieved from: <https://jamanetwork.com/journals/jama/fullarticle/2648612>

Moore, S. (2018). **How can we use patient feedback more effectively to improve care?** Nursing Times [online]; 114: 12, 45-48. Retrieved from: <https://www.nursingtimes.net/roles/nurse-managers/how-can-we-use-patient-feedback-more-effectively-to-improve-care/7026793.article>

Morian, S. and Mello, MM. (2013). **Survey Finds Public Support for Legal Interventions directed at Health Behavior To Fight Noncommunicable Disease**. Health Affairs 32, Number 3 (2013): 486–496. Retrieved from: <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2012.0609>

Moretto, N., Kendall, E., Whitty, J., Byrnes, J., Hills, A., Gordon, L., Turrkstra, E., Scuffham, P. and Comans, T. (2014). **Yes, The Government Should Tax Soft Drinks: Findings from a Citizens' Jury in Australia**. International Journal of Environmental Research and Public Health, 11(3), 2456-2471. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3986986/>

Morrison, C. and Dearden, A. (2013). **Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service design**. Health Policy, 112 (2013), 179–186. Retrieved from: <https://www.sciencedirect.com/science/article/pii/S0168851013001334>

Needham, C. (2009). **SCIE Research briefing 31: Co-production: an emerging evidence base for adult social care transformation**. Retrieved from: <https://www.scie.org.uk/publications/briefings/briefing31/>

Needham, C (2010). **Debate: Personalized public services—a new state/citizen contract?** Public Money and Management, Volume 30, 2010 - Issue 3. Retrieved from: <https://www.tandfonline.com/doi/full/10.1080/09540961003794246>

Needham, C. and Carr, S. (2013). **Coproduction in Social Care: What It Is and How To Do It**. National Co-Production Conference\_24\_October\_2013. Retrieved from: [http://www.govint.org/fileadmin/user\\_upload/Events/National\\_Co-Production\\_Conference\\_24\\_October\\_2013/Catherine\\_Needham\\_Birmingham\\_University.pdf](http://www.govint.org/fileadmin/user_upload/Events/National_Co-Production_Conference_24_October_2013/Catherine_Needham_Birmingham_University.pdf)

NESTA (2013). **Redefining consultations: Changing relationships at the heart of care**. Retrieved from: <https://www.nesta.org.uk/report/redefining-consultations-changing-the-relationships-at-the-heart-of-health/>

NHS Direct Wales (2019). **NHS Direct Encyclopaedia website**. Retrieved from: <https://www.nhsdirect.wales.nhs.uk/encyclopaedia/default.aspx>

NHS England (2018). **House of Care – a framework for long term condition care**. Retrieved from: <https://www.england.nhs.uk/ourwork/clinical-policy/ltc/house-of-care/>

NHS England (2019). **About the Information Standard**. Website. Retrieved from: <https://www.england.nhs.uk/tis/about/>

NHS England (2019a). **National Patient and Staff Surveys**. Retrieved from: <https://www.england.nhs.uk/statistics/statistical-work-areas/patient-surveys/>

NHS England (2019b). **Universal Personalised Care: Implementing the Comprehensive Model**. Retrieved from: <https://www.england.nhs.uk/wp-content/uploads/2019/01/universal-personalised-care.pdf>

NHS England (2019c). **Patient and public participation in commissioning health and care: Statutory guidance for clinical commissioning groups**. Retrieved from: <https://www.england.nhs.uk/wp-content/uploads/2017/05/patient-and-public-participation-guidance.pdf>

NHS Home (Undated). **NHS Home website**. Retrieved from: <https://www.nhs.uk/>

NHS Transformation Unit (2018). **Clinical redesign and engagement**. Retrieved from: <https://www.transformationunitgm.nhs.uk/wp-content/uploads/2018/10/UPDATED-NHS-Transformation-Unit-Clinical-redesign.pdf>

NHS Wales (Undated). **Governance e-manual: Supporting Guidance - Patient Centred Care**. Retrieved from: <http://www.wales.nhs.uk/governance-emanual/supporting-guidance-patient-centred-care>

NICE (2007). **Behaviour change: general approaches**. Retrieved from: <https://www.nice.org.uk/guidance/ph6/chapter/Appendix-D-gaps-in-the-evidence>



NICE (2014). **Behaviour change: individual approaches**. Retrieved from:  
<https://www.nice.org.uk/guidance/ph49/chapter/11-Gaps-in-the-evidence>

NICE (2015). **Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes**. Retrieved from:  
<https://www.nice.org.uk/guidance/ng5/chapter/person-centred-care>

NICE (2018). **Community engagement overview**. Retrieved from:  
<https://pathways.nice.org.uk/pathways/community-engagement#content=view-node%3Anodes-overarching-principles-of-good-practice>

Ocloo, J. and Matthews, R. (2016). **From tokenism to empowerment: progressing patient and public involvement in healthcare improvement**. BMJ Quality & Safety 2016;25, 626-632. Retrieved from: <https://qualitysafety.bmj.com/content/25/8/626.info>

Parliamentary Review (2018). **The Parliamentary Review of Health and Social Care in Wales**. Retrieved from: <https://gov.wales/docs/dhss/publications/180116reviewen.pdf>

Patient Information Forum (2013). **Making the Case for Information: The evidence for investing in high quality health information for patients and the public**. Retrieved from:  
[https://www.pifonline.org.uk/wp-content/uploads/2013/05/PiF\\_Report\\_case\\_for\\_Information.pdf](https://www.pifonline.org.uk/wp-content/uploads/2013/05/PiF_Report_case_for_Information.pdf)

Pickles, J., Hide, E. and Maher, L. (2008). **Experience based design: a practical method of working with patients to redesign services**. Clinical Governance: An International Journal, Volume 13 Issue 1, 51-58. Retrieved from:  
<https://doi.org/10.1108/14777270810850634>

Policy Innovation Research Unit (2017). **Evaluation of Direct Payments in Residential Care Trailblazers: Final report**. Retrieved from:  
<https://piru.lshtm.ac.uk/assets/files/DP%20Trailblazer%20Final%20Report.pdf>

Practice Solutions (Undated). **National Social Services Citizen Panel for Wales**. Retrieved from: <https://www.practicesolutions-ltd.co.uk/en/page/citizen-panel>

Prior, SJ. and Campbell, S. (2018). **Patient and Family Involvement: A Discussion of Co-Led Redesign of Healthcare Services**. Journal of Participatory Medicine, 2018 Volume 10 Issue 1. Retrieved from:  
[https://eprints.utas.edu.au/26759/1/124183\\_Patient%20and%20Family%20Involvement.pdf](https://eprints.utas.edu.au/26759/1/124183_Patient%20and%20Family%20Involvement.pdf)

Public Health Wales and Co-Production Wales (2015). **Seeing is Believing: Case Studies**. Retrieved from:



<http://www.goodpractice.wales/SharedFiles/Download.aspx?pageid=96&mid=187&fileid=79>

Public Health Wales (2019). **A Taxing Issue? The Tax System and Healthier Lifestyles in Wales.** Retrieved from: <https://phw.nhs.wales/files/taxation-and-public-health/phw-a-taxing-issue-2-pdf/>

Reform (2019). **Proceed with caution: What makes personal budgets work?** Retrieved from: [https://reform.uk/sites/default/files/2019-02/Personal%20Budgets\\_AW\\_4\\_0.pdf](https://reform.uk/sites/default/files/2019-02/Personal%20Budgets_AW_4_0.pdf)

Renedo, A. and Marston, C. (2011). **Healthcare Professionals' Representations of 'Patient and Public Involvement' and Creation of 'Public Participant' Identities: Implications for the Development of Inclusive and Bottom-Up Community Participation Initiatives.** Journal of Community and Applied Social Psychology, 21, 268–280 (2011). Retrieved from: <https://onlinelibrary.wiley.com/doi/epdf/10.1002/casp.1092>

Rhodes, R., Janssen, I., Bredin, S., Warburton, D. and Bauman, A. (2017). **Physical activity: Health impact, prevalence, correlates and interventions.** Psychology and Health, Volume 32 Issue 8 (2017), 942–975. Retrieved from: <https://www.tandfonline.com/doi/full/10.1080/08870446.2017.1325486>

Samaranayake, P., Dadich, A., Fitzgerald, A. and Zeitz, K. (2016). **Developing an evaluation framework for clinical redesign programs: lessons learnt.** Journal of Health, Organization and Management, Volume 30 Issue 6, 950-970. Retrieved from: <https://researchdirect.westernsydney.edu.au/islandora/object/uws:37322>

SCIE (2013). **Co-production in social care: What it is and how to do it.** Social Care Institute for Excellence Adults' Services: SCIE guide 51. Retrieved from: [https://www.ndti.org.uk/uploads/files/Coproductio\\_n\\_Guide51Fin.pdf](https://www.ndti.org.uk/uploads/files/Coproductio_n_Guide51Fin.pdf)

Scottish Government (2018). **Good practice in shared decision-making and consent.** Retrieved from: <https://www.gov.scot/publications/good-practice-shared-decision-making-consent/>

Scottish Government, (2018a). **Health and care experience survey 2017 to 2018: national results.** Retrieved from: <https://www.gov.scot/publications/health-care-experience-survey-2017-18-national-results/>

Scottish Government, (2019). **Realising Realistic Medicine: Chief Medical Officer for Scotland annual report 2015-2016.** Retrieved from: <https://www.gov.scot/publications/chief-medical-officer-scotland-annual-report-2015-16-realising-realistic-9781786526731/>

SERIO (2018). **Public Engagement in Health: A Literature Review**. Commissioned by Healthwatch England. Retrieved from:  
<https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/Healthwatch%20England%20Literature%20Review.pdf>

Shay, LA. and Lafata, JE. (2015). **Where is the evidence? A systematic review of shared decision making and patient outcomes**. Medical Decision Making, 2015 January; 35(1), 114–131. Retrieved from:  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4270851/pdf/nihms623951.pdf>

Sheard, L; Marsh, C; O'Hara, J; Armitage, G; Wright, J and Lawton, R. (2017). **The Patient Feedback Response Framework - Understanding why UK hospital staff find it difficult to make improvements based on patient feedback: A qualitative study**. Retrieved from: Social Science and Medicine, 2017 Apr;178:19-27. Retrieved from:  
<https://www.ncbi.nlm.nih.gov/pubmed/28189820>

Shortell, SM., Poon, BY., Ramsay, PP., Rodriguez, HP., Ivey, SL., Huber, T., Rich J. and Summerfelt, T (2016). **A Multilevel Analysis of Patient Engagement and Patient-Reported Outcomes in Primary Care Practices of Accountable Care Organizations**. Journal of General Internal Medicine, 2017 Jun;32(6), 640-64. Retrieved from:  
<https://www.ncbi.nlm.nih.gov/pubmed/28160187>

Slade, M. (2017). **Implementing shared decision-making in routine mental health care**. World Psychiatry, 16:2, June 2017. Retrieved from:  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5428178/>

Smith, K., Escobar, O. and Weakley, S. (2017). **Lay understandings of health inequalities and potential policy responses- comparing data from a national survey and three citizens' juries**. The Scottish Public Health Observatory. Retrieved from:  
<https://www.scotpho.org.uk/media/1725/phins-2017-6-kat-smith.pdf>

South Wales Programme (2014). **Final Report of the South Wales Programme Board**. Retrieved from:  
<http://www.wales.nhs.uk/sitesplus/documents/1077/Final%20Report%20of%20the%20South%20Wales%20Programme%20Board%204%20February%2020141.pdf>

Stacey, D., Legare, F. and Lewis, KB. (2017). **Patient Decision Aids to Engage Adults in Treatment or Screening Decisions**. Journal of the American Medical Association, 2017;318(7), 657-658. Retrieved from:  
<https://jamanetwork.com/journals/jama/fullarticle/2648613>

Staveley, I. and Sullivan, P (2015). **We need more guidance on shared decision making.** British Journal of General Practice, 2015 Dec; 65(641), 663–664. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4655730/>

Stewart, E. (2013). **What is the point of citizen participation in health care?** Journal of Health Services Research and Policy, 18(2), 124–126. Retrieved from: <https://journals.sagepub.com/doi/full/10.1177/1355819613485670>

1000 Lives plus (2019). **Making Choices Together website.** Retrieved from: <http://www.1000livesplus.wales.nhs.uk/making-choices-together>

Tousignant-Laflamme, T., Christopher, S., Llewly, D., Ledbetter, L., Cook, CJ. and Cook, CE. (2017). **Does shared decision making results in better health related outcomes for individuals with painful musculoskeletal disorders? A systematic review.** Journal of Manual and Manipulative Therapy, Volume 25, 2017 - Issue 3: Enhancing Chronic Pain Management for the Manual Therapist. Retrieved from: <https://www.tandfonline.com/doi/abs/10.1080/10669817.2017.1323607>

Turner, S., Ramsay, A., Perry, C., Boaden, R., McKevitt, C., Morris, S., Pursani, N., Rudd, A., Tyrrell, P., Wolfe, C. and Fulop, N. (2016). **Lessons for major system change: centralization of stroke services in two metropolitan areas of England.** Journal of Health Services Research and Policy, 2016 Volume 21(3) 156–165. Retrieved from: <https://journals.sagepub.com/doi/pdf/10.1177/1355819615626189>

Vedam, S., Stoll, K., Martin, K., Ribashkin, N., Partridge, S., Thordarson, D., Jolicoeur, G. and the Changing Childbirth in BC Steering Council (2017). **The Mother's Autonomy in Decision Making (MADM) scale: Patient-led development and psychometric testing of a new instrument to evaluate experience of maternity care.** PLoS One, 2017; 12(2): e0171804 . Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5322919/>

Wakefield, M., Loken, B. and Hornik, R. (2010). **Use of mass media campaigns to change health behaviour.** The Lancet, Volume 376 Issue 9748, 1261-1271. Retrieved from: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(10\)60809-4/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(10)60809-4/fulltext)

Wales Audit Office (2019). **Integrated Care Fund.** Retrieved from: <https://www.audit.wales/system/files/publications/integrated-care-fund-report-eng.pdf>

Wellings, D. (2016). **Using insight and feedback in the NHS.** Presentation for The Kings Fund. Retrieved from: <https://www.kingsfund.org.uk/audio-video/dan-wellings-using-insight-feedback-nhs>

Welsh Government (2011). **Guidance for engagement and consultation on changes to health services.** Retrieved from:

<http://www.wales.nhs.uk/sitesplus/documents/900/Guidance%20on%20Engagement%20and%20Consultation.pdf>

Welsh Government (2015). **Written Statement - Social Services and Well-being (Wales) Act 2014: An update on legislative, national and regional implementation.** Retrieved from: <https://gov.wales/about/cabinet/cabinetstatements/previous-administration/2015/sswellbeingactupdate/?lang=en>

Welsh Government. (2018). **A Healthier Wales: our Plan for Health and Social Care.** Retrieved from: <https://gov.wales/topics/health/publications/healthier-wales/?lang=en>

Welsh Government (2018a). **Health and social services Transformation Fund.** Ministerial Statement. Retrieved from: <https://gov.wales/topics/health/publications/transform/?lang=en>

Welsh Government (2018b). **National Survey for Wales, 2017-18: Hospital and GP services.** Retrieved from: <https://gweddiill.gov.wales/docs/statistics/2018/181024-national-survey-wales-2017-18-hospital-gp-services-en.pdf>

Welsh Government (2019). **Measuring the Mountain: What Really Matters in Social Care to Individuals in Wales? Report of a citizens' jury.** Retrieved from: <https://gov.wales/docs/dhss/publications/measuring-the-mountain.pdf>

West, R. (2017). **Tobacco smoking: Health impact, prevalence, correlates and interventions.** Psychology and Health, Volume 32 Issue 8 – Health Behaviours, 1018–1036. Retrieved from: <https://www.tandfonline.com/doi/full/10.1080/08870446.2017.1325890>

Wharton, H. and Evans A. (2019). **Systems change: what it is and how to do it.** Retrieved from: <https://londonfunders.org.uk/systems-change-what-it-and-how-do-it>

Wigan Council (2019). **What is The Deal?** Retrieved from: <https://www.wigan.gov.uk/council/the-deal/the-deal.aspx>

Wilson, P. and Booth, A. (2015). **Evidence to inform the commissioning of social prescribing.** University of York Centre for Reviews and Dissemination. Retrieved from: [https://www.york.ac.uk/media/crd/Ev%20briefing\\_social\\_prescribing.pdf](https://www.york.ac.uk/media/crd/Ev%20briefing_social_prescribing.pdf)

World Health Organization. Regional Office for Europe (1999). **Healthy living: what is a healthy lifestyle?** Retrieved from: <http://www.who.int/iris/handle/10665/108180>

Xu, RH., Cheung, AWL. and Wong, ELW (2017). **The relationship between shared decision-making and health-related quality of life among patients in Hong Kong SAR, China.** International Journal for Quality in Health Care, Volume 29 Issue 4, 534–540. Retrieved from: <https://academic.oup.com/intqhc/article/29/4/534/3861699>

## Author Details

**Dr Paul Worthington** is a Research Associate with the Wales Centre for Public Policy

**Sarah Quarmby** is a Research Assistant with the Wales Centre for Public Policy

**Dan Bristow** is Director of Policy and Practice with the Wales Centre for Public Policy

The authors would like to thank Simon Burrall and Sarah Allan from Involve, Dan Wellings from The Kings Fund, Helen Buckingham from The Nuffield Trust, Dr Clodagh Harris from University College, Cork and Dr Oliver Escobar from the University of Edinburgh.

For further information please contact:

**Wales Centre for Public Policy**

+44 (0) 29 2087 5345

[info@wcpp.org.uk](mailto:info@wcpp.org.uk)

**OGL** This report is licensed under the terms of the Open Government License