Literature search: UserAge – Understanding user participation in research in various disciplines

Searches in Embase, Scopus, Web of Science, Academic Search Complete

Embase, 2017-09-15
('user participation':ti OR 'public involvement':ti OR 'user involvement':ti OR 'participant involvement' OR 'patient partnership')
AND research:ab,ti AND
('attitudes':ab,ti OR 'beliefs':ab,ti OR 'opinions':ab,ti OR 'perceptions':ab,ti OR 'ideas':ab,ti OR 'judgements':ab,ti OR 'ways of thinking':ab,ti OR experiences:ab,ti OR 'the views of users':ab,ti)
Limit to articles, article in press, reviews, English.
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AND TITLE-ABS-KEY (research) AND TITLE-ABS-KEY (attitude* OR belief* OR opinion* OR perception* OR ideas OR judgement* OR experience*)
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TITLE ("user participation" OR "public involvement" OR "user involvement" OR "participant involvement" OR "patient partnership")
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TOPIC: (attitude* OR belief* OR opinion* OR perception* OR ideas OR judgement* OR experience*)

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TI ("user participation" OR "public involvement" OR "user involvement" OR "participant involvement" OR "patient partnership") AND AB research AND AB (attitude* OR belief* OR opinion* OR perception* OR ideas OR judgement* OR experience*)
Limit to English, peer-reviewed journals
80 hits

301 references after deduplication in EndNote.

1. *Public involvement in health research: a case study of one NHS project over 5 years*, 2010. p. 17-28.

   Background: Public involvement, both in the National Health Service (NHS) and in clinical research, is promoted as an important democratic principle. The declared aims are to reduce professional autocracy and allow a broader ownership of the research agenda; also to improve the design of, and recruitment and retention of patients to, clinical studies. There have been a number of national initiatives in the UK to improve public input to clinical research activities, but very few reports of effective and sustainable partnerships over time. This study reports the evaluation of one example, which is embedded in the NHS and university partnerships in the Norfolk area of England. Objectives: Evaluate: • Putting principles into practice of public involvement in research over a 5 year period for one specific project (Patient and Public Involvement in Research). • How the model contributes to, and impacts upon, all stages of the research process. • Attitudes of the research community and lay volunteers to their mutual experiences of public involvement. • Key factors and strengths of this project, and areas for improvement. Methods: A mixed methods approach related to the 5 years from start of 2003 to end of 2007. This used descriptive statistics of volunteer activity, interviews with key stakeholders (13), questionnaires (53% response rate), and focus group with 10 volunteers to explore emergent themes. We analysed findings using a policy framework approach. Results: About 47 of the original 55 volunteers remained on the panel after 5 years. All have undertaken training, 38% have been involved in the full range of research activities offered, and 75% have attended at least one research project meeting. Some are active in governance, ethics, and advisory committees. Both the research community and the volunteers are very positive about the project. The researchers find it provides well prepared personnel, and gives a speedy and efficient way of fulfilling the expectations of funders for lay input. The volunteers find it gives them important opportunities to influence the quality of research and thus support improvements in patient care. Areas for improvement include increasing social diversity among the volunteers, and improving feedback on input from volunteers, without which volunteers tend to lose confidence and motivation. Conclusion: Long-term sustainable and valuable public input to research is possible. Key factors are committing resources, embedding the service in the infrastructure of a research consortium, and ongoing responsiveness by NHS staff and researchers. Additional activity to recruit and support access may be needed to attract people from a broad range of sociodemographic backgrounds. Some volunteers want more involvement than this model currently offers. [ABSTRACT FROM AUTHOR]

   Case Study

2. Patient and public involvement in research. Nurse Researcher, 2013. 20(3): p. 1-1.

   An introduction is presented wherein the author discusses challenges of involving people who have experienced similar health conditions in the research.

3. Abayneh, S., H. Lempp, A. Alem, D. Alemayehu, T. Eshetu, C. Lund, . . . C. Hanlon. **Service user involvement in mental health system strengthening in a rural African setting: Qualitative study**. BMC Psychiatry, 2017. 17(1).

Background: It is essential to involve service users in efforts to expand access to mental health care in integrated primary care settings in low- and middle-income countries (LMICs). However, there is little evidence from LMICs to guide this process. The aim of this study was to explore barriers to, and facilitators of, service user/caregiver involvement in rural Ethiopia to inform the development of a scalable approach. Methods: Thirty nine semi-structured interviews were carried out with purposively selected mental health service users (n = 13), caregivers (n = 10), heads of primary care facilities (n = 8) and policy makers/planners/service developers (n = 8). The interviews were audio-recorded and transcribed in Amharic, and translated into English. Thematic analysis was applied. Results: All groups of participants supported service user and caregiver involvement in mental health system strengthening. Potential benefits were identified as (i) improved appropriateness and quality of services, and (ii) greater protection against mistreatment and promotion of respect for service users. However, hardly any respondents had prior experience of service user involvement. Stigma was considered to be a pervasive barrier, operating within the health system, the local community and individuals. Competing priorities of service users included the need to obtain adequate individual care and to work for survival. Low recognition of the potential contribution of service users seemed linked to limited empowerment and mobilization of service users. Potential health system facilitators included a culture of community oversight of primary care services. All groups of respondents identified a need for awareness-raising and training to equip service users, caregivers, service providers and local community for involvement. Empowerment at the level of individual service users (information about mental health conditions, care and rights) and the group level (for advocacy and representation) were considered essential, alongside improved, accessible mental health care and livelihood interventions. Conclusion: As Ethiopia increases access to mental health care, a fundamental barrier to service user involvement is beginning to be addressed. Our study identified further barriers that need to be tackled, including a supportive political climate, and receptiveness amongst stakeholders. The findings will inform the development of a model of service user involvement, which will be piloted and evaluated. © 2017 The Author(s).
http://dx.doi.org/10.1186/s12888-017-1352-9

4.   Aberg, A.C., K. Halvorsen, I. From, A.B. Bruhn, L. Oestreicher, A. Melander-Wikman. **A Study Protocol for Applying User Participation and Co-Learning-Lessons Learned from the eBalance Project**. International Journal of Environmental Research and Public Health, 2017. 14(5).
The eBalance project is based on the idea that serious exergames-i.e., computer gaming systems with an interface that requires physical exertion to play-that are well adapted to users, can become a substantial part of a solution to recognized problems of insufficient engagement in fall-prevention exercise and the high levels of fall-related injuries among older people. This project is carried out as a collaboration between eight older people who have an interest in balance training and met the inclusion criteria of independence in personal activities of daily living, access to and basic knowledge of a computer, four staff working with the rehabilitation of older adults, and an interdisciplinary group of six research coordinators covering the areas of geriatric care and rehabilitation, as well as information technology and computer science. This paper describes the study protocol of the project's initial phase which aims to develop a working partnership with potential users of fall-prevention exergames, including its conceptual underpinnings. The qualitative methodology was inspired by an ethnographical approach implying combining methods that allowed the design to evolve through the study based on the participants' reflections. A participatory and appreciative action and reflection (PAAR) approach, accompanied by inquiries inspired by the Normalization Process Theory (NPT) was used in interactive workshops, including exergame testing, and between workshop activities. Data were

collected through audio recordings, photos, and different types of written documentation. The findings provide a description of the methodology thus developed and applied. They display a methodology that can be useful for the design and development of care service and innovations for older persons where user participation is in focus.
http://dx.doi.org/10.3390/ijerph14050512

5.   Abma, T.A., V.E. Baur. **User involvement in long-term care. Towards a relational care-ethics approach**. Health Expectations, 2015. 18(6): p. 2328-2339.
Background User involvement in long-term care has become official policy in many countries. Procedural and managerial approaches to user involvement have numerous shortcomings in long-term care. What is needed is a different approach that is beneficial and tuned to the needs of clients and professionals. Aim This article presents a care-ethics approach to involvement. We illustrate this approach and its practical implementation by examining a case example of user involvement in long-term elderly care. Methodology This case example is based on an action research project in a residential care home in the Netherlands. Seven female clients participated in the process, as well as diverse groups of professionals from this residential care home. Results The clients were concerned about meals, and collectively they became empowered and came up with ideas for improving meals. Professionals also shared the clients' experiences with meals, first in homogeneous groups and then in heterogeneous meetings with the client group. This process led to the development of partnership relations between clients and professionals. Conclusion Our findings suggest that a care-ethics approach to user involvement is a means to increase resident empowerment in long-term care. Clients and professionals start sharing their experiences and values through dialogue, and they develop mutual trust and openness while doing so.
http://dx.doi.org/10.1111/hex.12202

6.   Aguirre, E., A. Spector, A. Streater, K. Burnell, M. Orrell. **Service users' involvement in the development of a maintenance cognitive stimulation therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers**. Dementia, 2011. 10(4): p. 459-473.
This study reports on the process of developing a maintenance programme manual following the Medical Research Council guidelines representing the 'phase I' or modelling. This study uses an inductive thematic analysis approach to examine user perceptions on the maintenance cognitive stimulation therapy (CST) programme. Three focus groups were carried out with people with dementia, three with staff, and three with family carers of people with dementia. In total 17 people with dementia, 13 staff and 18 family carers took part in separate focus groups. The main findings from the user focus clearly supports the recent draft NICE guidelines on dementia (NICE-SCIE, 2006) that states that all people with mild/moderate dementia should be 'given the opportunity to participate in a structured group of cognitive stimulation programme'. People with dementia highly valued the opportunity to take part in a mental stimulating group programme and found it vital in keeping them healthy and active. Most family carers and staff were very positive but expressed concerns about the effectiveness of this type of programme and gave real life examples where the idea of 'use it or lose it' did not apply. Results from the focus groups will be used in order to produce a new version of the maintenance CST draft manual and this will be evaluated in a large randomized controlled trial (RCT). © The Author(s) 2011.
http://dx.doi.org/10.1177/1471301211417170

7.   Aidemark, J., L. Askenas, A. Nygardh, A. Stromberg, *User involvement in the co-design of self-care support systems for heart failure patients*, in *Conference on Enterprise Information Systems/International Conference on Project Management/Conference on Health and Social Care*

Information Systems and Technologies, Centeris/Projman / Hcist 2015, M.M. CruzCunha, et al., Editors. 2015. p. 118-124.

8. Algeo, N., D. Hunter, A. Cahill, C. Dickson, J. Adams. **Usability of a digital self-management website for people with osteoarthritis: A UK patient and public involvement study**. International Journal of Therapy & Rehabilitation, 2017. 24(2): p. 78-82.
The article presents a study which examined the usability of a digital self-management website for individuals with osteoarthritis. In a study conducted by the Arthritis Research UK Centre of Excellence for Sport, Exercise and Osteoarthritis patient and public involvement (PPI) representatives, their attitudes on the use of digital electronic health (e-health) services to self-manage joint pain were examined. Based on the results, e-health can serve as motivational tool in pain management.
http://dx.doi.org/10.12968/ijtr.2017.24.2.78

9. Aly, S.S.A., M.S.E. Amer. **Public involvement in sustainable development: A public participation process in the sidi gaber railway station development project, Alexandria, Egypt**. WIT Transactions on Ecology and the Environment, 2011. 150: p. 537-552.
Public Participation (PP) in sustainable development helps the decision makers to acquire information about the public's preferences. So it plays a vital role in the decisions about choice of projects and formulates its design policies. PP is designed to help assure that the people's will is done; it gives the opportunity for people to be heard and to understand what will be done in a specific project. On a legality side, PP gives legitimacy for decisions, support for plans and builds trust in government. A vested interest in PP had grown in Egypt and in most other developed countries, the public became much more concerned about participation and involvement in governmental decision making processes than they had been before. For that, the confidence between the public and decision makers has increased. This paper aims to design the PP process for the Sidi Gaber railway station development project, Alexandria, Egypt. It will discuss the methods of PP practice and highlights the importance of the participation process in fulfilling people's needs and requirements, it explains the benefits that will be gained in the future by enriching environmental democracy. The paper concludes that stakeholders do have influence over decisions and the government should have the ability to manage the conflicts, to deal with anger and aggressive behaviour and to gain the public trust instead of mistrust by ignoring PP. Sidi Gaber station has a special location, a unique architectural style and a historical value; so the research carried on a questionnaire to know the public opinion about this project especially from the logic of heritage rehabilitation and maintenance, and from the environmental point of view. © 2011 WIT Press.
http://dx.doi.org/10.2495/SDP110441

10. Arblaster, K., L. Mackenzie, K. Willis. **Service user involvement in health professional education: is it effective in promoting recovery-oriented practice?** Journal of Mental Health Training, Education and Practice, 2015. 10(5): p. 325-336.
Purpose – The purpose of this paper is to evaluate how mental health service user involvement in health professional education adds value to student learning about recovery-oriented practice and to determine the quality and suitability of instruments used in studies to evaluate this involvement in terms of their: relationship to recovery-oriented practice; and psychometric properties. Design/methodology/approach – Studies of service user involvement were reviewed to identify their research objectives. These were mapped against an Australian recovery-oriented practice capability framework together with the constructs measured by instruments used in these studies. Psychometric properties for each instrument were evaluated using the COSMIN checklist.

Findings – While research objectives are not stated in terms of recovery-oriented practice, they do relate to some elements of a recovery-oriented practice framework. No instrument measures outcomes against all recovery-oriented practice domains. The AQ has the strongest evidence for its psychometric properties. The most commonly used instrument measures only stigma and has poorly validated psychometric properties. Originality/value – This paper demonstrates that the "value add" of service user involvement in health professional education has been poorly defined and measured to date. Learning from lived experience is central to a recovery-orientation and is an expectation of health professional education programmes. Defining objectives for service user involvement in terms of recovery-oriented practice and developing an instrument which measures student learning against these objectives are important areas for ongoing research supporting improved approaches to supporting people's recovery. © 2015, Emerald Group Publishing Limited.
http://dx.doi.org/10.1108/JMHTEP-04-2015-0016

11. Archard, P.J., D. Murphy. **A practice research study concerning homeless service user involvement with a programme of social support work delivered in a specialized psychological trauma service**. Journal of Psychiatric and Mental Health Nursing, 2015. 22(6): p. 360-370.
Accessible summary: Homeless persons are known to be highly vulnerable to psychological trauma, in events triggering periods of homelessness and the considerable social isolation and adversity suffered when homeless. This study provides an account of how mental health support work is experienced by homeless service users when it is informed by a person-centred, non-directive approach and implemented by trainee health and social care professionals under the auspices of a specialized psychological trauma service. The study draws upon material gathered from interviews with service users domiciled in supported housing for homeless persons and support workers who practiced on the programme. The service users who participated in the study valued support work that combined practical and relational elements, but would have preferred a longer-term involvement. They also spoke of feelings of disconnection and estrangement from others including their peers in supported housing. The support worker participants valued the flexibility they had when working on the programme to tailor their intervention to service users' individual needs. Practice implications of the study are discussed. These include the need to minimize barriers to accessing support, facilitate informal time between professionals and homeless service users, and manage intervention endings sensitively when temporary staffing arrangements are in place. Abstract: Homeless people are a population known to be highly vulnerable to trauma, in triggering events to becoming homeless and the considerable social isolation, discrimination, and adversity suffered when homeless. Currently, there is a paucity of research into mental health service delivery to homeless persons and the influence it imparts in individual lives. This article presents a qualitative 'practice research' study into a pilot programme of social support work delivered in a specialized psychological trauma service to homeless service users. The programme was grounded in a non-directive, person-centred approach and staffed by student social workers. The study aim was to explore the support work programme as it was received by service users domiciled in supported housing for homeless persons, encompassing experiencing the programme, worker-service user engagement and contextual influences bearing upon positive outcomes. Narrative interviews gathered the impressions of service users and support workers and the data arising from these interviews was analysed thematically. Service user participants valued support work that combined practical and relational elements, but would have preferred a longer-term involvement. They also spoke of feelings of disconnection and estrangement from their peers in the supported accommodation and their families. The worker participants valued the flexibility of person-centred work tailored to

service users' individual needs and echoed service user concerns around the short-term nature of their involvement. Psychiatric nurses carrying out, or supervising, mental health support work with homeless service users should be mindful of the potential impact of temporary staffing arrangements on continuity of care. They should also consider how working from a person-centred perspective and addressing client's practical needs may aid in developing rapport and trust with homeless service users. © 2015 John Wiley & Sons Ltd
http://dx.doi.org/10.1111/jpm.12229

12. Atoof, F., M.R. Eshraghian, M. Mahmoodi, K. Mohammad, F.R. Jeddi, F. Abootalebi. **Patients and Public Involvement in Patient Safety and Treatment Process in Hospitals Affiliated to Kashan University of Medical Sciences, Iran, 2013**. Nursing and Midwifery Studies, 2015. 4(2).
Background: In the recent decades, healthcare providers had a perspective of benevolent paternalism. Nowadays, the patients' role has changed and they have a significant obligation to participate in their caring decisions. Objectives: The current study aimed to investigate the involvement of patients and public in the patient safety and treatment process in hospitals affiliated to Kashan University of Medical Sciences, Kashan, Iran, 2013. Patients and Methods: A cross-sectional study was conducted in the hospitals affiliated to Kashan University of Medical Sciences in 2013. Subjects included all of the 18 chief managers, 10% of nurses in each hospital, and 375 patients. Data collection instruments included a questionnaire and a checklist designed according to the research objectives. Data analysis was performed using the SPSS ver.13. Descriptive statistics, percentage and frequencies, were calculated for all variables and analyzed by Chi-square test. Results: In the treatment process, 81 patients (21.61%), 50 nurses (80.6%) and 15 chief managers (83.3%) had awareness about Patient Bill of Rights. In patient Safety, 19.73% of the patients stated that hospitals received their feedbacks. Management activities were weak in evaluation. All of the six hospitals (100%) had a defined process to perform satisfaction surveys' quality improvement and patient authentication policy. Conclusions: Patient and public participation in Kashan hospitals are not adhered well. As the patient has an important role in improving the quality of services, more use of mass media especially local newspapers, hospital websites, and training programs are suggested to inform both the patients and public on their rights and roles in improving the healthcare services.

13. Awenat, Y.F., C. Moore, P.A. Gooding, F. Ulph, A. Mirza, D. Pratt. **Improving the quality of prison research: A qualitative study of ex-offender service user involvement in prison suicide prevention research**. Health Expectations, 2017.
Background: Suicide is the leading cause of avoidable death in prisons worldwide and suicide prevention is an international priority. Consequently, there is an urgent need to develop evidence-based treatments. We conducted a randomized controlled trial of a novel suicide prevention psychological therapy for male prisoners. To promote ecological validity by addressing the "real-world" situation of suicidal prisoners, we involved a consultant group of ex-offenders with past experience of being suicidal during imprisonment. Service user involvement in prison research is challenging and underdeveloped. Objective: We aimed to investigate the ex-offender service user consultants' experiences of being involved in the research. Design: Individual qualitative interviews were conducted and analysed using an Interpretative Phenomenology Analysis (IPA) framework. Setting/participants: The study was conducted at a university in North England, UK, comprising four ex-offenders with experience of being suicidal during past imprisonments. Results: Two superordinate themes were identified: "Working Together" depicted participants' perceptions of the pivotal role of good relationships with researchers, and "Journey of Change" outlined how participants' involvement in the research impacted on their personal

lives. Discussion: Little is known about how to successfully involve ex-offender service users in research. Our results indicate the conditions necessary for successfully engaging ex-offender service users in research and have important implications for improving the quality of prison research. Conclusions: Involving forensic service users in research is feasible and should be encouraged, as despite certain challenges, it is highly rewarding both for the research and the ex-offender service users. © 2017 John Wiley & Sons Ltd.
http://dx.doi.org/10.1111/hex.12590

14. Bailey, K., B. Blandford, T. Grossardt, J. Ripy. **Planning, technology, and legitimacy: structured public involvement in integrated transportation and land-use planning in the United States**. Environment and Planning B-Planning & Design, 2011. 38(3): p. 447-467.
The authors have measured an Arnstein gap, that is, a significant difference between desired and actual levels of citizen participation in planning processes. This Arnstein gap exists because even well-intentioned professionals have an unrealistic expectation of achieving consensus across large planning scales. Further, it is often hoped or believed that technologies of representation will somehow accomplish consensus. The authors argue this is not possible without developing a stronger theoretical framework for their deployment in planning in democratic societies. The purpose of this research is to move the public closer to the center of the public infrastructure planning and design process in a productive, efficient, and more satisfactory manner, that is, to close the Arnstein gap. The authors adapt a participatory framework, called structured public involvement (SPI), for integrating visualization and geospatial technologies into large-scale public involvement in planning domains. The authors discuss how SPI using the casewise visual evaluation method is applied in collaboration with planners. A case study is presented of integrated transportation and land-use planning for an Indiana city. The results demonstrate that SPI achieves high levels of stakeholder satisfaction in addition to providing high-quality planning and design guidance for professionals.
http://dx.doi.org/10.1068/b35128

15. Baldursdottir, R., R. Flo, T. Hurnasti, L. Jensen, K. Sandberg, *User involvement in the development of assistive technology in the Nordic countries (USDAT)*. Assistive Technology - Added Value to the Quality of Life, ed. C. Marincek, et al. Vol. 10. 2001. 95-98.
16. Ball, M.P., J.R. Bobe, M.F. Chou, T. Clegg, P.W. Estep, J.E. Lunshof, . . . G.M. Church. **Harvard Personal Genome Project: Lessons from participatory public research**. Genome Medicine, 2014. 6(2).
Background: Since its initiation in 2005, the Harvard Personal Genome Project has enrolled thousands of volunteers interested in publicly sharing their genome, health and trait data. Because these data are highly identifiable, we use an 'open consent' framework that purposefully excludes promises about privacy and requires participants to demonstrate comprehension prior to enrollment. Discussion: Our model of non-anonymous, public genomes has led us to a highly participatory model of researcher-participant communication and interaction. The participants, who are highly committed volunteers, self-pursue and donate research-relevant datasets, and are actively engaged in conversations with both our staff and other Personal Genome Project participants. We have quantitatively assessed these communications and donations, and report our experiences with returning research-grade whole genome data to participants. We also observe some of the community growth and discussion that has occurred related to our project. Summary: We find that public non-anonymous data is valuable and leads to a participatory research model, which we encourage others to consider. The implementation of this model is greatly facilitated by web-based tools and methods and participant education. Project results are

long-term proactive participant involvement and the growth of a community that benefits both researchers and participants.
http://dx.doi.org/10.1186/gm527

17. Banks, M.S., *Understanding IT-Enabled Social Action Networks: Construction, Sustainability, and User Participation*, in *Advancing Cancer Education and Healthy Living in Our Communities: Putting Visions and Innovations into Action*, Y. Quintana, A.V. Villalobos, and D. May, Editors. 2012. p. 85-90.

18. Barber, R., J.D. Boote, G.D. Parry, C.L. Cooper, P. Yeeles, S. Cook. Can the impact of public involvement on research be evaluated? A mixed methods study. Health Expectations, 2012. 15(3): p. 229-241.
Background Public involvement is central to health and social research policies, yet few systematic evaluations of its impact have been carried out, raising questions about the feasibility of evaluating the impact of public involvement. Objective To investigate whether it is feasible to evaluate the impact of public involvement on health and social research. Methods Mixed methods including a two-round Delphi study with pre-specified 80% consensus criterion, with follow-up interviews. UK and international panellists came from different settings, including universities, health and social care institutions and charitable organizations. They comprised researchers, members of the public, research managers, commissioners and policy makers, self-selected as having knowledge and/or experience of public involvement in health and/or social research; 124 completed both rounds of the Delphi process. A purposive sample of 14 panellists was interviewed. Results Consensus was reached that it is feasible to evaluate the impact of public involvement on 5 of 16 impact issues: identifying and prioritizing research topics, disseminating research findings and on key stakeholders. Qualitative analysis revealed the complexities of evaluating a process that is subjective and socially constructed. While many panellists believed that it is morally right to involve the public in research, they also considered that it is appropriate to evaluate the impact of public involvement. Conclusions This study found consensus among panellists that it is feasible to evaluate the impact of public involvement on some research processes, outcomes and on key stakeholders. The value of public involvement and the importance of evaluating its impact were endorsed. © 2011 Blackwell Publishing Ltd.
http://dx.doi.org/10.1111/j.1369-7625.2010.00660.x

19. Barki, H., J. Hartwick. Measuring user participation, user involvement, and user attitude. MIS Quarterly: Management Information Systems, 1994. 18(1): p. 59-79.
Defining user participation as the activities performed by users during systems development, user involvement as the importance and personal relevance of a system to its user, and user attitude as the affective evaluation of a system by the user, this study aims to: (1) develop separate measures of user participation, user involvement, and user attitude, (2) identify key dimensions of each construct, and (3) investigate the relationships among them. Responses from users in organizations developing new information systems were used to create an overall scale measuring user participation (along with three subscales reflecting the dimensions of responsibility, user-IS relationship, and hands-on activities), an overall scale measuring user involvement (along with two subscales reflecting the dimensions of importance and personal relevance), and a scale measuring user attitude. Analysis of the data provides evidence for the reliability and validity of the three constructs and their dimensions. User participation has long been considered a key variable in the successful development of information systems. However, past research has failed to clearly demonstrate its benefits. The measures developed in this study provide a useful starting point for deciphering the precise nature of the relationship among user

participation, involvement, and attitude during systems implementation.

20. Barnes, M., G. Wistow. **Achieving a strategy for user involvement in community care**. Health & Social Care in the Community, 1994. 2(6): p. 347-356.
This paper presents an overview of findings from an evaluation of the Birmingham Community Care Special Action Project (CCSAP). CCSAP was intended to deliver an inter-agency, user-oriented strategy for community care. It pre-dated the reforms introduced by the National Health Service and Community Care Act and, indeed, may have influenced some aspects of those reforms. Lessons from the evaluation can assist agencies wishing to develop a strategy for user involvement. In particular, the evaluation indicated the need to be clear about: the purposes of involvement; who it is intended should be involved; importance of establishing effective mechanisms both to secure action in response to issues raised, and the continuation and development of involvement itself. The evaluation contributed to the development of involvement and this experience has also enabled us to reflect on the contribution research can play in the development of user involvement strategies. Copyright © 1994, Wiley Blackwell. All rights reserved
http://dx.doi.org/10.1111/j.1365-2524.1994.tb00184.x

21. Barr, J., R. Bull, K. Rooney. **Developing a patient focussed professional identity: an exploratory investigation of medical students' encounters with patient partnership in learning**. Advances in health sciences education : theory and practice, 2015. 20(2): p. 325-338.
Patient encounters are central to the provision of learning opportunities for medical students and their development as medical professionals. The primary aim of the study reported in this paper was to discover how partnering medical students with patients with chronic illness in undergraduate learning influenced the development of a patient centred professional identity and professionalism. An exploratory interpretive research design was used to address the research aim within a patient partner program (P3). Three qualitative data collection methods were used: (1) focus groups (2) extended response questionnaire and (3) semi-structured interviews. Data were coded and analysed thematically. The professional identity of medical students is constructed along traditional lines in the preclinical years. Patient-partnership offers a disruption to this development by way of an intersection with patients with chronic illness which potentially allows meaningful construction of what a patient-centred identity should be. This point of reflection provides an opportunity to engage at a higher level in medical identity development and professionalism. The findings discussed in this paper further stimulate the patient-centred agenda by understanding the conflict associated with the student-patient nexus in medical education and its potential for building professionalism and a patient-centred professional identity. To continue the drive for a patient-centred professional identity there must be ongoing engagement with patients in medical education, preferably commencing early in a student's journey so that it becomes the expected norm. This study has highlighted that a true patient-centred emphasis is being encountered too late in their socialisation process.
http://dx.doi.org/10.1007/s10459-014-9530-8

22. Basic, S.C. **SERVICE USER INVOLVEMENT IN SOCIAL WORK PRACTICE, EDUCATION AND RESEARCH IN THE FEDERATION OF BOSNIA AND HERZEGOVINA**. Ljetopis Socijalnog Rada, 2009. 16(2): p. 241-257.
Despite the fact that the social work profession is considered to be a profession "promoting ... empowerment and liberation of individuals in order to attain greater level of well-being", the inclusion of the user perspective is a relatively new and still much debated phenomenon. Having

in mind that the involvement of service users as experience experts in social work practice, education and research is a very demanding and complex process, the paper analyses a number of challenges faced by social workers, teachers and researchers in their everyday work due to the requirement of inclusion of the service user perspective. The idea of service user involvement in planning, execution and evaluation of curricular contents is a quite recent one in Bosnia and Herzegovina since the social work education reflects the idea on professionals (social workers, teachers or researchers) as ultimate knowledge holders. The author defines two categories of factors obstructing the service user involvement in the education and research process: one is related to education institutions and the other to service users, i.e. their organizations, and discusses necessary prerequisites for stronger connections between institutions (departments of social work), practice and service users.

23. Berg, R.C., A. Gamst, M. Said, K.B. Aas, S.H. Songe, K. Fangen, O. Rysstad. **True User Involvement by People Living With HIV is Possible: Description of a User-driven HIV Clinic in Norway**. Journal of the Association of Nurses in AIDS Care, 2015. 26(6): p. 732-742.
The Greater Involvement of People Living with or Affected by HIV principle highlights the various contributions HIV-infected people can make in HIV program development and implementation. We present a unique example of how service users' involvement led to a complete organizational redesign of an outpatient HIV clinic in Southern Norway. We applied a user-driven, case study method, which showed that establishing a user board laid the foundation for the redesign process, as the board provided a clear infrastructure of user involvement and developed a set of user-defined targets for services. The main targets-optimal health, holistic care and treatment, and empowerment-were operationalized as a set of action points, such as establishing HIV nurse coordinators. While there is no single method for user involvement, we offer useful ideas that can help others develop an involvement project that is effective and sustainable. © 2015 The Authors. http://dx.doi.org/10.1016/j.jana.2015.07.002

24. Bickerstaff, K., R. Tolley, G. Walker. **Transport planning and participation: The rhetoric and realities of public involvement**. Journal of Transport Geography, 2002. 10(1): p. 61-73.
The new direction in transport policy, embodied in the 1998 White Paper, has brought with it a sea change in political thinking about the objectives and process of local transport planning. In this paper, we consider 'the realities' of how one cornerstone of this 'new' agenda, a duty on authorities to undertake 'public participation' in producing their local transport plans, has been conceptualised and integrated within the wider planning practice. Drawing on a research project which involved a survey of English highway authorities and a content analysis of policy documents we evaluate experiences in relation to four key principles of the participation process. The paper concludes that whilst there is considerable activity on the surface, evidence of substantive impacts on local transport planning or a strategic approach to the participation process is sparse - a situation which is, we argue, traceable back to the lack of clarity in central government policy and guidance. © 2002 Elsevier Science Ltd. All rights reserved. http://dx.doi.org/10.1016/S0966-6923(01)00027-8

25. Boaz, A., D. Biri, C. McKevitt. <mark>Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom?</mark> Health Expectations, 2016. 19(3): p. 592-601.
BackgroundThe policy imperative to engage the public and patients in research can be seen as part of a wider shift in the research environment. This study addresses the question: Has there been a shift in attitudes to Patient and Public Involvement (PPI) and <mark>Public Engagement in Science</mark>

(PES) amongst researchers? MethodsAttitudes to PPI and PES within a cluster of three NIHR supported Biomedical Research Centres were explored through in-depth interviews with 19 researchers. ResultsParticipants distinguished PPI (as an activity involving patients and carers in research projects and programmes) from PES (as an activity that aims to communicate research findings to the public, engage the public with broader issues of science policy or promote a greater understanding of the role of science in society). While participants demonstrated a range of attitudes to these practices, they shared a resistance to sharing power and control of the research process with the public and patients. ConclusionWhile researchers were prepared to engage with the public and patients and listed the advantages of engagement, the study revealed few differences in their underlying attitudes towards the role of society in science (and science in society) to those reported in previous studies. To the participants science remains the preserve of scientists, with patients and the public invited to tinker at the edges'.
http://dx.doi.org/10.1111/hex.12295

26.   Boëte, C. **Scientists and public involvement: A consultation on the relation between malaria, vector control and transgenic mosquitoes**. Transactions of the Royal Society of Tropical Medicine and Hygiene, 2011. 105(12): p. 704-710.
Among the hopes for vector-based malaria control, the use of transgenic mosquitoes able to kill malaria parasites is seen as a potential way to interrupt malaria transmission. While this potential solution is gaining some support, the ethical and social aspects related to this high-tech method remain largely unexplored and underestimated. Related to those latter points, the aim of the present survey is to determine how scientists working on malaria and its vector mosquitoes perceive public opinion and how they evaluate public consultations on their research. This study has been performed through a questionnaire addressing questions related to the type of research, the location, the nationality and the perception of the public involvement by scientists. The results suggest that even if malaria researchers agree to interact with a non-scientific audience, they (especially the ones from the global North) remain quite reluctant to have their research project submitted in a jargon-free version to the evaluation and the prior-agreement by a group of non-specialists. The study, by interrogating the links between the scientific community and the public from the perspective of the scientists, reveals the importance of fostering structures and processes that could lead to a better involvement of a non specialist public in the actual debates linking scientific, technological and public health issues in Africa. © 2011 Royal Society of Tropical Medicine and Hygiene.
http://dx.doi.org/10.1016/j.trstmh.2011.08.006

27.   Boivin, A., K. Currie, B. Fervers, J. Gracia, M. James, C. Marshall, . . . G.I.N. Public. **Patient and public involvement in clinical guidelines: international experiences and future perspectives**. Quality & safety in health care, 2010. 19(5): p. e22.
Clinical practice guidelines (CPG) are important tools for improving patient care. Patient and public involvement is recognised as an essential component of CPG development and implementation. The Guideline International Network Patient and Public Involvement Working Group (G-I-N PUBLIC) aims to support the development, implementation and evaluation of guideline-oriented patient and public involvement programmes (PPIPs). To develop an international practice and research agenda on patient and public involvement in CPG. 56 CPG developers, researchers, and patient/public representatives from 14 different countries, were consulted in an international workshop. Recommendations were validated with G-I-N PUBLIC steering committee members. Many CPG organisations have set up PPIPs that use a range of participation, consultation and communication methods. Current PPIPs aim to improve the quality

and responsiveness of CPGs to public expectations and needs, or to foster individual healthcare decisions. Some organisations use structured involvement methods, including providing training for patient and public representatives. A number of financial, organisational and sociopolitical barriers limit patient and public involvement. The paucity of process and impact evaluations limits our current understanding of the conditions under which patient and public involvement is most likely to be effective. Greater international collaboration and research are needed to strengthen existing knowledge, development and evaluation of patient and public involvement in CPG.

28.   Boivin, A., P. Lehoux, J. Burgers, R. Grol. **What are the key ingredients for effective public involvement in health care improvement and policy decisions? A randomized trial process evaluation**. Milbank Quarterly, 2014. 92(2): p. 319-350.
Context In the past 50 years, individual patient involvement at the clinical consultation level has received considerable attention. More recently, patients and the public have increasingly been involved in collective decisions concerning the improvement of health care and policymaking. However, rigorous evaluation guiding the development and implementation of effective public involvement interventions is lacking. This article describes those key ingredients likely to affect public members' ability to deliberate productively with professionals and influence collective health care choices. Method We conducted a trial process evaluation of public involvement in setting priorities for health care improvement. In all, 172 participants (including 83 patients and public members and 89 professionals) from 6 Health and Social Services Centers in Canada participated in the trial. We videorecorded 14 one-day meetings, and 2 nonparticipant observers took structured notes. Using qualitative analysis, we show how public members influenced health care improvement priorities. Findings Legitimacy, credibility, and power explain the variations in the public members' influence. Their credibility was supported by their personal experience as patients and caregivers, the provision of a structured preparation meeting, and access to population-based data from their community. Legitimacy was fostered by the recruitment of a balanced group of participants and by the public members' opportunities to draw from one another's experience. The combination of small-group deliberations, wider public consultation, and a moderation style focused on effective group process helped level out the power differences between professionals and the public. The engagement of key stakeholders in the intervention design and implementation helped build policy support for public involvement. Conclusions A number of interacting active ingredients structure and foster the public's legitimacy, credibility, and power. By paying greater attention to them, policymakers could develop and implement more effective public involvement interventions. © 2014 The Authors The Milbank Quarterly published by Wiley Periodicals, Inc. on behalf of The Milbank Memorial Fund. http://dx.doi.org/10.1111/1468-0009.12060

29.   Boote, J., W. Baird, C. Beecroft. **Public involvement at the design stage of primary health research: A narrative review of case examples**. Health Policy, 2010. 95(1): p. 10-23.
Objective: To review published examples of public involvement in research design, to synthesise the contributions made by members of the public, as well as the identified barriers, tensions and facilitating strategies. Design: Systematic literature search and narrative review. Findings: Seven papers were identified covering the following topics: breast-feeding, antiretroviral and nutrition interventions; paediatric resuscitation; exercise and cognitive behavioural therapy; hormone replacement therapy and breast cancer; stroke; and parents' experiences of having a pre-term baby. Six papers reported public involvement in the development of a clinical trial, while one reported public involvement in the development of a mixed methods study. Group meetings were the most common method of public involvement. Contributions that members of the public made

to research design were: review of consent procedures and patient information sheets; outcome suggestions; review of acceptability of data collection procedures; and recommendations on the timing of potential participants into the study and the timing of follow-up. Numerous barriers, tensions and facilitating strategies were identified. Conclusions: The issues raised here should assist researchers in developing research proposals with members of the public. Substantive and methodological directions for further research on the impact of public involvement in research design are set out. © 2009 Elsevier Ireland Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.healthpol.2009.11.007

30.   Boote, J.D., M. Dalgleish, J. Freeman, Z. Jones, M. Miles, H. Rodgers. **'But is it a question worth asking?' A reflective case study describing how public involvement can lead to researchers' ideas being abandoned**. Health Expectations, 2014. 17(3): p. 440-451.
Background It is good practice for the public to be involved in developing research ideas into grant applications. Some positive accounts of this process have been published, but little is known about when their reactions are negative and when researchers' ideas are abandoned. Objective To present a case study account of when an academic-led idea for funding was not supported by stroke survivors and carers who were asked to contribute to its development, together with a reflection on the implications of the case from all the stakeholders involved. Design A reflective case study of a research idea, developed by an academic researcher, on which stakeholders were consulted. Participants University researchers, clinicians, public involvement managers, and stroke survivors and carers from the NIHR's Stroke Research Network. Findings Although the idea met with the approval of health professionals, who were keen to develop it into a funding bid, the stroke survivors and carers did not think the idea worth pursuing. This lack of patient and carer support led to the idea being abandoned. Reflecting on this, those involved in the consultation believed that the savings accrued from abandoning the idea, in terms of ensuring that public money is not wasted, should be seen as an important benefit of public involvement in the research process. Conclusion Little is known about the role of the public in the abandonment of research ideas. We recommend that further research is undertaken into this important contribution that patients and the public can make to health research.
http://dx.doi.org/10.1111/j.1369-7625.2012.00771.x

31.   Bradley, Q. **'Putting our mark on things': The identity work of user participation in public services**. Critical Social Policy, 2013. 33(3): p. 384-402.
New relationships between service users and the welfare state have emerged as a result of governmental strategies of public service reform in which participation has appeared as the cure for a putative welfare dependency. A new public has been invoked in technologies of governance which have conflated responsible citizenship with participation in the marketplace and have aimed to change the behaviour of welfare service users accordingly. This paper investigates the ability of welfare service users to resist, or amend, the disciplinary intentions of these discourses, to constitute counter-publics', and to formulate their own visions of public services. Drawing on research with English social housing tenants engaged in participation with their quasi-public landlords, and applying a theoretical framework based on the work of feminist and queer theorist Judith Butler, the paper explores the behavioural effects of participation on tenants and evidences their use of consumerist and communitarian discourses to construct alternative perceptions of a public', and re-imagine their relationship with public services.
http://dx.doi.org/10.1177/0261018312468306

32.   Brataas, H.V., H. Bjugan, T. Wille, O. Hellzen. **Experiences of day care and collaboration among**

people with mild dementia. Journal of Clinical Nursing, 2010. 19(19-20): p. 2839-2848.
Aims.: The study was designed to assess how a day care programme once a week, for seven weeks, with group collaboration and social and cultural activities was experienced by clients. The aim was to provide some insight into how older adults with mild cognitive impairment perceive and experience day care. Background.: As a consequence of social withdrawal, older adults with mild dementia may suffer a loss of meaningful social life and mental stimulus. Person-centred and collaborative day care may provide support to remaining abilities and facilitate for social activities. Little is known about client experiences and whether and how day care gives meaning to everyday life of persons with mild dementia. Design.: A qualitative interview study in a narrative content analysis design. Methods.: This study involved narrative interviews with nine Norwegian clients, aged 77-88 years of age, living at home, all being old people with mild dementia. Results.: Three main themes emerged: 'Ambivalence Shifts to Interest', 'Meaningful Engagement Engenders Wellbeing' and 'Social Fellowship Promotes Life Contentment'. The findings gave insights into how people with mild dementia had positive experiences from a once-a-week day programme. Conclusions.: This study demonstrates feelings of more meaningful lives, well-being and contentment as effects of collaborative day care participation. Safe transfer was a prerequisite to participate. There is a need of more research on how to facilitate person-centred and collaborative day care provided for groups in different contexts, culturally pluralistic groups and groups of younger seniors with mild dementia. Relevance to clinical practice.: Persons with mild dementia may practice remaining social and collaborative skills when care facilitate and moderate participant involvement. Therefore, facilitating for clients' feelings of control in secure environments, narrative conversations, group activities and collaborative group interaction are suggested. © 2010 Blackwell Publishing Ltd.
http://dx.doi.org/10.1111/j.1365-2702.2010.03270.x

33. Brooks, F. **»When I was on the ward«: The contribution of patient narratives to public involvement in health care decision-making**. Neurologie und Rehabilitation, 2008. 14(1): p. 24-30.
Aims: This paper sets out to provide an account of the forms of knowledge and expertise participants brought to a representational form of public involvement in healthcare. The findings are drawn from a two-year ethnographic study of an initiative by an acute hospital in the UK that aimed to involve members of the local community in health care decision-making, through the creation of a patient and public council. Methods: Data triangulation was achieved by a multi-method approach to the conduct of the fieldwork. The methods consisted of: a) Observation of all council meetings (42 hours), b) Individual and focus group interviews with councillors (n = 17) and c) Interviews with hospital staff and managers (n = 35). Results: Councillors drew almost exclusively from their experiential knowledge to construct and advance their agendas for the work of the council. Experiential knowledge and narratives was found to be very influential in constructing the types of contributions from the patient councillors. The patient councillors narratives provided a direct and largely unanticipated challenge to the agendas promoted by the health care workers. This resulted in particular tensions between the patient councillors and professionals concerned with the nature of expertise and the form of patients' contribution to health care delivery. The paper outlines these contested areas and describes the ways in which both patients and staff moved to create a shared set of understandings in order to progress the work of the council. Conclusions: The paper highlights the contribution of personal narratives to public participation and the value that knowledge derived from personal experiences can have for service development. A key finding relates to the importance of professional repositioning and training vis-à-vis the credibility of patients' narratives, as a starting point for shared understandings and the development of improvements in service organisation. However

situated and experiential knowledge cannot be treated as unproblematic, instead an understanding of the partiality of such knowledge needs to be created and consequently where such knowledge can be appropriately drawn upon. © Hippocampus Verlag 2008.

34.   Brown, I. **Organizational values in general practice and public involvement: Case studies in an urban district**. Health and Social Care in the Community, 2001. 9(3): p. 159-167.
A multiple case study design was used to explore dimensions of organizational values in general practice with respect to developing public involvement. The study was undertaken in an urban district in England with data collected through in-depth individual and focus group interviews with service providers and service users. Four general practice organizations were randomly selected for study after sorting all in the district according to their record of developing involvement activities. The case studies provide evidence of how organizational values can differ markedly in general practice in relation to ideas of public involvement, with consequences for the quantity and quality of activities for involving local people and service users. The differences manifest themselves in the beliefs and attitudes of service providers about the purpose of the organization and the types of relationships that are appropriate with service users and local people. Service users appear to be very perceptive to the underlying ethos and purpose to their practice organization and this affects their responsiveness to initiatives for their involvement. The dimensions of the different values found in the study appear to be essentially the same as a number of established empirical findings of variations in values in general practice: an orientation to a narrow medical role and to general practice as a business are associated with a low valuation of involvement; an orientation to teamwork and to a broader social role appear more congruent with the development of involvement. Power is a critical issue in this setting with evidence in the study of the dominance of the medical practitioners in establishing organizational values and the nature of public involvement activities.
http://dx.doi.org/10.1046/j.1365-2524.2001.00292.x

35.   Bruni, R.A., A. Laupacis, W. Levinson, D.K. Martin. **Public involvement in the priority setting activities of a wait time management initiative: A qualitative case study**. BMC Health Services Research, 2007. 7.
Background. As no health system can afford to provide all possible services and treatments for the people it serves, each system must set priorities. Priority setting decision makers are increasingly involving the public in policy making. This study focuses on public engagement in a key priority setting context that plagues every health system around the world: wait list management. The purpose of this study is to describe and evaluate priority setting for the Ontario Wait Time Strategy, with special attention to public engagement. Methods. This study was conducted at the Ontario Wait Time Strategy in Ontario, Canada which is part of a Federal-Territorial-Provincial initiative to improve access and reduce wait times in five areas: cancer, cardiac, sight restoration, joint replacements, and diagnostic imaging. There were two sources of data: (1) over 25 documents (e.g. strategic planning reports, public updates), and (2) 28 one-on-one interviews with informants (e.g. OWTS participants, MOHLTC representatives, clinicians, patient advocates). Analysis used a modified thematic technique in three phases: open coding, axial coding, and evaluation. Results. The Ontario Wait Time Strategy partially meets the four conditions of 'accountability for reasonableness'. The public was not directly involved in the priority setting activities of the Ontario Wait Time Strategy. Study participants identified both benefits (supporting the initiative, experts of the lived experience, a publicly funded system and sustainability of the healthcare system) and concerns (personal biases, lack of interest to be involved, time constraints, and level of technicality) for public involvement in the Ontario Wait

Time Strategy. Additionally, the participants identified concern for the consequences (sustainability, cannibalism, and a class system) resulting from the Ontario Wait Times Strategy. Conclusion. We described and evaluated a wait time management initiative (the Ontario Wait Time Strategy) with special attention to public engagement, and provided a concrete plan to operationalize a strategy for improving public involvement in this, and other, wait time initiatives. © 2007 Bruni et al; licensee BioMed Central Ltd.
http://dx.doi.org/10.1186/1472-6963-7-186

36.   Buchecker, M., M. Hunziker, F. Kienast. **Participatory landscape development: overcoming social barriers to public involvement**. Landscape and Urban Planning, 2003. 64(1-2): p. 29-46.
Since the early seventies, a considerable part of the Swiss population has perceived the actual development of the landscape as unwelcome and problematic. In spite of the efforts in science and politics this problem could not be reduced effectively. The measures taken concentrated on protecting the landscape. According to our hypothesis a sustainable landscape development does not only require protection, but also and maybe most of all the participation of the local residents in shaping the landscape. So the problem of the landscape is that participation is somehow blocked. This study tried to provide the foundations for a new strategy to a sustainable landscape development by finding answers to the following questions: What prevents local residents from participating in the processes that shape their landscape? How could they be encouraged to participate? These questions were investigated with methods of qualitative social science research (interviews, photo experiments, action research). The investigation was carried out in two rural communities, which differed in their degree of urbanisation. We found that the residents' participation was mainly prevented by the persistent identification with the village community, which is connected with a pressure to adapt to collective standards. To foster participation new communicative instruments are needed, which allow to exchange ideas without risking to be ostracised. Such instruments were evaluated in the two communities and proved to be effective. At the same time, it became clear that fostering a participatory landscape development requires a long-term learning-process. (C) 2002 Elsevier Science B.V. All rights reserved.
http://dx.doi.org/10.1016/s0169-2046(02)00199-8

37.   Buck, D., C. Gamble, L. Dudley, J. Preston, B. Hanley, P.R. Williamson, . . . E.P.A. Grp. <mark>From plans to actions in patient and public involvement: qualitative study of documented plans and the accounts of researchers and patients sampled from a cohort of clinical trials</mark>. Bmj Open, 2014. 4(12).
Patient and public involvement (PPI) in research is increasingly required, although evidence to inform its implementation is limited. Objective: Inform the evidence base by describing how plans for PPI were implemented within clinical trials and identifying the challenges and lessons learnt by research teams. Methods: We compared PPI plans extracted from clinical trial grant applications (funded by the National Institute for Health Research Health Technology Assessment Programme between 2006 and 2010) with researchers' and PPI contributors' interview accounts of PPI implementation. Analysis of PPI plans and transcribed qualitative interviews drew on the Framework technique. Results: Of 28 trials, 25 documented plans for PPI in funding applications and half described implementing PPI before applying for funding. Plans varied from minimal to extensive, although almost all anticipated multiple modes of PPI. Interview accounts indicated that PPI plans had been fully implemented in 20/25 trials and even expanded in some. Nevertheless, some researchers described PPI within their trials as tokenistic. Researchers and contributors noted that late or minimal PPI engagement diminished its value. Both groups perceived uncertainty about roles in relation to PPI, and noted contributors' lack of confidence

and difficulties attending meetings. PPI contributors experienced problems in interacting with researchers and understanding technical language. Researchers reported difficulties finding 'the right' PPI contributors, and advised caution when involving investigators' current patients. Conclusions: Engaging PPI contributors early and ensuring ongoing clarity about their activities, roles and goals, is crucial to PPI's success. Funders, reviewers and regulators should recognise the value of preapplication PPI and allocate further resources to it. They should also consider whether PPI plans in grant applications match a trial's distinct needs. Monitoring and reporting PPI before, during and after trials will help the research community to optimise PPI, although the need for ongoing flexibility in implementing PPI should also be recognised.
http://dx.doi.org/10.1136/bmjopen-2014-006400

38.   Bäck, A., S. Vainikainen, P. Näkki, T. Reti, R. Sarvas, L. Seppälä, . . . H. Hietanen, *Semantically supported media services with user participation: Report on the RISE-project*, in *VTT Publications*2006. p. 3-99.
       This publication presents the main results of the project "Rich Semantic Media for Private and Professional Users" (RISE). The background to the launch of the project was the identification of two important developments: the emergence of user-generated content and Semantic Web technologies. The goal was to study what kind of new opportunities semantic metadata and combining commercial media content with user-created material give to media companies and their suppliers for product and service development. The publication gives an overview on recent developments relating to utilising user-generated content and metadata in public Web applications, and an update on development on Semantic Web technologies related issues on their relevance to the application development made in the project. The project chose to explore research issues by building prototypes. Each of the prototypes is presented including a user scenario, implementation, results, discussion and future work. • The StorySlotMachine is travelling related application, which allows users to make their own guidebooks to be used during the trip. After the trip users can make presentations combining their own photos and commercial content. Ontologies are used for automatic aggregation and to offer content that deals with the topic. • The Remix Engine prototype is a Web-based video editing and compilation application that lets the user combine his or her own media with commercial media with the help of pre-made templates. The end product, a video, is composed of professional material that includes team logos, TV brands, advertisements, and so on. • DiMaS is a Digital Content Distribution Management System for multimedia producers to publish their work on P2P file sharing networks. The system enables producers to insert content metadata, to manage intellectual property and usage rights, and to charge for the consumption. Applications like StorySlotMachine and RemixEngine could be built in connection to media archives, like news archives, or in connection to encyclopaedia, where the material is already modular. If and when users do the final aggregating and editing work themselves, the costs for offering content this way are not high after the initial investment in the tools and metadata have been made. Commercial media must be able to offer more value to the users than free services and utilising ontologies in making services more intelligent is one opportunity. There are still challenges for building this kind of services: A big issue in utilising semantic metadata and Semantic Web technologies is developing and maintaining ontologies. Another issue is adding semantic metadata to the content. Also legal issues like commercialisation of the content creation activity, intellectual property rights within the creators, the brand image of the content or the group, and managing the liability risks in content production need to be solved. If media companies turn their content into more modular format and add semantic metadata to support reusability and active exploration of content they have more opportunities to create new consumer applications with rich user experience.

39.   Cabiati, E., M.L. Raineri. **Learning from service users' involvement: a research about changing stigmatizing attitudes in social work students**. Social Work Education, 2016. 35(8): p. 982-996.
        Stigmatizing attitudes can create barriers to forming partnership with service users and to developing people's empowerment. So, social work education must help students overcome their stigmatizing attitudes. A useful strategy for bringing about changes is service users' and carers' involvement in social work education, providing students with direct exposure to stigmatized people in roles that emphasize their humanity and strengths, rather than their deficits. The present study assessed the impact of a one-day meeting with service users and carers members of self-help and mutual-aid groups on freshman social work students. Students completed an adapted version of Attitudes to Mental Illness Questionnaire before and after the meeting, and answered several qualitative questions. Data comparisons suggest that after face-to-face contact with service users and carers, social work students showed reduced stigmatizing attitudes. Implications for further research and social work education are discussed. © 2016 Informa UK Limited, trading as Taylor & Francis Group.
        http://dx.doi.org/10.1080/02615479.2016.1178225

40.   Campbell, H., R. Marshall. **Public involvement and planning: Looking beyond the one to the many**. International Planning Studies, 2000. 5(3): p. 321-344.
        A central theme in both current theoretical debate within planning and policy statements by the British Government is the perceived need for enhanced public involvement. Implicit in these concerns is the assumption that the existing structures of local governance should be modified. Government in the form of politicians and their paid staff acting on behalf of the wider community is increasingly conceptualized as unrealistic, ineffective and out-moded. Consequently, terms such as 'decentralization', 'community empowerment', 'collaboration' and 'public participation' have become the phrases of the moment. There is considerable ambiguity surrounding these terms but at their core lies the notion that those outside the town hall should be given more influence over local decision making. The parallels between New Labour's rhetoric about community empowerment and normative theorizing in planning which stresses the importance of open inclusionary dialogue is striking. Much of the existing literature concerning public involvement focuses on the failure in practice of many initiatives to achieve an often unspecified notion of 'true' or 'full' participation. As a result there has been a tendency to concentrate on attempting to refine the approach adopted, frequently leaving to one side how community-led initiatives can be reconciled with the existing structure of representative democracy. Most of the reasoning underlying current debate about public involvement seems to be founded on the belief that it is simply a good thing. Research in the Bay Area of California is drawn upon, where public willingness to articulate views and the associated mechanisms to foster such an activity are a much more taken-for-granted part of local government practice than is usually the case in Britain. The purpose is to look beyond the operational concerns to explore in detail what happens to government when people participate. The analysis is based on a conceptual framework which focuses on the interests served by public involvement. The findings emphasize the need for planners to be much more sophisticated in the way they handle the problematic of balancing personal interests with the collective good, including how different forms of knowledge can be reconciled.

41.   Carlisle, G.S. **Public involvement in the development control process**. Planner, 1987. 73(10): p.

23-25.

The primary aim of the thesis was to investigate the success or otherwise of public participation methods employed by Swansea City Council, and to produce a set of specific recommendations to improve that system. It took very little time to discover the alarming dearth of statistical or any other information on either the nature of, or the success of, public involvement in the control process in England and Wales. In order to provide the necessary base data, a series of <mark>questionnaire surveys</mark> was launched to adduce not only the necessary statistics, but also to canvass the opinions of the 3 main groups involved - councillors, officers and the public. There is a summary of the research undertaken and the principal conclusions reached.-Author

42.   Carrick, R., A. Mitchell, K. Lloyd. <mark>User involvement in research: Power and compromise</mark>. Journal of Community & Applied Social Psychology, 2001. 11(3): p. 217-225.
The extent to which collaborative research can redress power imbalances is debated with reference to some of the: relevant literature. Different ways in which research can be collaborative and power shared between researchers and participants are discussed. The benefits and challenges specific to collaboration in the area of mental health research are considered, illustrated with examples from research we conducted into the experience of taking antipsychotic medication. Copyright (C) 2001 John Wiley & Sons, Ltd.
http://dx.doi.org/10.1002/casp.623

43.   Challenor, R., M. FitzGerald, Z. Warwick. **Developing quality indicators for sexually transmitted infection services with patient and public involvement**. International Journal of STD and AIDS, 2010. 21(5): p. 329-331.
The views of genitourinary (GU) medicine clinic populations in two locations (university teaching hospital and district general hospital) were sought regarding service quality measures. In Plymouth, patients were invited to participate in a qualitative interview. Twenty GU medicine patients (10 men, 10 women; age range 17-63 years) were interviewed and consistent themes emerged. In Taunton, patients were invited to complete a quantitative survey. Twenty patients (10 men, 10 women; age range 17-48 years) were asked to rank the importance of suggested quality measures. The qualitative and quantitative approaches produced different results but were complementary. Service quality indicators were finalized at a multidisciplinary team meeting with three public members. Quality indicators need to be challenging yet achievable and it is difficult to judge precisely where standards should be set.We hope other services may wish audit performance against these proposed local measures. If such data were to be pooled, it would provide valuable evidence for 'SMART' (Specific, Measurable, Attainable, Relevant, Time-based) service quality indicators that are challenging yet achievable for the majority of clinics. This paper demonstrates that it is possible to obtain GU medicine patient views despite problems with confidentiality and 'one-stop' clinic visits.
http://dx.doi.org/10.1258/ijsa.2009.009320

44.   Chambers, E., A. Clarke, J. Cooke. <mark>Patient & public involvement in community research</mark>. Journal of Community Nursing, 2009. 23(7).
The value of engaging patients and member of the public in research is widely acknowledged in UK policy and the literature. Best Research for Best Health: A new National Health Research Strategy (DH, 2006) emphasised the importance of involving service users and carers in the research process and it is a requisite of applications to funding bodies such as the Clinical Trials Advisory and Awards Committee (CTAAC) and the Department of Health (Research for Patient Benefit). Although the principle of involving patients and the wider public in research seems

straightforward in theory, what does it mean for nurses in practice? Using the research literature and the experiences of the authors as academic and user researchers, we aim to explore the ways in which nurses may actively engage service users and carers in research undertaken in the community. First, though, it is important to ask what is meant by patient and public involvement in research. © Copyright JCN 2009.

45. Chambers, M., S. McAndrew, F. Nolan, B. Thomas, P. Watts, X. Kantaris. **Service user involvement in the coproduction of a mental health nursing metric: The Therapeutic Engagement Questionnaire**. Health Expectations, 2017. 20(5): p. 871-877.
Service users' involvement in mental health service research is increasingly acknowledged as important, yet, whilst involving users of mental health services as research participants is commonplace, seeking out their experience and indeed their expertise to facilitate the development of tools to be used within mental health services is in its infancy. This article describes the involvement and views of service users in the development of a nursing metricthe Therapeutic Engagement Questionnaire. It presents their role in the three stages of development: generation, statement reduction and authentication.
http://dx.doi.org/10.1111/hex.12526

46. Clarke, S.P., S. Holttum. **Staff perspectives of service user involvement on two clinical psychology training courses**. Psychology Learning and Teaching, 2013. 12(1): p. 32-43.
This study investigated both negative and positive staff perspectives of service user involvement on two clinical psychology training courses as part of an ongoing process of service evaluation. Ten clinical psychology staff from two training courses were interviewed over the telephone by a current trainee clinical psychologist using a semi-structured interview method. Data were coded into textual units of meaning and then analysed using content analysis. The categories most cited by participants regarding the positives of service user involvement were that service user involvement 'develops trainees' learning' and 'challenges power differences'. For opportunities of service user involvement to provide benefits to the training courses, most participants cited 'meaningful versus tokenistic involvement', followed by 'strategic involvement'. Regarding negatives and barriers, those most cited were 'differences of opinion or agendas' and 'lack of resources'. Whilst the findings suggested that the service user involvement initiatives on both courses have been well received, research is needed into how service users also experience the process. Interventions that facilitate staff reflection and processing of multiple perspectives were also recommended, particularly with regards to negative experiences of service user involvement.
http://dx.doi.org/10.2304/plat.2013.12.1.32

47. Collier, R., T. Stickley. **From service user involvement to collaboration in mental health nurse education: developing a practical philosophy for change**. The Journal of Mental Health Training, Education and Practice, 2010. 5(4): p. 4-11.
This paper reports on the development of an educational programme of work that is a collaboration between nursing educationalists and service users. Attention is given to the philosophical dimension of the work. The project is considered in the light of four related components that formed the basis of the enterprise, namely: philosophy, organisation, research and teaching (PORT). The perceptions of those who have participated in the project are commented upon. It is argued that in order to achieve social and mediation change within this educational setting, evidence of the mutual acceptance and understanding of difference has to be present. This can establish common ground between philosophical approaches. These approaches emerge from practice, from how people interact with each other, and not the other way around.

48.   Coon, J.T., R. Gwernan-Jones, D. Moore, M. Richardson, C. Shotton, W. Pritchard, . . . T. Ford. <mark>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</mark>. Health Expectations, 2016. 19(5): p. 1084-1097.
        Background The benefits of end-user involvement in health-care research are widely recognized by research agencies. There are few published evaluations of end-user involvement in systematic reviews. Objectives (i) Describe end-user involvement in a complex mixed-methods systematic review of ADHD in schools, (ii) reflect on the impact of end-user involvement, (iii) highlight challenges and benefits experienced and (iv) provide suggestions to inform future involvement. Methods End-users were involved in all stages of the project, both as authors and as members of an advisory group. In addition, several events were held with groups of relevant end-users during the project. Results End-user input (i) guided the direction of the research, (ii) contributed to a typology of interventions and outcomes, (iii) contributed to the direction of data analysis and (iv) contributed to the robustness of the syntheses by demonstrating the alignment of interim findings with lived experiences. Challenges included (i) managing expectations, (ii) managing the intensity of emotion, (iii) ensuring that involvement was fruitful for all not just the researcher, (iv) our capacity to communicate and manage the process and (v) engendering a sense of involvement amongst end-users. Conclusions End-user involvement was an important aspect of this project. To minimize challenges in future projects, a recognition by the project management team and the funding provider that end-user involvement even in evidence synthesis projects is resource intensive is essential to allow appropriate allocation of time and resources for meaningful engagement.
        http://dx.doi.org/10.1111/hex.12400

49.   Cossar, J., E. Neil. <mark>Service User Involvement in Social Work Research: Learning from an Adoption Research Project</mark>. British Journal of Social Work, 2015. 45(1): p. 225-240.
        Service user involvement in research has triggered debate about epistemology, power relationships between researchers and participants, ethics and the validity of research findings. The social work profession encourages respect for service users and promotion of their rights-values which arguably should be reflected in social work research. This paper presents a case study of service user involvement in a government-funded adoption research project. The research team included a birth relative consultant group and the paper discusses both the process and outcomes of their involvement. The benefits and costs of service user involvement are highlighted. Reflections from the consultants about their experiences of being involved in the research are included. The discussion positions the project in relation to existing theories and models of service user involvement.
        http://dx.doi.org/10.1093/bjsw/bct108

50.   Cotterell, P. Exploring the value of service user involvement in data analysis: 'Our interpretation is about what lies below the surface'. Educational Action Research, 2008. 16(1): p. 5-17.
        In this article the process and outcomes of service user involvement in the analysis of data are discussed. The analysis formed part of a doctoral participatory research project, which involved researcher and service users working together. The focus of the research was on the experience and needs of service users with life limiting conditions including any influence on the experience

produced by social factors. Service users with a range of life limiting conditions took part in the research. A separate group of service users affected by life limiting conditions formed the Service User Research Advisory Group (SURAG) that met 32 times over three years and was an integral part of the research. A novel and workable collaborative analysis approach is described along with the identification of similarities and differences between researcher and service user interpretations of data.
http://dx.doi.org/10.1080/09650790701833063

51.   Cotterell, P., G. Harlow, C. Morris, P. Beresford, B. Hanley, A. Sargeant, . . . K. Staley. **Service user involvement in cancer care: The impact on service users**. Health Expectations, 2011. 14(2): p. 159-169.
Background Service user involvement is embedded in the United Kingdom's National Health Service, but knowledge about the impact of involvement on service users, such as the benefits and challenges of involvement, is scant. Our research addresses this gap. Objective To explore the personal impact of involvement on the lives of service users affected by cancer. Design We conducted eight focus groups with user groups supplemented by nine face-to-face interviews with involved individuals active at a local, regional and national level. Thematic analysis was conducted both independently and collectively. Setting and participants Sixty-four participants, engaged in involvement activities in cancer services, palliative care and research, were recruited across Great Britain. Results We identified three main themes: (i) 'Expectations and motivations for involvement'- the desire to improve services and the need for user groups to have a clear purpose, (ii) 'Positive aspects of involvement'- support provided by user groups and assistance to live well with cancer and (iii) 'Challenging aspects of involvement'- insensitivities and undervaluing of involvement by staff. Conclusions This study identified that involvement has the capacity to produce varied and significant personal impacts for involved people. Involvement can be planned and implemented in ways that increase these impacts and that mediates challenges for those involved. Key aspects to increase positive impact for service users include the value service providers attach to involvement activities, the centrality with which involvement is embedded in providers' activities, and the capacity of involvement to influence policy, planning, service delivery, research and/or practice. © 2010 Blackwell Publishing Ltd.
http://dx.doi.org/10.1111/j.1369-7625.2010.00627.x

52.   Cresswell, K., Z. Morrison, S. Crowe, A. Robertson, A. Sheikh. **Anything but engaged: user involvement in the context of a national electronic health record implementation**. Informatics in primary care, 2011. 19(4): p. 191-206.
The absence of meaningful end user engagement has repeatedly been highlighted as a key factor contributing to 'failed' implementations of electronic health records (EHRs), but achieving this is particularly challenging in the context of national scale initiatives. In 2002, the National Health Service (NHS) embarked on a so-called 'top-down' national implementation strategy aimed at introducing commercial, centrally procured, EHRs into hospitals throughout England. We aimed to examine approaches to, and experiences of, user engagement in the context of a large-scale EHR implementation across purposefully selected hospital care providers implementing early versions of nationally procured software. We conducted a qualitative, case-study based, socio-technically informed, longitudinal investigation, purposefully sampling and collecting data from four hospitals. Our data comprised a total of 123 semi-structured interviews with users and managers, 15 interviews with additional stakeholders, 43 hours of non-participant observations of meetings and system use, and relevant organisation-specific documents from each case study site. Analysis was thematic, building on an existing model of user engagement that was originally developed in

the context of studying the implementation of relatively simple technologies in commercial settings. NVivo8 software was used to facilitate coding. Despite an enduring commitment to the vision of shared EHRs and an appreciation of their potential benefits, meaningful end user engagement was never achieved. Hospital staff were not consulted in systems choice, leading to frustration; they were then further alienated by the implementation of systems that they perceived as inadequately customised. Various efforts to achieve local engagement were attempted, but these were in effect risk mitigation strategies. We found the role of clinical champions to be important in these engagement efforts, but progress was hampered by the hierarchical structures within healthcare teams. As a result, engagement efforts focused mainly on clinical staff with inadequate consideration of management and administrative staff. This work has allowed us to further develop an existing model of user engagement from the commercial sector and adapt it to inform user engagement in the context of large-scale eHealth implementations. By identifying key points of possible engagement, disengagement and re-engagement, this model will we hope both help those planning similar large-scale EHR implementation efforts and act as a much needed catalyst to further research in this neglected field of enquiry.

53.   Damodaran, L. **User involvement in the systems design process - A practical guide for users**. Behaviour & Information Technology, 1996. 15(6): p. 363-377.
Increasingly users find themselves 'involved' in IT design projects. This occurs because the organizational culture of the parent organization purports to promote participation, or because structured design methods are being used which require users to play a part. In either case users who find themselves required to participate in IT projects are frequently unclear about what this requires. In most organizations surprisingly little briefing on the users' role in design projects is provided. Users are therefore confused about their brief and concerned about their lack of expertise in computing. Although research reports on participatory design (PD) projects abound, little coherent guidance for the key stakeholders representing users' interests is available. The contents of this paper go some way towards filling the gap. Clear differentiation is made in the paper between the roles of the different players involved. Detailed guidance is provided for meeting the varied requirements of the different roles. For example, the roles of 'top' management and 'middle' management in supporting user involvement are explored, their special responsibilities specified and required actions listed. The need for an infrastructure to support user involvement and how to create one is discussed. Guidance is provided on, for example, the representation process and the factors to consider in selecting user representatives. The role of user representatives is particularly problematical and therefore receives particularly close attention. Finally guidance is given regarding the common pitfalls in Quality Assurance procedures and especially how to avoid the procedures becoming a meaningless 'rubber-stamping' exercise. The guidance presented is grounded in the extensive experience of the author in participative design processes in a wide variety of contexts including the footwear industry, a major UK government department and a telecommunications and broadcasting company.
http://dx.doi.org/10.1080/014492996120049

54.   Davies, K., M. Gray, S.A. Webb. **Putting the parity into service-user participation: An integrated model of social justice**. International Journal of Social Welfare, 2014. 23(2): p. 119-127.
Models of service-user participation have derived from citizenship or consumerist agendas, neither of which has achieved the structural reforms important for the most marginalised social work clients. This article proposes Fraser's model of parity of participation' as an appropriately multifaceted frame for capturing the social justice aspirations of service-user participation. A

qualitative case study compared the experiences and expectations of people who had used Australian mental health services with a sample who had used Australian homelessness services to examine their expectations of participation at individual and representative levels. The findings reinforce concerns from Fraser's research about the tendency for identity-based consumerist notions of participation to reify group identity. This leads to tokenistic service-user involvement strategies that have little impact on participation at a structural level. Fraser's parity of participation is shown to have untested potential to reshape service-user participation to meet the social justice aspirations of social work clients. Key Practitioner Message: . Innovative, service-user driven strategies for collaboration will be those which challenge existing power structures; . Service users want their contributions to decision making to generate identifiable change in the system of social services; . The success of service-user participation strategies might be the extent to which political, economic and cultural opportunities are enhanced. http://dx.doi.org/10.1111/ijsw.12049

55.   Daykin, N., M. Sanidas, V. Barley, S. Evans, J. McNeill, N. Palmer, . . . P. Turton. **Research reports. Developing consensus and interprofessional working in cancer services: The case of user involvement**. Journal of Interprofessional Care, 2002. 16(4): p. 405-406.
           http://dx.doi.org/10.1080/1356182021000008346

56.   de Bere, S.R., S. Nunn. **Towards a pedagogy for patient and public involvement in medical education**. Medical Education, 2016. 50(1): p. 79-92.
        ContextThis paper presents a critique of current knowledge on the engagement of patients and the public, referred to here as patient and public involvement (PPI), and calls for the development of robust and theoretically informed strategies across the continuum of medical education. MethodsThe study draws on a range of relevant literatures and presents PPI as a response process in relation to patient-centred learning agendas. Through reference to original research it discusses three key priorities for medical educators developing early PPI pedagogies, including: (i) the integration of evidence on PPI relevant to medical education, via a unifying corpus of literature; (ii) conceptual clarity through shared definitions of PPI in medical education, and (iii) an academically rigorous approach to managing complexity in the evaluation of PPI initiatives. ResultsAs a response to these challenges, the authors demonstrate how activity modelling may be used as an analytical heuristic to provide an understanding of a number of PPI systems that may interact within complex and dynamic educational contexts. ConclusionThe authors highlight the need for a range of patient voices to be evident within such work, from its generation through to dissemination, in order that patients and the public are partners and not merely objects of this endeavour. To this end, this paper has been discussed with and reviewed by our own patient and public research partners throughout the writing process. Discuss ideas arising from the article at discuss.
        http://dx.doi.org/10.1111/medu.12880

57.   De Freitas, C., M. García-Ramirez, A. Aambø, S.C. Buttigieg. **Transforming health policies through migrant user involvement: Lessons learnt from three European countries**. Psychosocial Intervention, 2014. 23(2): p. 105-113.
        Designing and implementing equitable health policies requires the involvement of all stakeholders. However, disadvantaged groups are under-represented in European health participatory mechanisms. Migrants and ethnic minorities (MEMs), for example, are consistently left out of policy-making fora. Additionally, MEMs lack a voice on the programmes that are intended to benefit them. This can jeopardize the responsiveness of health policies to MEM needs

and undermine the development of diversity sensitive care, making way for increased inequities in health. It is necessary therefore to investigate innovative strategies capable of fostering MEMs' participation. Community psychology is particularly promising in this respect as it aims to mobilize the resources that communities possess, rather than simply teaching people to use services developed by others. Moreover, it highlights collaborative/participatory research approaches, which privilege the involvement of all stakeholders. By employing a community psychology approach, this paper looks at three European countries -the Netherlands, Norway and Spain- and summarizes lessons learnt from their experiences with migrant user involvement. The cases reported address different aspects of involvement, including: community mobilization, sociopolitical development, and creation of community alliances and coalitions. Its analysis offers several insights that can transform policy-making into a more inclusive process. © 2014 Colegio Oficial de Psicólogos de Madrid. Production by Elsevier España, S.L. All rights reserved. http://dx.doi.org/10.1016/j.psi.2014.07.007

58.   de Moor, K., K. Berte, L. de Marez, W. Joseph, T. Deryckere, L. Martens. **User-driven innovation? Challenges of user involvement in future technology analysis**. Science and Public Policy, 2010. 37(1): p. 51-61.
       The shift from the traditional push towards more user-driven innovation strategies in the information and communications technologies domain has urged companies to place the user at the core of their innovation process in a more systematic way. In this paper we reflect on the implications of this new innovation context for traditional product development processes. Given these implications, two challenges are discussed that are crucial to true user-driven innovation, i.e. the challenge of continuously involving the user and the need for tools to facilitate the integration of knowledge into the increasingly interdisciplinary development process. Drawing on our own experiences in the interdisciplinary Research On Mobile Applications and Services (ROMAS) project, which focused on future mobile applications in a living lab setting, we illustrate how the two challenges can be tackled. © Beech Tree Publishing 2010. http://dx.doi.org/10.3152/030234210X484775

59.   de Piccoli, N., C. Rollero. **Public involvement in social and political participation processes: A gender perspective**. Journal of Community and Applied Social Psychology, 2010. 20(3): p. 167-183.
       One interesting perspective from which to investigate participation processes is that of gender (Angelique & Culley, 2007). The disparity between male and female participation is evident, in particular when dealing with politics. The research reported here examines any differences between men and women in three different groups: non-participants (N = 201), social participants (N = 167) and political participants (N = 184). Two specific aspects were considered: (a) the perception of sociopolitical control, that is leadership competence and policy control, and (b) the perception of costs and benefits derived from participation. In focusing on such perceptions, if any difference could be evidenced, we aimed to investigate if this difference was determined by gender, by the type of participation or by the interaction of gender and participation. Data show that leadership competence and policy control were both influenced by the type of participation. An interaction effect of gender and type of commitment for policy control was observed and gender had a direct effect on leadership competence. These results suggest that the gender gap seems to be connected more to the context than to effective gender characteristics. Other data on the perception of costs and benefits are discussed. © 2009 John Wiley & Sons, Ltd. http://dx.doi.org/10.1002/casp.1027

60. de Waal, B., R. Batenburg, P. Breman, *What Makes User Participation Work? A Project Management View on Variation in User Participation*, in *Proceedings of the 10th European Conference on Management Leadership and Governance*, V. Grozdanic, Editor 2014. p. 69-77.

61. Deckers, E.J.L., S.A.G. Wensveen, R.M.C. Ahn, C.J. Overbeeke, Acm. **Designing for Perceptual Crossing to Improve User Involvement**. 29th Annual Chi Conference on Human Factors in Computing Systems, 2011: p. 1929-1937.
   In this paper we describe our research on how to design for perceptive activity in artifacts in order for perceptual crossing between subject and artifact to happen. We base our research on the phenomenology of perception [19] and on ecological psychology [10]. Perceptual crossing is believed to be essential to share perception and thereby to feel involved in the situation [5,15]. We propose a theoretical model in which perceptive connections between user, artifact and event are presented. We designed an artifact to function as physical hypotheses [9] and show the design relevance of the model. In an experiment we investigate how the user's feeling of involvement is influenced in relation to differentiations of the proposed theoretical model. The results of our experiment show that indeed perceptual crossing between user and artifact influences the user's feeling of involvement with the artifact in their common space. We conclude with describing several design notions important for designing for perceptive activity in artifacts.

62. Dent, M., C. Fallon, C. Wendt, J. Vuori, M. Puhor, C. De Pietro, S. Silva. **Medicine and user involvement within European healthcare: A typology for European comparative research**. International Journal of Clinical Practice, 2011. 65(12): p. 1218-1220.
   User involvement is encouraged within the European Union (EU) within healthcare, most commonly in the form of patient choice. This has recently been further extended in relation to cross-border hospital care (1). The nature of user involvement, however, extends beyond the role of consumer choice to include that of the citizen and of the coproducer reflecting the reality that user involvement goes beyond choice of hospital to include issues surrounding future plans for health services within a region (10,11) and engaging patients in expert patient programmes (21).
   http://dx.doi.org/10.1111/j.1742-1241.2011.02803.x

63. Dexter, G., M. Larkin, C. Newnes. **A qualitative exploration of Child Clinical Psychologists' understanding of user involvement**. Clinical Child Psychology and Psychiatry, 2012. 17(2): p. 246-265.
   'Service User Involvement' is a key directive for mental health services. This is thought to be especially complex in child services-despite evidence that it can be achieved-because of the need to use developmentally-appropriate tools. Children are in a multi-faceted position of disempowerment when they enter mental health services; attempts to involve them in these services are entangled with intricate power issues. To explore these issues, eight Clinical Psychologists who work with children were interviewed about their views and experiences of User Involvement. Their accounts were analysed by drawing on Foucauldian Discourse Analysis. The resulting account demonstrates how children are consistently positioned as both vulnerable and powerless (in contrast to parents and professionals). This has the effect of rendering them as less-than-ideal candidates for involvement in service evaluation and planning, in a context where parents may seem to offer a more straightforward option to professionals, and where those professionals see themselves as having to operate within certain constraints. © 2011 The Author(s).
   http://dx.doi.org/10.1177/1359104511400970

64. Diederiks, E.M.A., H.C.M. Hoonhout. **Radical Innovation and End-User Involvement: The Ambilight**

Case. Knowledge, Technology & Policy, 2007. 20(1): p. 31-38.
To make technology research more effective and to deal with fierce cost competition, technology research should be more focused on radical innovation and needs to adopt a more end-user-focused approach. Product improvement is already quite often building on knowledge collected around consumers' experiences with these products to come with a next, improved generation of products. However, in case of creating novel products from "scratch," this will be more difficult. The user-centered research approach including insights, scenarios, and experience prototypes provides a good method to incorporate the consumer perspective in the earliest stages of the product creation process. The development of the Ambilight TV will be used as a case to illustrate this approach. [ABSTRACT FROM AUTHOR]

http://dx.doi.org/10.1007/s12130-007-9002-z

65.   Dilworth-Anderson, P., S.W. Williams. **Recruitment and retention strategies for longitudinal African American caregiving research: The family caregiving project**. Journal of Aging and Health, 2004. 16(5 SUPPL.): p. 137S-156S.
Objectives: This article provides a detailed discussion, guided by a culturally competent approach, on recruitment and retention strategies used to study caregiving to older dependent elders in African American families. Methods: The study (lasting from 1995 through 2000) included collecting three waves of data, 9 months apart, among 202 caregiving units (containing a maximum of three caregivers per unit). Results: Four key strategies were identified as useful in recruiting and retaining the sample: (a) assigning the same interviewers to communicate with and interview study participants for each wave of data collection, (b) ensuring that all interviewers are knowledgeable of possible family dynamics and social issues within the African American community (e.g., access to health care, income and education issues, and discrimination), (c) providing a mechanism by way of a toll-free number for all participants to contact the project staff at the participant's convenience, and (d) allowing flexibility in scheduling and rescheduling interviews at the participant's convenience. Discussion: Researchers need to acquire knowledge and develop skills that will foster culturally competent approaches when studying diverse cultural groups, which involves incorporating the beliefs, values, and attitudes of a cultural group in every phase of the research project, from conceptualization to interpretation of findings. Additionally, a genuine interest in, knowledge of, and respect for the population are necessary to help improve participant involvement in longitudinal research among African American caregivers.
http://dx.doi.org/10.1177/0898264304269725

66.   Doll, W.J., X. Deng. **The Collaborative Use of Information Technology: End-User Participation and Systems Success**. Information Resources Management Journal (IRMJ), 2001. 14(2): p. 6-16.
User participation seems especially important in the development of collaborative work systems where the technology is used by a work group to coordinate its joint activities. Users rather than systems analysts are often the best source of information on how they will use information technology to collaborate. It is almost an axiom of systems development that end users should participate in a broad range of activities/decisions, and that they should be permitted to participate in these decisions as much as they want. Despite these widely held beliefs, research

has not focused on the differential efficacy of user participation in collaborative versus non-collaborative applications. Building upon the work of behavioral scientists who study participative decision making, Doll and Torkzadeh (1991) present a congruence construct of participation that measures whether end users participate as much as they want in key systems analysis decisions. Using a sample of 163 collaborative and 239 non-collaborative applications, this research focuses on three research questions: (1) Is user participation more effective in collaborative applications? (2) What specific decision issues enhance user satisfaction and productivity? and (3) Can permitting end-users to participate as much as they want on some issues be ineffective or even dysfunctional? The results indicate that user participation is more effective in collaborative applications. Of the four decision issues tested, only participation in information needs analysis predicts end-user satisfaction and task productivity. Encouraging end users to participate as much as they want on a broad range of systems analysis issues such as project initiation, information flow analysis, and format design appears to be, at best, a waste of time and, perhaps, even harmful. These findings should help managers and analysts make better decisions about how to focus participatory efforts and whether end users should participate as much as they want in the design of collaborative systems. © 2001, IGI Global. All rights reserved. http://dx.doi.org/10.4018/irmj.2001040101

67.   Donovan, S., F. Ross, E. Smith. **Circles of learning: using the World Café method to build knowledge on service user involvement**. Education for Primary Care, 2005. 16(1): p. 85-86.
This article focuses on primary care. At the annual meeting of the Society for Academic Primary Care in Glasgow, they led a workshop on user involvement in research using the World Cafe approach. This approach involves supporting focused discussions in small groups at conversation tables, which are then developed in progressive rounds of approximately 20-30 minutes each. This is a creative, if unorthodox approach to generating ideas, which challenges the usual format of structure and authority within a discussion group. Participants in the workshop were mostly academic researchers, general practitioners and other professionals working in primary care.

68.   Dorer, G., P. Harries, L. Marston. **Measuring social inclusion: A staff survey of mental health service users' participation in community occupations**. British Journal of Occupational Therapy, 2009. 72(12): p. 520-530.
Mental health service users frequently experience social exclusion and limited occupational engagement. A survey was conducted to gather staff reports of 199 service users' levels of engagement and social inclusion across eight domains of community occupation. The staff reported that the majority of service users (54%) engaged in two or fewer of the community occupation domains over a 7-day period, the most common being the use of local facilities (92%) and contact with family and friends (61%). The staff reports suggested that far fewer service users were engaged in the other domains: day centres (25%), education (14%), sport (13%), arts (12%), employment (11%) and faith (8%). With regard to social inclusion, activities occurred most frequently in mainstream settings for the domains of faith (100%), use of local facilities (98%), sport (80%), and family and friends (79%). Lower levels of social inclusion were reported for the other domains. Statistical analysis revealed that service users' occupational engagement related to their accommodation type, age and gender, but not to ethnicity. These findings indicate that further research is needed to explore service users' views on social inclusion and what they feel would support them to engage in community occupations at a level that suits their individual needs. © The College of Occupational Therapists Ltd.
http://dx.doi.org/10.4276/030802209X12601857794691

69. Dudley, L., C. Gamble, A. Allam, P. Bell, D. Buck, H. Goodare, . . . B. Young. **A little more conversation please? Qualitative study of researchers' and patients' interview accounts of training for patient and public involvement in clinical trials**. Trials, 2015. 16(1).

Background: Training in patient and public involvement (PPI) is recommended, yet little is known about what training is needed. We explored researchers' and PPI contributors' accounts of PPI activity and training to inform the design of PPI training for both parties. Methods: We used semi-structured qualitative interviews with researchers (chief investigators and trial managers) and PPI contributors, accessed through a cohort of clinical trials, which had been funded between 2006 and 2010. An analysis of transcripts of audio-recorded interviews drew on the constant comparative method. Results: We interviewed 31 researchers and 17 PPI contributors from 28 trials. Most researchers could see some value in PPI training for researchers, although just under half had received such training themselves, and some had concerns about the purpose and evidence base for PPI training. PPI contributors were evenly split in their perceptions of whether researchers needed training in PPI. Few PPI contributors had themselves received training for their roles. Many informants across all groups felt that training PPI contributors was unnecessary because they already possessed the skills needed. Informants were also concerned that training would professionalise PPI contributors, limiting their ability to provide an authentic patient perspective. However, informants welcomed informal induction 'conversations' to help contributors understand their roles and support them in voicing their opinions. Informants believed that PPI contributors should be confident, motivated, intelligent, focussed on helping others and have relevant experience. Researchers looked for these qualities when selecting contributors, and spoke of how finding 'the right' contributor was more important than accessing 'the right' training. Conclusions: While informants were broadly receptive to PPI training for researchers, they expressed considerable reluctance to training PPI contributors. Providers of training will need to address these reservations. Our findings point to the importance of reconsidering how training is conceptualised, designed and promoted and of providing flexible, learning opportunities in ways that flow from researchers' and contributors' needs and preferences. We also identify some areas of training content and the need for further consideration to be given to the selection of PPI contributors and models for implementing PPI to ensure clinical trials benefit from a diversity of patient perspectives. © Dudley et al.; licensee BioMed Central.
http://dx.doi.org/10.1186/s13063-015-0667-4

70. Dugan, S.A., K. Karavolos, E.B. Lynch, C.S. Hollings, F. Fullam, B.S. Lange-Maia, L.H. Powell. **A Multimethod Investigation Into Physical Activity in Midlife Women**. Journal of physical activity & health, 2016. 13(12): p. 1351-1359.

BACKGROUND: Physical inactivity in midlife women is associated with increased intra-abdominal adipose tissue development. We describe an innovative multimethod study 1) to better understand barriers to physical activity (PA) and 2) to engage midlife women to product test physical activities and identify local community-based providers and sustainable and fun PA experiences.
METHODS: Formative research on PA barriers from the Chicago site Study of Women's Health Across the Nation (SWAN) ancillary study of midlife women was used to develop a pilot testing measure. Feasibility, acceptability and sustainability of the PA activities were determined using the measure.
RESULTS: Desirable locations and/or instructors were identified. The first 2 groups identified, pilot tested, and then ranked activities for their ability to promote sustained PA. The 6 top-ranked were: circuit training, total body fitness, kickboxing, Zumba, Pilates, and pedometer. The final group pilot tested highly ranked PA in 2-week blocks, and ranked pedometer and Zumba in their top 3.

CONCLUSION: Consensus was reached regarding activities that could be valuable in promoting sustained PA in midlife women. Choosing convenient sites and popular instructors further facilitates sustainability. Building relationships with key community partners is essential for sustainability. Community-based participant involvement in study design is a critical element in developing a healthy living intervention.
http://dx.doi.org/10.1123/jpah.2015-0565

71.   Eidhammer, G., F.A. Fluttert, S. Bjørkly. **User involvement in structured violence risk management within forensic mental health facilities -- a systematic literature review**. Journal of clinical nursing, 2014. 23(19-20): p. 2716-2724.
        AIMS AND OBJECTIVES: To examine empirical literature on user involvement in collaboration between patients and nurses. The scope of the review was limited to structured violence risk management interventions in forensic mental health settings.
BACKGROUND: Violence in forensic mental health settings represents a significant problem for patients and staff. Structured violence risk management interventions in forensic mental health have been reported to ignore patient participation, despite the growing attention on user involvement in clinical practice.
DESIGN: A systematic review.
METHOD: Searches were conducted in six databases: the Cochrane Systematic Reviews, MEDLINE, CINAHL, ProQuest, ScienceDirect and PsycINFO. Papers were assessed according to a predetermined set of inclusion and exclusion criteria.
RESULTS: After searches of the reference lists of retrieved articles were conducted, only three papers met the inclusion criteria.
CONCLUSIONS: This review has shown that empirical research on the topic of risk management interventions in which patients are involved is scarce.
RELEVANCE TO CLINICAL PRACTICE: There is barely any research evidence of the clinical effect of user involvement approaches on violence risk management in forensic mental health practice. Therefore, we suggest that clinicians may learn from positive experiences concerning user involvement in general psychiatry and carefully adapt and test them out in the forensic treatment context.
http://dx.doi.org/10.1111/jocn.12571

72.   Elstad, T.A., A.H. Eide. **User participation in community mental health services: exploring the experiences of users and professionals**. Scandinavian Journal of Caring Sciences, 2009. 23(4): p. 674-681.
        Increased user participation and community integration are central aims for contemporary mental health policy in many countries. User participation in community mental health services is developed through practice; from interaction between service-users and professionals working on the ground level. Despite this, there is a lack of research exploring users' and professionals' experiences and views based on the practice of user participation. The objective of this study was to illuminate user participation in a community mental health context based on the experiences of users and professionals within the same services. A qualitative study with an explorative design was applied. Preliminary data analyses based on a field study within three community mental health centres in a Norwegian city lead to our specific focus on experiences of user participation. This theme was explored in individual interviews with 10 users and two group interviews with six professionals. This article is based on the data from these interviews. All informants valued user participation in the service and highlighted the importance of the environment. Users and professionals did, however, highlight interesting issues of user participation from different

perspectives. We developed the findings into three main themes: (i) user participation - experiences and preferences, (ii) an environment that promotes user participation and (iii) professional help, responsibility and user participation. Developing service-users' influence through participation is important, not only on the political and organisational level, but also in the contexts where users and professionals meet and collaborate. Self-determination in how to use services means that there are opportunities for receiving support without being subjected to control. Community mental health services which provide flexible, accepting environments with possibilities for both support and challenges may enhance participation and give all users possibilities to have an influence.
http://dx.doi.org/10.1111/j.1471-6712.2008.00660.x

73.   Evans, D. <mark>Patient and public involvement in research in the English NHS: a documentary analysis of the complex interplay of evidence and policy</mark>. Evidence & Policy, 2014. 10(3): p. 361-377.
The last 20 years have seen significant international shifts towards greater patient and public involvement (PPI) in health research and development (R&D). In England, then first health R&D strategy in 1991 did not mention PPI.Twenty years later, PP I is deeply embedded within the National Institute for Health Research.This article examines the evolving relationship between evidence and policy on PPI in research through a documentary analysis of English health R&D policy documents published between 1991 and 2010. It then considers what model of the research-policy interface best explains the expansion of PPI in research and why this is important.
http://dx.doi.org/10.1332/174426413x662770

74.   Evans, D., E. Bird, A. Gibson, S. Grier, T.L. Chin, M. Stoddart, A. Macgowan. **Extent, quality and impact of patient and public involvement in antimicrobial drug development research: A systematic review**. Health Expectations, 2017.
Background: Patient and public involvement (PPI) is increasingly recognized as bringing a range of benefits to clinical and health services research. Recent systematic reviews have identified and synthesized many benefits (eg higher recruitment rates) and some costs (eg extra time need). Much of the literature focuses on PPI in long-term conditions rather than more acute health care in which the majority of microbiological research is undertaken. Objectives: The aim was to identify the extent, quality and impact of PPI in antimicrobial drug development research. Objectives were to identify any relevant reporting of PPI in antimicrobial research; appraise the quality of reporting on PPI using recognized PPI reporting and critical appraisal tools; and extract and synthesize data on the impact of PPI. Search strategy: A systematic review was undertaken with a search strategy based on four word groups (PPI, patients, antimicrobial drug development and outcomes). Eight online databases were searched. Inclusion criteria: English language publication, publication between 1996 and 2016 and studies describing PPI in antimicrobial drug development research. Main results: No studies were found through online searching that met the search strategy and inclusion criteria. One relevant protocol paper with a brief mention of PPI was identified through expert recommendation. Commentary papers recommending PPI were identified through website searching and expert opinion. Discussion and conclusions: Despite strong policy guidance encouraging PPI at the international and national levels, and anecdotal accounts of PPI taking place, evidence for the extent, quality and impact of PPI in antimicrobial drug development research has not yet appeared in the peer-reviewed literature. © 2017 John Wiley & Sons Ltd.
http://dx.doi.org/10.1111/hex.12587

75.   Evans, D.H., R.J. Bacon, E. Greer, A.M. Stagg, P. Turton. **'Calling executives and clinicians to**

account': user involvement in commissioning cancer services. Health Expectations, 2015. 18(4): p. 504-515.

Background English NHS guidance emphasizes the importance of involving users in commissioning cancer services. There has been considerable previous research on involving users in service improvement, but not on involvement in commissioning cancer services. Objective To identify how users were involved as local cancer service commissioning projects sought to implement good practice and what has been learned. Design Participatory evaluation with four qualitative case studies based on semi-structured interviews with project stakeholders, observation and documentary analysis. Users were involved in every stage from design to analysis and reporting. Setting and participants Four English cancer network user involvement in commissioning projects, with 22 stakeholders interviewed. Results Thematic analysis identified nine themes: initial involvement, preparation for the role, ability to exercise voice, consistency and continuity, where decisions are made, closing the feedback loop, assessing impact, value of experience and diversity. Discussion Our findings on the impact of user involvement in commissioning cancer services are consistent with other findings on user involvement in service improvement, but highlight the specific issues for involvement in commissioning. Key points include the different perspectives users and professionals may have on the impact of user involvement in commissioning, the time necessary for meaningful involvement, the importance of involving users from the beginning and the value of senior management and PPI facilitator support and training. Conclusions Users can play an important role in commissioning cancer services, but their ability to do so is contingent on resources being available to support them.
http://dx.doi.org/10.1111/hex.12051

76. Fellinger, M.J., M. Amering. **User Involvement in Mental Health Care Teaching**. European Psychiatry, 2015. 30: p. 166-166.

User Involvement in mental health care teaching The emerging evidence-base forrecovery-orientation includes the urgent call for a partnership approach topsychiatric practice, service developments, research and education. The role ofthe lived experience in teaching is an essential component of initiatives aimedat implementing recovery-orientation. User involvement in teaching mental healthprofessionals has become a common feature of mental health training curriculain English speaking countries. Data indicate that this form of teaching is feasibleand acceptable to both teachers with and without a lived experience and to studentsof different professional backgrounds. Current research however mostly concernstrainings of mental health nurses. Types of user involvement vary considerably froman active role in the development of curricula and training materials as wellas teaching to more passive and collaborative approaches. Published datamainly focus on students' response showing beneficial outcomes, such asattitudinal changes, reduced anxiety and increased confidence in communicatingwith patients as well as insight into users' experience of services and needsfor improvement. Only few studies highlightthe perspective of the users as teachers with more positive, e.g. empowerment, than negative experiences, e.g. voyeurism. Clear expectations and specifictraining and supervision have been identified by educators as conducivefactors, while tokenistic and unprepared inputs lead to problematic situations. Further research needs to define adequate outcome measurements for different contextsand subjects under study as well as methods that are able to address multipleperspectives as well as long-term effects. [ABSTRACT FROM AUTHOR]

original published version of the material for the full abstract. (Copyright applies to all Abstracts.)
http://dx.doi.org/10.1016/S0924-9338(15)30136-X

77.   Felton, A., T. Stickley. **Pedagogy, power and service user involvement**. Journal of Psychiatric and Mental Health Nursing, 2004. 11(1): p. 89-98.
       This paper explores mental health nurse educators' perceptions of the involvement of service users in preregistration nurse education. The idea for the study was developed from a local group of people including service users, lecturers and students committed to finding ways to develop service user involvement in education. This qualitative study uses semi-structured interviews to explore participants' perceptions in depth. Five lecturers who teach on the diploma programme based at a large teaching hospital were interviewed. The results suggest that the current situation of involving service users at the research site was ineffective. The concepts of 'role' and power relationships were used to explore the reasons for this. The development of service user involvement in education is complex and requires further research.
       http://dx.doi.org/10.1111/j.1365-2850.2004.00693.x

78.   Fitzpatrick, P., A.J. Sinclair. **Learning through public involvement in environmental assessment hearings**. Journal of Environmental Management, 2003. 67(2): p. 161-174.
       This research examined the opportunities for critical education available to participants of a federal environmental assessment (EA) that includes hearings. The Sable Gas Panel Review, an assessment of a natural gas project situated in the Maritimes, was undertaken between 1996 and 1997. This study documented what participants learned through their experiences and how that learning was facilitated. Primary data collection emphasized the use of semi-structured interviews to record the experientially based observations of panel participants. Primary data were supported by a review of material submitted by hearing participants for consideration by the panel, and complemented with literature related to EA, environmental education, and transformational learning theories. Evidence was considered in terms of assessment-specific operational definitions, developed from Shor (1993) [Education is politics: Paulo Freire's Critical Pedagogy. In: McLaren, P., Leonard, P. (Eds.), Paulo Freire: A critical Encounter, Routledge, New York, pp. 25-35] ten indicators of critical education. The study revealed that participants of the Sable Gas panel review had an opportunity to engage in critical education. While it is important to acknowledge that the panel did not set out to engage participants in a 'critical educational' experience, each of the 10 operational definitions of critical education used in the study were addressed to varying degrees through activities undertaken by the panel secretariat. Results illustrate the types of educational opportunities, such as a class on how to participate in a quasi-judicial hearing, and the importance of participant-led research that can arise out of the panel review process. The findings of this research contribute to the evolving literature regarding the role of critical education in EA and environmental management. Understanding the existing scope of critical education within a panel review provides the foundation for identifying opportunities for expanding the capacity of the existing EA process to facilitate learning by participants. © 2002 Elsevier Science Ltd. All rights reserved.
       http://dx.doi.org/10.1016/S0301-4797(02)00204-9

79.   Forbat, L., G. Hubbard. <mark>Service user involvement in research may lead to contrary rather than collaborative accounts: findings from a qualitative palliative care study</mark>. Journal of Advanced Nursing, 2016. 72(4): p. 759-769.
       Aim. The aim of this study was to explore what data emerge when former carergivers (co-researchers) are trained to interview current care-givers about their experiences. Background.

Despite a trend of involving service users in conducting research interviews, there have been few examinations of how and whether a common service user identity has an impact on the data generated. Design. Four co-researchers were recruited, trained and supported to conduct qualitative interviews with 11 current carers of people receiving palliative services. Conversation analysis was used to examine the conversational characteristics of the research interviews. Data were collected in 2010-2011. Results. Conversation analysis identified that interactional difficulties were evident across the data. When co-researchers talked about their own experiences as carers, interviewees frequently changed the topic of conversation, thereby closing-down opportunities for further disclosure or elaboration from the interviewee about the original topic. Conclusion. Conversation analysis identifies how caregiving identities are co-constructed and points where there is agreement and disagreement in the co-construction.
http://dx.doi.org/10.1111/jan.12865

80.   Forbat, L., G. Hubbard, N. Kearney. <mark>Patient and public involvement: Models and muddles</mark>. Journal of Clinical Nursing, 2009. 18(18): p. 2547-2554.
Aims and objectives. This paper explores the range of models of involvement which are drawn upon in an empirical study and which are invoked in the literature and policy. The results and discussion of the study help to excavate and explore the muddle of conceptualisations of involvement and how this leads to difficulties for practitioners, patients and managers in implementing the relevant policy. Background. Patient and public involvement has developed an important profile internationally within health and social care policy. However, its importance as a rhetorical device has not been accompanied by adequate developments in how it is operationalised. Design. Cross-sectional study, with an intervention conducted at three sites, and non-intervention measures taken at two control sites. Methods. This paper draws on an empirical study of involvement. Focus groups were conducted with a lung cancer team and people affected by cancer at five health boards across Scotland. Chief executives of each of these five health boards also took part in individual interviews. Participants were asked to describe their ideas of what involvement is and their application of it. Results. A range of ways of conceptualising involvement were apparent. Few of these moved beyond the use of patient satisfaction questionnaires. At times, troubling understandings were articulated, for example, using public meetings to communicate decisions about service closures to the public. Conclusion. The slow escalation of involvement is in part because of the myriad ways in which it is conceptualised and discussed. Thus, we conclude that one of the greatest barriers to truly integrating patient involvement into health services, policy and research is the conceptual muddle with which involvement is articulated, understood and actioned. Relevance to clinical practice. Clinicians need to be supported to seek clarity in the use and operationalisation of involvement if the agenda is to be truly adopted and strengthened. © 2009 Blackwell Publishing Ltd.
http://dx.doi.org/10.1111/j.1365-2702.2008.02519.x

81.   Fox, J. 'The view from inside': understanding service user involvement in health and social care education. Disability & Society, 2011. 26(2): p. 169-177.
Service users are increasingly involved in health and social care education, whilst the government is committed to increasing access to employment for people with mental health needs. The benefits of involving service users in social work education have been identified, including increasing skills, confidence, and building capacity; yet there is little research that reflects on the personal costs of involvement. An understanding of the social model of disability underpinned by the recovery approach enables us to conceptualise more equal involvement of experts by experience in health and social care education. This enables us to respect their inclusion by noting

that it is our non-disabled environment which disables and excludes people from the work place, whilst an understanding of recovery requires us to accept that people with mental distress may have to manage the limitations of their distress in the work place rather than live a life completely free of symptoms.
http://dx.doi.org/10.1080/09687599.2011.544057

82.   Frankham, J., F. Tracy. Troubling the field of service user involvement in research. Contemporary Social Science, 2012. 7(1): p. 73-89.
        This paper sets out to interrogate two key issues in the field of service user or public engagement in research. These relate to privileging personal experience as a way of knowing and the forms of knowledge production that are assumed to take place in research partnerships. In both instances it is suggested that current orthodoxies may 'close down' opportunities for learning and understanding rather than democratising them. The final section of the paper suggests alternative ways of thinking about these aspects of service user involvement in research. These include 'troubling' identity claims and the forms of knowledge that tend to accompany them, a reconceptualisation of how they have come to be known in research partnerships and a reorientation towards the centrality of relations/hips in these research endeavours. © 2012 Copyright Academy of Social Sciences.
        http://dx.doi.org/10.1080/21582041.2012.658431

83.   Froggatt, K., C. Goodman, H. Morbey, S.L. Davies, H. Masey, A. Dickinson, . . . C. Victor. Public involvement in research within care homes: benefits and challenges in the APPROACH study. Health Expectations, 2016. 19(6): p. 1336-1345.
        Background: Public involvement in research (PIR) can improve research design and recruitment. Less is known about how PIR enhances the experience of participation and enriches the data collection process. In a study to evaluate how UK care homes and primary health-care services achieve integrated working to promote older people's health, PIR was integrated throughout the research processes. Objectives: This paper aims to present one way in which PIR has been integrated into the design and delivery of a multisite research study based in care homes. Design: A prospective case study design, with an embedded qualitative evaluation of PIR activity. Setting and participants: Data collection was undertaken in six care homes in three sites in England. Six PIR members participated: all had prior personal or work experience in care homes. Data collection: Qualitative data collection involved discussion groups, and site-specific meetings to review experiences of participation, benefits and challenges, and completion of structured fieldwork notes after each care home visit. Results: PIR members supported recruitment, resident and staff interviews and participated in data interpretation. Benefits of PIR work were resident engagement that minimized distress and made best use of limited research resources. Challenges concerned communication and scheduling. Researcher support for PIR involvement was resource intensive. Discussion and conclusions: Clearly defined roles with identified training and support facilitated involvement in different aspects of the data collection process. This can also ensure that vulnerable older people who participate in research have a positive experience that reinforces the value of their views. © 2015 The Authors Health Expectations Published by John Wiley & Sons Ltd.
        http://dx.doi.org/10.1111/hex.12431

84.   Froggatt, K., N. Preston, M. Turner, C. Kerr. Patient and public involvement in research and the Cancer Experiences Collaborative: benefits and challenges. Bmj Supportive & Palliative Care, 2015. 5(5): p. 518-521.

Aims and objectives The involvement of patients in the design and conduct of research is increasingly promoted by policy and research bodies. The experiences of individuals who become involved in research in this way are not well understood. This study aims to describe the experiences of people's participation in patient and public involvement (PPI) in supportive and palliative care research, specifically with respect to the benefits and challenges of participation for the individuals and the broader research support structures. Methods In this qualitative exploratory study, semistructured interviews were undertaken with individuals who had a cancer diagnosis and were involved in a supportive and palliative care research collaborative over a period of 6 years. Recruitment was through the host university organisations involved in the research collaborative. A thematic analysis was undertaken to identify commonalities and differences across their experiences. Findings The eight participants in the study were highly motivated and undertook PPI in research alongside other voluntary activities. They identified a number of research and personal benefits: bringing a lay perspective into research, making a difference and personal gains. Personal gains concerned support, new knowledge and skills and greater confidence. The challenges to participation that were identified included the emotional and practical nature of the work, issues of language and identifying the difference made. Conclusions Involvement in supportive and palliative care research is valued by people with a cancer diagnosis, but there are ongoing issues of emotional support and good communication through the use of appropriate language in documentation.
http://dx.doi.org/10.1136/bmjspcare-2013-000548

85.   Fudge, N., C.D.A. Wolfe, C. McKevitt. **Assessing the promise of user involvement in health service development: Ethnographic study**. BMJ, 2008. 336(7639): p. 313-317.
Objectives: To understand how the policy of user involvement is interpreted in health service organisations and to identify factors that influence how user involvement is put into practice. Design: Ethnographic study using participant observation, interviews, and collection of documentary evidence. Setting: A multiagency modernisation programme to improve stroke services in two London boroughs. Participants: Service users, National Health Service managers, and clinicians. Results: User involvement in the programme was initiated and led by professionals. Professionals determined the areas of service improvement service users could participate in. A wide range of activities were considered "user involvement," from patient satisfaction surveys to service users delivering peer support. Involvement tended to be most active in the least technical areas and areas with least input from clinicians. Factors that might explain this included organisational structure, the vagueness of the concept of user involvement, the value attributed to service users' experiential knowledge, and variations in professional and service user understandings of and commitment to involvement. The gains of involvement were harder to identify in terms of impact on services. More evident were the personal gains for those involved: satisfaction of feeling listened to by professionals, social opportunities of meeting others in a similar situation, and increased knowledge about stroke and services available. Conclusions: User involvement may not automatically lead to improved service quality. Healthcare professionals and service users understand and practise user involvement in different ways according to individual ideologies, circumstances, and needs. Given the resource implications of undertaking user involvement in service development there is a need for critical debate on the purpose of such involvement as well as better evidence of the benefits claimed for it.
http://dx.doi.org/10.1136/bmj.39456.552257.BE

86.   Gabe, J., G. Olumide, M. Bury. **'It takes three to tango': A framework for understanding patient partnership in paediatric clinics**. Social Science and Medicine, 2004. 59(5): p. 1071-1079.

Since the late 1990s, the term 'partnership' has increasingly been inserted into the literature and rhetoric of the UK health-care system. In this paper, the assumptions and implications surrounding the usage of the term in relation to doctor-patient interaction are examined in the context of paediatric services. The paper considers recent ideas about partnership in medical encounters, especially those of Charles et al., and the extent to which they are applicable to children. The paper then goes on to develop a framework for understanding patient-partnership issues. It is argued that any investigation of partnership will need to take account of the organisational and legal setting, as well as the beliefs and agendas that all parties bring to the medical encounter. In the context of paediatrics, the perspectives of three actors - the child, parent and health service professional - need to be explored. Our framework allows for different sorts of 'coalition' to develop between these actors as they try to reconcile their perspectives in the clinic and offers a situationally contextualised view of partnership. We also argue that these matters require study outside as well as inside the clinic, through the use of a range of methods, including those that help children at home review their involvement in decision making in the clinic. © 2004 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.socscimed.2003.09.035

87.   Gagnon, M.P., M. Desmartis, J. Gagnon, M. St-Pierre, M. Rhainds, M. Coulombe, . . . F. Légaré.
FRAMEWORK for USER INVOLVEMENT in HEALTH TECHNOLOGY ASSESSMENT at the LOCAL LEVEL: VIEWS of HEALTH MANAGERS, USER REPRESENTATIVES, and CLINICIANS. International Journal of Technology Assessment in Health Care, 2015. 31(1-2): p. 68-77.
Objectives: The aim of this study was to explore stakeholders' points of views regarding the applicability and relevance of a framework for user involvement in health technology assessment (HTA) at the local level. We tested this framework in the context of the assessment of alternative measures to restraint and seclusion among hospitalized adults and those living in long-term-care facilities. Methods: Twenty stakeholders (health managers, user representatives, and clinicians) from seven regions of Quebec participated in a semi-structured interview. A thematic analysis of the transcribed interviews was performed. Results: The findings highlighted the relevance and applicability of the framework to this specific HTA. According to interviewees, direct participation of users in the HTA process allows them to be part of the decision-making process. User consultation makes it possible to consider the views of a wide variety of people, such as marginalized and vulnerable groups, who do not necessarily meet the requirements for participating in HTA committees. However, some user representatives emphasized that user consultation should be integrated into a more holistic and participatory perspective. The most frequent barrier associated with user involvement in HTA was the top-down health system, which takes little account of the user's perspective. Conclusions: The proposed framework was seen as a reference tool for making practitioners and health managers aware of the different mechanisms of user involvement in HTA and providing a structured way to classify and describe strategies. However, there is a need for more concrete instruments to guide practice and support decision making on specific strategies for user involvement in HTA at the local level. Copyright © Cambridge University Press 2015.
http://dx.doi.org/10.1017/S0266462315000070

88.   Garnett, K., T. Cooper, P. Longhurst, S. Jude, S. Tyrrel. **A conceptual framework for negotiating public involvement in municipal waste management decision-making in the UK**. Waste Management, 2017. 66: p. 210-221.
The technical expertise that politicians relied on in the past to produce cost-effective and environmentally sound solutions no longer provides sufficient justification to approve waste

facilities. Local authorities need to find more effective ways to involve stakeholders and communities in decision-making since public acceptance of municipal waste facilities is integral to delivering effective waste strategies. This paper presents findings from a research project that explored attitudes towards greater levels of public involvement in UK waste management decision-making. The study addressed questions of perception, interests, the decision context, the means of engagement and the necessary resources and capacity for adopting a participatory decision process. Adopting a mixed methods approach, the research produced an empirical framework for negotiating the mode and level of public involvement in waste management decision-making. The framework captures and builds on theories of public involvement and the experiences of practitioners, and offers guidance for integrating analysis and deliberation with public groups in different waste management decision contexts. Principles in the framework operate on the premise that the decision about 'more' and 'better' forms of public involvement can be negotiated, based on the nature of the waste problem and wider social context of decision-making. The collection of opinions from the wide range of stakeholders involved in the study has produced new insights for the design of public engagement processes that are context-dependent and 'fit-for-purpose'; these suggest a need for greater inclusivity in the case of contentious technologies and high levels of uncertainty regarding decision outcomes. http://dx.doi.org/10.1016/j.wasman.2017.04.022

89.   Gauvin, F.P., J. Abelson, M. Giacomini, J. Eyles, J.N. Lavis. **"It all depends": Conceptualizing public involvement in the context of health technology assessment agencies**. Social Science & Medicine, 2010. 70(10): p. 1518-1526.
        There have been calls in recent years for greater public involvement in health technology assessment (HTA). Yet the concept of public involvement is poorly articulated and little attention has been paid to the context of HTA agencies. This article investigates how public involvement is conceptualized in the HTA agency environment. Using qualitative concept analysis methods, we reviewed the HTA literature and the websites of HTA agencies and conducted semi-structured interviews with informants in Canada. Denmark, and the United Kingdom. Our analysis reveals that HTA agencies' role as bridges or boundary organizations situated at the frontier of research and policymaking causes the agencies to struggle with the idea of public involvement. The HTA community is concerned with conceptualizing public involvement in such a way as to meet scientific and methodological standards without neglecting its responsibilities to healthcare policymakers. We offer a conceptual tool for analyzing the nature of public involvement across agencies, characterizing different domains, levels of involvement, and types of publics. (C) 2010 Elsevier Ltd. All rights reserved. http://dx.doi.org/10.1016/j.socscimed.2010.01.036

90.   Geller, E.S., T.D. Berry, T.D. Ludwig, R.E. Evans, M.R. Gilmore, S.W. Clarke. **A conceptual framework for developing and evaluating behavior change interventions for injury control**. Health Education Research, 1990. 5(2): p. 125-137.
        This paper addresses issues and research needs in the domain of behavior modification for injury control. Although much of the discussion focuses on traffic safety, the concepts and principles are applicable to all areas of injury control (e.g. on the job and in the home). Field research that has increased safety belt use is reviewed briefly to illustrate a tripartite classification of injury control factors (i.e. environmental, individual, or behavioral variables), and to introduce a heuristic framework for categorizing and evaluating behavior change strategies. A multiple intervention level hierarchy depicts a progressive segmentation of the target population as more effective (and costly) interventions are implemented; and a taxonomy of 24 behavior change techniques

includes a scoring system for predicting short and long term effects of intervention programs. It is presumed that more risk-prone individuals require higher-level interventions, which are those that provide specific response information and extrinsic controls, while also eliciting active participant involvement, social support, and perceptions of autonomy. Although extrinsic controls increase the immediate impact of an intervention program, these techniques may jeopardize response maintenance when the program is withdrawn.

91.   Gibson, A., J. Welsman, N. Britten. Evaluating patient and public involvement in health research: from theoretical model to practical workshop. Health Expectations, 2017. 20(5): p. 826-835. BackgroundThere is a growing literature on evaluating aspects of patient and public involvement (PPI). We have suggested that at the core of successful PPI is the dynamic interaction of different forms of knowledge, notably lay and professional. We have developed a four-dimensional theoretical framework for understanding these interactions. AimWe explore the practical utility of the theoretical framework as a tool for mapping and evaluating the experience of PPI in health services research. MethodsWe conducted three workshops with different PPI groups in which participants were invited to map their PPI experiences on wall charts representing the four dimensions of our framework. The language used to describe the four dimensions was modified to make it more accessible to lay audiences. Participants were given sticky notes to indicate their own positions on the different dimensions and to write explanatory comments if they wished. Participants' responses were then discussed and analysed as a group. ResultsThe three groups were distinctive in their mapped responses suggesting different experiences in relation to having a strong or weak voice in their organization, having few or many ways of getting involved, addressing organizational or public concerns and believing that the organization was willing to change or not. DiscussionThe framework has practical utility for mapping and evaluating PPI interactions and is sensitive to differences in PPI experiences within and between different organizations. The workshops enabled participants to reflect collaboratively on their experiences with a view to improving PPI experiences and planning for the future. http://dx.doi.org/10.1111/hex.12486

92.   Gilbert, D. Nothing about us without us: What patient and public involvement means to CHI. Quality in Primary Care, 2003. 11(1): p. 61-65.

93.   Gillard, S., L. Simons, K. Turner, M. Lucock, C. Edwards. Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study. Qualitative Health Research, 2012. 22(8): p. 1126-1137. Patient and public involvement in health research is increasingly well established internationally, but the impacts of involvement on the research process are hard to evaluate. We describe a process of qualitative data analysis in a mental health research project with a high level of mental health service user and carer involvement, and reflect critically on how we produced our findings. Team members not from research backgrounds sometimes challenged academic conventions, leading to complex findings that would otherwise have been missing. An essential component of how we coproduced knowledge involved retaining methodological flexibility so that nonconventional research voices in the team could situate and critique what was conventionally known. Deliberate and transparent reflection on how "who we are" informed the knowledge we produced was integral to our inquiry. We conclude that reflecting on knowledge (co)production is a useful tool for evaluating the impact of patient and public involvement on health research. http://dx.doi.org/10.1177/1049732312448541

94.   Goldblatt, H., O. Karnieli-Miller, M. Neumann. <mark>Sharing qualitative research findings with participants: Study experiences of methodological and ethical dilemmas</mark>. Patient Education and Counseling, 2011. 82(3): p. 389-395.
        Objective: Sharing qualitative research findings with participants, namely member-check, is perceived as a procedure designed to enhance study credibility and participant involvement. It is rarely used, however, and its methodological usefulness and ethical problems have been questioned. This article explores benefits and risks in applying member-check when studying healthcare topics, questioning the way it should be performed. Methods: We discuss researchers' experiences in applying member-check, using four examples from three different studies: healthcare-providers' experiences of working with sexual-abuse survivors; adolescents' exposure to domestic-violence, and delivering and receiving bad news. Results: Methodological and ethical difficulties can arise when performing member-check, challenging the day-to-day researcher-participant experience, and potentially, the physician-patient relationship. Conclusion: Applying member-check in healthcare settings is complex. Although this strategy has good intentions, it is not necessarily the best method for achieving credibility. Harm can be caused to participants, researchers and the doctor-patient relationship, risking researchers' commitment to ethical principles. Practice implications: Because participants' experience regarding member-check is difficult to predict, such a procedure should be undertaken cautiously. Prior to initiating member-check, researchers should ask themselves whether such a procedure is potentially risky for participants; and if anonymity cannot be guaranteed, use alternative procedures when needed. © 2010 Elsevier Ireland Ltd.
        http://dx.doi.org/10.1016/j.pec.2010.12.016

95.   Goodman, C., E. Mathie, M. Cowe, A. Mendoza, D. Westwood, D. Munday, . . . S. Barclay. **Talking about living and dying with the oldest old: public involvement in a study on end of life care in care homes**. Bmc Palliative Care, 2011. 10.
        Background: Public involvement in research on sensitive subjects, such as death and dying, can help to ensure that questions are framed to reflect the interests of their peers, develop a shared understanding of issues raised, and moderate the often unequal power relationship between researcher and participant. This paper describes the contribution and impact of older members of a Public Involvement in Research group (PIRg) to a study on living and dying in care homes. Methods: A longitudinal study, with a mixed method approach, its aims were to capture key experiences, events and change over one year, of older people resident in participating care homes in the East of England. Residents were interviewed up to three times and their case notes were reviewed four times over the year. Interviews were semi structured, and recorded. Four members of a Public Involvement in Research group (PIRg) contributed to preliminary discussions about the research and three were involved with many of the subsequent stages of the research process including the facilitation of discussion groups with residents. Results: There were three areas where the involvement of the Public Involvement in Research group (PIRg) positively influenced the study process. These were recruitment, governance and safeguarding, and in collaboration with the residents in the care homes, the discussion and interpretation of emergent findings. PIRg members were of similar age to the residents and their involvement provided different and often more reflective insights of the significance of the findings for the participants. There were examples where decision making about the range of PIRg participation was not always negotiable, and this raised issues about power relationships within the team. Nevertheless, PIRg members expressed personal benefit and satisfaction through participating in the research and a commitment to continue to support research with this older age group. Conclusions: The contribution of the PIRg supported a successful recruitment process that exceeded response rates

of other studies in care homes. It safeguarded residents during the conduct of research on a sensitive topic and helped in validating the interview data gathered by the researchers through the discussion groups facilitated by the PIRg. There were power differentials that persisted and affected PIRg participation. The study has showed the value of developing job descriptions and a more formal means of setting out respective expectations. Future research may wish to elicit the views of focal participants in such studies about the mediation of research by public involvement in research.
http://dx.doi.org/10.1186/1472-684x-10-20

96.   Gordon, L., A. Dickinson, M. Offredy, J. Smiddy. A research note on the benefit of patient and public involvement in research: The experience of prostate cancer patients regarding information in radiotherapy. Radiography, 2017. 23(2): p. 167-170.
Aim: To explore the inclusion of patient and public involvement (PPI) in a qualitative study on the experiences of men with prostate cancer regarding information in radiotherapy. Method: The application of PPI to one doctoral research study is explored with respect to two perspectives: firstly, involvement of a patient reference group who informed the research design and materials, and secondly, the involvement of a public involvement in research group (PIRg) in advising the researcher during the design process. Discussion: PPI is recognised as an important component of contemporary health research. PPI is becoming a common and essential requirement for high quality research projects and yet literature exploring or reporting the involvement and influence of PPI is sparse. Consideration is given to the national PPI landscape that has shaped public involvement in health research. Conclusion: The contribution of PPI to this study appears to have been beneficial to the development and evaluation of the study design, the self-worth of the reference group participants and demonstrates that the value of PPI in health research should not be underestimated. (C) 2017 The College of Radiographers. Published by Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.radi.2017.02.004

97.   Gove, D., A. Diaz-Ponce, J. Georges, E. Moniz-Cook, G. Mountain, R. Chattat, L. Øksnebjerg. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). Aging and Mental Health, 2017: p. 1-7.
This paper reflects Alzheimer Europe's position on PPI (patient and public involvement) in the context of dementia research and highlights some of the challenges and potential risks and benefits associated with such meaningful involvement. The paper was drafted by Alzheimer Europe in collaboration with members of INTERDEM and the European Working Group of People with Dementia. It has been formally adopted by the Board of Alzheimer Europe and endorsed by the Board of INTERDEM and by the JPND working group 'Dementia Outcome Measures - Charting New Territory'. Alzheimer Europe is keen to promote the involvement of people with dementia in research, not only as participants but also in the context of PPI, by generating ideas for research, advising researchers, being involved in consultations and being directly involved in research activities. This position paper is in keeping with this objective. Topics covered include, amongst others, planning involvement, establishing roles and responsibilities, training and support, managing information and input from PPI, recognising the contribution of people with dementia involved in research in this way, promoting and protecting the rights and well-being of people with dementia, training and support, and promoting an inclusive approach and the necessary infrastructure for PPI in dementia research. © 2017 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group
http://dx.doi.org/10.1080/13607863.2017.1317334

98.   Grayson, T., Y.H. Tsang, D. Jolly, K. Karban, P. Lomax, C. Midgley, . . . P. Williams. ==Include me in: User involvement in research and evaluation.== Mental Health and Social Inclusion, 2013. 17(1): p. 35-42.
        Purpose-This paper aims to discuss the experiences of a group of eight user and carer researchers from learning disability and mental health services who worked together in a research project. The research was to find out about the changes that took place as over 300 people moved from hostel accommodation into independent tenancies. These moves were part of a three year project involving a partnership between a local authority and a housing association. Design/methodology/approach-The evaluation was based on a model of user participation. Findings-User involvement in research can mean different things with different levels of involvement, from consultation through to user-controlled research. In this paper the authors discuss some of the challenges in doing this kind of evaluation study, as well as the opportunities that came from involving users and carers in the research. This includes how the researchers got involved and some of the activities they did. Research limitations/implications-The authors also describe some of the difficulties that were faced, including payments and criminal record checks. The ways in which people were trained and supported to take part and stay involved are outlined as well as how the group feel that they have learnt new skills and increased their confidence. Originality/value-This paper adds the voices of the co-researchers to the literature and provides lessons learned for other researchers in this area. © Emerald Group Publishing Limited. All rights reserved.
        http://dx.doi.org/10.1108/20428301311305296

99.   Green, J., J. Spink, N. Small, J. Young. PATIENT EXPERIENCE OF COMMUNITY HOSPITAL - CHALLENGES TO USER INVOLVEMENT. Age & Ageing, 2005. 34: p. i13-i13.
        Discusses research being done on the experiences of older patients in community hospitals. Reference to a study by J. Green and colleagues, presented at the autumn meeting of the British Geriatrics Societies in October 2004; Methodology and results.

100.   Grime, J., B. Dudley. Developing written information on osteoarthritis for patients: facilitating user involvement by exposure to qualitative research. Health Expectations, 2014. 17(2): p. 164-173.
        Introduction In developing a guidebook on osteoarthritis (OA), we collaborated with people who have chronic joint pain (users). But to advise, users need to be aware of and sensitive about their own state of knowledge and educationalists argue that adults sometimes lack such awareness. This paper will report on our experience of providing users with findings from qualitative research to increase awareness of their level of knowledge. Method A summary of the results from qualitative research into people's experiences of living with chronic pain was sent to individual members of two groups of users. It was then used to structure group meetings held to help identify information needed for the guidebook. Findings Some users found the summary difficult to read and suggested how to simplify it. Nevertheless, it helped most users to become aware of the experiences and views of others who have OA and thus become more sensitive to their own level of knowledge. It also helped them recall experiences that stimulated practical suggestions for managing joint pain in everyday life and provided a way of gently challenging the views of users when they appeared to assume that their views were widely held. The discussions brought to light gaps in the research literature. Conclusion We believe this way of involving users by exposing them to qualitative research findings about lay experiences of living with OA effectively facilitated the users' contributions to the needs of those who have to live with OA, and we believe it has wider applications.

http://dx.doi.org/10.1111/j.1369-7625.2011.00741.x

101.   Grogan, A., M. Coughlan, B. O' Mahony, G. McKee. **The development of a patient partnership programme and its impact on quality improvements in a comprehensive haemophilia care service**. Haemophilia, 2012. 18(6): p. 875-880.
It has long been advocated that patient input in service quality development is essential. We have developed a model of quality evaluation and improvement within a comprehensive haemophilia service, and describe the issues and improvements that resulted from the process. The project utilized an action research methodology. Seven patients were recruited from the haemophilia service for the initial focus groups. The main themes initially explored were as follows: patient experience of the outpatient, inpatient and weekend services and provision of information. The focus group data were analysed using basic content analysis. The main themes the initial focus group identified were the need to optimize the annual review, emergency care and inpatient facilities. Following this, the haemophilia care team worked on improving these issues. At the second focus group the patients contributed at a higher level patient participation. Patients assisted in addressing outstanding issues such as ID alert card content and the algorithm of care for emergency services. Finally, a patient panel was developed and the relationship became one of direct negotiation and partnership with the haemophilia team to address issues within the service. The expectations and needs of patients attending the haemophilia comprehensive care service are complex. The process of including patients as partners at the highest level of patient involvement evolved and proved an effective method of service evaluation and development, facilitating lateral decision-making, not only improving care directly, but also improving the user experience.
http://dx.doi.org/10.1111/j.1365-2516.2012.02885.x

102.   Grundy, A.C., P. Bee, O. Meade, P. Callaghan, S. Beatty, N. Olleveant, K. Lovell. **Bringing meaning to user involvement in mental health care planning: A qualitative exploration of service user perspectives**. Journal of Psychiatric and Mental Health Nursing, 2016. 23(1): p. 12-21.
Background: Service users wish to be involved in care planning but typically feel marginalized in this process. Qualitative explorations of the barriers and enablers of user involvement in mental health care planning are limited. Question: How is user involvement in care planning conceptualized by service users and how can meaningful involvement be instilled in the care planning process? Methods: In 2013, we conducted five focus groups (n = 27) and 23 individual interviews with current or recent adult users of secondary care mental health services (n = 27) in England. Eight users participated in both. Data were analysed using Framework Analysis. Results: Ten themes emerged from the data: these themes encompassed procedural elements (connection; contribution; currency; care consolidation; and consequence), service user characteristics (capacity and confidence) and professional enablers (consultation; choice; and clarity of expression). Procedural elements were discussed most frequently in service user discourse. Discussion: The process of care planning, centred on the user-clinician relationship, is key to user involvement. Implications for Practice: Users describe a common model of meaningful involvement in care planning. Their requests, summarized through a 10C framework of care planning involvement, provide clear direction for improving service users satisfaction with care planning and enhancing the culture of services. © 2016 John Wiley & Sons Ltd.
http://dx.doi.org/10.1111/jpm.12275

103.   Haarsma, F., A. Moser, M. Beckers, H. van Rijswijk, E. Stoffers, A. Beurskens. **The perceived impact of public involvement in palliative care in a provincial palliative care network in the Netherlands: A**

qualitative study. Health Expectations, 2015. 18(6): p. 3186-3200.
Background and objective: Public involvement in palliative care is challenging and difficult, because people in need of palliative care are often not capable of speaking up for themselves. Patient representatives advocate for their common interests. The aim of our study was to examine in depth the current practice of public involvement in palliative care. Setting and sample: The study was conducted in the province of Limburg in the Netherlands, with six palliative care networks. Study participants were 16 patient representatives and 12 professionals. Method: This study had a descriptive design using qualitative methods: 18 in-depth interviews and three focus groups were conducted. The critical incident technique was used. The data were analysed using an analytical framework based on Arnstein's involvement classification and the process of decision making. Impact categories as well as facilitators and barriers were analysed using content analysis. Findings and conclusion: The perceived impact of public involvement in palliative care in terms of citizen control and partnership is greatest with regard to quality of care, information development and dissemination, and in terms of policymaking with regard to the preparation and implementation phases of decision making. The main difference in perceived impact between patient representatives and professionals relates to the tension between operational and strategic involvement. Patient representatives experienced more impact regarding short-term solutions to practical problems, while professionals perceived great benefits in long-term, strategic processes. Improving public involvement in palliative care requires positive attitudes, open communication, sufficient resources and long-term support, to build a solid basis for pursuing meaningful involvement in the entire decision-making process. © 2015 John Wiley & Sons Ltd.
http://dx.doi.org/10.1111/hex.12308

104.   Hainz, T., S. Bossert, D. Strech. ==Collective agency and the concept of 'public' in public involvement: A practice-oriented analysis.== Bmc Medical Ethics, 2016. 17.
Background: Public involvement activities are promoted as measures for ensuring good governance in challenging fields, such as biomedical research and innovation. Proponents of public involvement activities include individual researchers as well as non-governmental and governmental organizations. However, the concept of 'public' in public involvement deserves more attention by researchers because it is not purely theoretical: it has important practical functions in the guidance, evaluation and translation of public involvement activities. Discussion: This article focuses on collective agency as one property a public as a small group of participants in a public involvement activity could exhibit. It introduces a prominent theoretical approach to collective agents as one specific kind of social entities and demonstrates how this approach can be applied to current practice in public involvement activities. A brief discussion of different types of representation as they are used in the existing literature on this topic is also included because representation and collective agency can be closely related to each other. Suggestions and ideas that are derived from this reasoning include the proposal to use a 'validity check' for the generation of collective agents as a regular element of certain types of public involvement activities, the consequences of combining collective agency and representativeness as a further property a public could exhibit, and standards for reporting the content of public involvement activities in scientific publications. Summary: This article discusses the importance of the concept of 'public' in public involvement activities, with a focus on biomedical research and innovation. It introduces various practically relevant ideas that are based on a theoretical analysis of collective agency as an important property a public can possess.
http://dx.doi.org/10.1186/s12910-015-0083-z

105.   Harding, E., C.J. Pettinari, D. Brown, M. Hayward, C. Taylor. **Service user involvement in clinical**

guideline development and implementation: Learning from mental health service users in the UK. International Review of Psychiatry, 2011. 23(4): p. 352-357.

The participation of service users and the public in the development of clinical guidelines is increasingly valued in international guideline programmes. This paper extends the findings of Harding et al.'s (2010) exploration of the views of service users who participated in developing NICE mental health guidelines. This analysis considered the relative value of personal versus professional knowledge and experience, the barriers to service users contributing effectively in guideline development, the unspoken 'rules 'concerning decision making, and issues of power and group dynamics. We combine these insights with observations from research in guideline development and with advances in the recovery movement and in the shared decision-making clinical model to suggest areas of improvement in guideline development, notably: translating evidence to recommendations, optimizing the acceptability of treatment recommendations to service users, and reconciling different types of knowledge.
http://dx.doi.org/10.3109/09540261.2011.606802

106.   Harding, N., J. McKinnon. <mark>User involvement in the standard-setting process: A research note on the congruence of accountant and user perceptions of decision usefulness</mark>. Accounting Organizations and Society, 1997. 22(1): p. 55-67.

This is an exploratory study which examines whether accountants and users of financial statements hold congruent or incongruent views on the decision usefulness of accounting information. This issue is important to the question of whether users require direct involvement in the standard-setting process, or whether their views may be adequately represented in the process by other participants such as accountants. Drawing on the sociology of professions literature under which professionals, such as accountants, are assumed to seek to maintain the judgement domain and indeterminacy of their professional task, it is hypothesised that accountant and user views on decision usefulness will be incongruent in those situations where a change in accounting method reduces judgement domain or indeterminacy. Specifically, it is hypothesised that, compared to users, accountants will perceive a lower degree of decision usefulness to be associated with a change in accounting method that reduces judgement domain or indeterminacy. Using a survey questionnaire, developed around a series of accounting method change scenarios, and administered to a sample of accountants and investment analysts (as an example of users), support was found for our hypothesis in relation to judgement domain, but not for indeterminacy. Copyright (C) 1996 Elsevier Science Ltd
http://dx.doi.org/10.1016/s0361-3682(96)00003-7

107.   Harrison, M., R. Palmer. <mark>Exploring patient and public involvement in stroke research: a qualitative study</mark>. Disability and Rehabilitation, 2015. 37(23): p. 2174-2183.

Purpose: To explore the experiences of patients and carers involved in patient and public involvement (PPI) activities for stroke research. Methods: Semi-structured interviews conducted with stroke survivors and carers (n=11) were analysed using thematic analysis. Results: Four key themes emerged: impact of PPI on the individual and the research process, credibility and expertise, level of involvement and barriers and facilitators to PPI for stroke survivors and carers. The perceived benefits to the research process included: asking questions, keeping researchers grounded and directing the research agenda. All participants drew upon their experiential expertise in their PPI role, but some also drew upon their professional expertise to provide additional credibility. Stroke survivors and carers can be involved in PPI at different levels of involvement simultaneously and the majority of participants wanted to be more involved. Barriers to involvement included: location, transport and stroke survivors capacity to concentrate and

comprehend complex information. Facilitators included: reimbursement for travel and time and professionals effort to facilitate involvement. Conclusions: PPI in stroke research benefits stroke survivors and carers and is perceived to benefit the research process. The barriers and facilitators should be considered by professionals intending to engage stroke survivors and carers collaboratively in research.Implications for RehabilitationThis study has implications for PPI in stroke rehabilitation research, which could also be extrapolated to stroke rehabilitation service development and evaluation.Professionals facilitating PPI need to invest in developing supportive relationships in order to maintain ongoing involvement.Professionals need to be aware of how the varied consequences of stroke might impede participation and strategies to facilitate involvement for all who wish to be involved.For each rehabilitation issue being considered professionals need to decide: (1) how representative of the specific rehabilitation population the PPI members need to be, (2) whether experience alone is sufficient or whether additional professional skills are required and (3) whether training is likely to assist involvement or potentially reduce the lay representation.
http://dx.doi.org/10.3109/09638288.2014.1001525

108.   Hartwick, J., H. Barki. ==EXPLAINING THE ROLE OF USER PARTICIPATION IN INFORMATION-SYSTEM USE.== Management Science, 1994. 40(4): p. 440-465.
Even though user participation in information system development has long been considered to be a critical factor in achieving system success, research has failed to clearly demonstrate its benefits. This paper proposes user involvement as an intervening variable between user participation and system use. Embedding the constructs of participation and involvement into the theoretical framework of Fishbein and Ajzen, a model is developed and tested in a field study of information system projects. Several key findings emerge from the study. User participation and user involvement represent two distinct constructs, with participation leading to involvement, and involvement mediating the relationship between participation and system use. The critical dimension of user participation is overall responsibility. The role of user participation and involvement is different, depending upon whether system use is mandatory or voluntary.
http://dx.doi.org/10.1287/mnsc.40.4.440

109.   Haswell, S., D. Bailey. **What is the role of a hospital service user's representative scheme for promoting service user involvement in mental health care delivery?** The Journal of Mental Health Training, Education and Practice, 2007. 2(1): p. 12-22.
This paper reports on the evaluation of a scheme to promote service user involvement in the care delivered by a mental health trust. A case study methodology was employed to describe the particularity of the scheme in context as experienced by service users and staff involved in its delivery. Mixed methods of semi-structured interviews and focus groups created the opportunity for all stakeholders to engage in action research through a mutual learning process about the scheme in operation with a view to making changes to improve and develop it in the future. The qualitative data collected was content analysed and grouped according to key themes, which included the benefits of the scheme, the conditions for it to work successfully, suggested changes, limitations of the scheme, and service user involvement generally in a hospital setting. The role of service users as both paid scheme co-ordinators and volunteer representatives highlights the contribution that people who use mental health services can play in influencing service delivery when employed in relevant and appropriate roles within a mental health organisation. © 2007, Emerald Group Publishing Limited
http://dx.doi.org/10.1108/17556228200700003

110. Haugen, L.S.Y., A. Envy, M. Borg, T.J. Ekeland, N. Anderssen. **Discourses of service user involvement in meeting places in Norwegian community mental health care: a discourse analysis of staff accounts**. Disability & Society, 2016. 31(2): p. 192-209.
In previous research, meeting places have been favourably addressed by service users, but they have also been contested as exclusionary. In this participatory explorative study, we sought to perform a contextual analysis of meeting places in Norway based on a discourse analysis of three focus group discussions with 15 staff members. We asked the following question: how do meeting-place employees discuss their concrete and abstract encounters with service users and their experiences? We focused on service user involvement, which was largely analysed as neoliberal consultation and responsibilisation. Service users were positioned as resisting responsibility trickling down and defending staffed meeting places. Social democratic discourse was identified in the gaps of neoliberal discourse, which is noteworthy given that Norway is a social democracy. This relates to global concerns about displacements of democracy. We suggest that meeting places appear to hold the potential for staff and service users to collaborate more democratically.
http://dx.doi.org/10.1080/09687599.2016.1139489

111. Hawk, S., R. Aldag. **Measurement biases in user involvement research**. Omega, 1990. 18(6): p. 605-613.
Considerable research has been conducted to demonstrate user involvement's effect on information system success. User involvement and system success typically have been measured by asking users for their perceptions of these variables. This paper reports on a field study conducted to investigate the possibility that this approach to measuring study variables tends to overstate the benefits of user involvement. The link of user involvement to user satisfaction is found to be significantly weaker when user involvement is assessed by systems analysts than when it is self reported. Further, this difference is found to be greater for systems with few users than for systems with many users. The findings suggest that common method variance and self-serving bias may have overstated the apparent benefits of user involvement in past research on information systems. Suggestions for future research are presented. © 1990.
http://dx.doi.org/10.1016/0305-0483(90)90052-B

112. Hawk, S.R. **Locus of control and computer attitude: The effect of user involvement**. Computers in Human Behavior, 1989. 5(3): p. 199-206.
Previous research has shown that individuals with an external locus of control have a less positive attitude toward computers and have greater difficulty in working with unfamiliar computer technology than individuals with an internal locus of control. Since past studies have not examined attitude towards a specific computer based information system (CBIS) that had been used regularly, the implications of past research on computer attitudes in a work setting are not clear. This study sought to investigate the relationship between locus of control and user attitude toward information systems used at work. Additionally, the impact of user involvement on this relationship was examined. A field study failed to provide support for the general assertion that locus of control affects a user's attitude towards a specific CBIS. When user involvement was considered, external-control users who had not been highly involved during CBIS development had a less positive attitude towards the CBIS than either internal-control users or external-control users who had been highly involved. © 1989.
http://dx.doi.org/10.1016/0747-5632(89)90014-9

113. Heiskari, J., L. Lehtola, *Investigating the State of User Involvement in Practice*, in *Apsec 09:*

Sixteenth Asia-Pacific Software Engineering Conference, Proceedings, S. Sulaiman and N.M.M. Noor, Editors. 2009. p. 433-440.

114.   Helfand, M. **AHRQ <mark>Series Editorial: Public involvement improves methods development in comparative effectiveness reviews</mark>**. Journal of Clinical Epidemiology, 2010. 63(5): p. 471-473.
            http://dx.doi.org/10.1016/j.jclinepi.2009.11.018

115.   Hellard, M.E., M.I. Sinclair, A.B. Forbes, C.K. Fairley. <mark>**Methods used to maintain a high level of participant involvement in a clinical trial**</mark>. Journal of Epidemiology and Community Health, 2001. 55(5): p. 348-351.
Objectives - To describe the strategies adopted to maintain high level participation throughout a community based clinical trial, and the reasons given by participants for why they participated in the study. Design - Observational study. Setting - Community based clinical trial in Melbourne, Australia that ran for 68 weeks and involved 2811 community based individuals from 600 families. A high level of commitment was required of the families; each participant completed a Health Diary each week of the 68 week study, as well as answering numerous other questionnaires, and providing faecal and blood samples. Main results - Only 41 of the 600 families withdrew from the study; the majority of these families withdrew because they sold their home and moved from the study area. The completion rate of Health Diaries averaged 90.7% over the 68 weeks of data collection. Of the 559 families who completed the study, 524 (93.7%) completed the Participation Questionnaire. The statement that received the highest rating for why families enrolled in the study was they thought the study was researching an important community issue. The statements that received the highest ratings for why families continued to participate in the study was the family being kept well informed about the study's progress and that the study was well run. Conclusions - The low numbers of withdrawals and the high level of participation throughout the study suggests the strategies of (a) having a non-aggressive recruitment method, (b) maintaining regular contact with the participants and (c) ensuring participants were kept well informed of the study's progress and constantly encouraged to continue participation were successful. The results also suggest people involve themselves in research because they perceive it to be of value to the community, not simply for personal gain. They indicated that they maintained their participation because it was a well run study and they were kept well informed throughout the study. http://dx.doi.org/10.1136/jech.55.5.348

116.   Hepworth, J.B., G.A. Vidgen, E. Griffin, A.M. Woodward. **The enhancement of information systems through user involvement in system design**. International Journal of Information Management, 1992. 12(2): p. 120-129.
Research on the information needs, information perceptions and information use of health promotion advisers suggests that systems analysis and design methodologies should be chosen with regard to the 'problem situation' which the information system will inhabit. Mandatory use of structured systems analysis and design methodology (SSADM) in the development of information systems for the United Kingdom National Health Service may be promoting a damagingly narrow view of information systems and failing to generate sufficient information awareness amongst system managers and users. Such methods do not support a view of total information resources appropriate to an information management approach. Use of alternative methods is demonstrated in order to show the value of an holistic approach to information, its environment and the individual and corporate players involved in its use. © 1992. http://dx.doi.org/10.1016/0268-4012(92)90018-L

117.   Herrero, A., H. San Martin. **Effects of the risk sources and user involvement on e-commerce**

adoption: application to tourist services. Journal of Risk Research, 2012. 15(7): p. 841-855.
Past research has focused on the dimensions (consequences) of perceived risk and the effect of global risk on e-commerce adoption by consumers. This paper uses a new approach to examine the influence of perceived risk on e-commerce adoption and, on the basis of the Theory of Planned behaviour (TPB), develops an integrative model that includes the effect of three risk sources (i.e. technology, vendor and product) on the attitude towards the website use and online purchasing intention of users. In addition, this study examines how involvement, one of the main determinants of consumer behaviour, affects the role of these sources of perceived risk in e-commerce adoption. The results obtained in a sample of 1083 users of tourist services suggest that technology risk is the main determinant of online purchasing intention, which is also influenced by the variables from the TPB model. For its part, the technology risk and vendor risk have a negative influence on attitude towards the website use. In addition, both types of risk have a higher negative effect on attitude in the case of high-involvement users, supporting the moderating influence of involvement on e-commerce adoption. From a practical point of view, the findings of this research help managers to implement actions aimed at reinforcing the users' trust in their websites and, consequently, at fostering the online purchase.
http://dx.doi.org/10.1080/13669877.2012.666758

118. Holgersson, J., E. Söderström. **Experiences from and attitudes towards applying user participation in public e-service development**. WEBIST 2014 - Proceedings of the 10th International Conference on Web Information Systems and Technologies, 2014. 1: p. 269-275.
It is evident that user participation is a vital component for successful public e-service development. However, it is also apparent that there is little guidance in e-government research about how user participation should be implemented in practice. Some high level guidelines can be found regarding user participation design schools but there is very little guidance in existing research regarding how these design schools can be implemented in practice. In this paper we have explored public administrations' experience of user participation, both in general systems development and in development of public e-services, in order to identify basic requirements that have to be fulfilled when implementing user participation in public eservice development. Thereafter we have applied these requirements on commonly used techniques to implement user participation in the light of three design schools: Participatory Design, User Centered Design, and User Innovation. Our results show that techniques to implement user participation in public eservice development must be adjusted to limited resources in terms of time and money as well as short development projects. Copyright © 2014 SCITEPRESS.

119. Hostgaard, A.M., P. Bertelsen, C. Nohr. **Methods to identify, study and understand End-user participation in HIT development**. Bmc Medical Informatics and Decision Making, 2011. 11.
Background: Experience has shown that for new health-information-technology (HIT) to be suc-cessful clinicians must obtain positive clinical benefits as a result of its implementation and joint-ownership of the decisions made during the development process. A prerequisite for achieving both success criteria is real end-user-participation. Experience has also shown that further research into developing improved methods to collect more detailed information on social groups participating in HIT development is needed in order to support, facilitate and improve real end-user participation. Methods: A case study of an EHR planning-process in a Danish county from October 2003 until April 2006 was conducted using process-analysis. Three social groups (physicians, IT-professionals and administrators) were identified and studied in the local, present perspective. In order to understand the interactions between the three groups, the national, historic perspective was included through a literature-study. Data were collected through

observations, interviews, insight gathered from documents and relevant literature. Results: In the local, present perspective, the administrator's strategy for the EHR planning process meant that there was no clinical workload-reduction. This was seen as one of the main barriers to the physicians to achieving real influence. In the national, historic perspective, physicians and administrators have had/have different perceptions of the purpose of the patient record and they have both struggled to influence this definition. To date, the administrators have won the battle. This explains the conditions made available for the physicians' participation in this case, which led to their role being reduced to that of clinical consultants-rather than real participants. Conclusion: In HIT-development the interests of and the balance of power between the different social groups involved are decisive in determining whether or not the end-users become real participants in the development process. Real end-user-participation is essential for the successful outcome of the process. By combining and developing existing theories and methods, this paper presents an improved method to collect more detailed information on social groups participating in HIT-development and their interaction during the development. This allows HIT management to explore new avenues during the HIT development process in order to support, facilitate and improve real end-user participation.
http://dx.doi.org/10.1186/1472-6947-11-57

120. Hostick, T. **Developing user involvement in mental health services**. Journal of psychiatric and mental health nursing, 1998. 5(6): p. 439-444.
This paper describes the user consultation component of a corporate approach to the mental health needs assessment of a local population. The context of the paper is established by presenting the views of users and user representatives on current mental health services. This is followed by the development of participants' views of an 'ideal' mental health service within the boundaries of technical feasibility. Three focus groups were held with current service users, and one group with user representatives. The users have extensive experience of a range of mental health services. The findings suggest that user representatives tend to represent their own needs rather than those of users. It would also seem that service users are not a homogeneous group, different groups having different priorities. Overall, users' views of current services generally reflect previous studies, but the 'ideal' approach seems to broaden the discussion and identify an agenda for change. This agenda is framed within categories of service delivery, service providers, labelling, advocacy, future research, leaving services, involvement, co-ordination, information, choice and accessibility. There is no clear role specifically identified for mental health nurses by users, but many opportunities are highlighted. Exploration of the utility of co-operative inquiry between mental health nurses and service users is recommended.

121. Howatson-Jones, I.L. **Using an auto/biographical approach to investigate nurses' learning**. Nurse researcher, 2011. 19(1): p. 38-42.
To develop methodological discussion about an 'auto/biographical' approach used to research nurses' learning. Structuring processes involved in auto/biographical approaches can reinterpret knowledge in different ways and help to examine the boundaries of experience, particularly when exploring what might be marginal spaces in cultures and institutions. The PhD study on which the paper is based explored the learning of registered nurses from two NHS trusts in the south of England. Purposive focus groups and biographical interviews were used as a data collection method. This is a methodology paper that discusses the auto/biographical approach used in the study to examine people's experiences. The focus is on auto/biographical moments as sites of meaning-making in an interconnected analysis frame and on developing a pen portrait to view research processes in more holistic terms. The prevailing argument is that biography offers a way

of enabling participants to find a voice through their history. This is about using a personal life story to enter a wider debate of how human activity is directed and organised and assumptions inherent in these processes. Auto/biographical methods can offer more holistic approaches to examining experiences by drawing together researcher and participant experiences in wholesome ways that are respectful. The interconnectedness avoids the abstractions that some other methods can sometimes impose, enabling fuller participant involvement in the research processes. IMPLICATIONS FOR PRACTICE/RESEARCH: Auto/biographical approaches appear particularly relevant for researching nursing because of their holistic nature. Implications for practice and research are found in the potential for developing personal and professional knowledge.

122.   Howe, A., S. Delaney, J. Romero, A. Tinsley, P. Vicary. Public involvement in health research: A case study of one NHS project over 5 years. Primary Health Care Research and Development, 2010. 11(1): p. 17-28.
        Public involvement, both in the National Health Service (NHS) and in clinical research, is promoted as an important democratic principle. The declared aims are to reduce professional autocracy and allow a broader ownership of the research agenda; also to improve the design of, and recruitment and retention of patients to, clinical studies. There have been a number of national initiatives in the UK to improve public input to clinical research activities, but very few reports of effective and sustainable partnerships over time. This study reports the evaluation of one example, which is embedded in the NHS and university partnerships in the Norfolk area of England. Evaluate: • Putting principles into practice of public involvement in research over a 5 year period for one specific project (Patient and Public Involvement in Research). • How the model contributes to, and impacts upon, all stages of the research process. • Attitudes of the research community and lay volunteers to their mutual experiences of public involvement. • Key factors and strengths of this project, and areas for improvement. A mixed methods approach related to the 5 years from start of 2003 to end of 2007. This used descriptive statistics of volunteer activity, interviews with key stakeholders (13), questionnaires (53% response rate), and focus group with 10 volunteers to explore emergent themes. We analysed findings using a policy framework approach. About 47 of the original 55 volunteers remained on the panel after 5 years. All have undertaken training, 38% have been involved in the full range of research activities offered, and 75% have attended at least one research project meeting. Some are active in governance, ethics, and advisory committees. Both the research community and the volunteers are very positive about the project. The researchers find it provides well prepared personnel, and gives a speedy and efficient way of fulfilling the expectations of funders for lay input. The volunteers find it gives them important opportunities to influence the quality of research and thus support improvements in patient care. Areas for improvement include increasing social diversity among the volunteers, and improving feedback on input from volunteers, without which volunteers tend to lose confidence and motivation. Long-term sustainable and valuable public input to research is possible. Key factors are committing resources, embedding the service in the infrastructure of a research consortium, and ongoing responsiveness by NHS staff and researchers. Additional activity to recruit and support access may be needed to attract people from a broad range of sociodemographic backgrounds. Some volunteers want more involvement than this model currently offers. © 2009, Cambridge University Press. All rights reserved. http://dx.doi.org/10.1017/S1463423609990405

123.   Hunter, D.J., K. Kieslich, P. Littlejohns, S. Staniszewska, E. Tumilty, A. Weale, I. Williams. Public involvement in health priority setting: future challenges for policy, research and society. Journal of

Health Organization and Management, 2016. 30(5): p. 796-808.
Purpose - The purpose of this paper is to reflect on the findings of this special issue and discusses the future challenges for policy, research and society. The findings suggest that challenges emerge as a result of legitimacy deficits of both consensus and contestatory modes of public involvement in health priority setting. Design/methodology/approach - The paper draws on the discussions and findings presented in this special issue. It seeks to bring the country experiences and case studies together to draw conclusions for policy, research and society. Findings - At least two recurring themes emerge. An underlying theme is the importance, but also the challenge, of establishing legitimacy in health priority setting. The country experiences suggest that we understand very little about the conditions under which representative, or authentic, participation generates legitimacy and under which it will be regarded as insufficient. A second observation is that public participation takes a variety of forms that depend on the opportunity structures in a given national context. Given this variety the conceptualization of public participation needs to be expanded to account for the many forms of public participation. Originality/value - The paper concludes that the challenges of public involvement are closely linked to the question of how legitimate processes and decisions can be generated in priority setting. This suggests that future research must focus more narrowly on conditions under which legitimacy are generated in order to expand the understanding of public involvement in health prioritization.
http://dx.doi.org/10.1108/jhom-04-2016-0057

124.   Hunton, J.E., J.D. Beeler. **Effects of user participation in systems development: A longitudinal field experiment**. Mis Quarterly, 1997. 21(4): p. 359-388.
This study examines the efficacy of user participation in developing an accounting application. The research takes place over a 19-month time frame, involves 516 clerical-level accounting subjects, and includes experimental manipulations in a field setting. The model of user participation and involvement proposed by Hartwick and Barki (1994) provides the foundation for the research framework. Their model is augmented by the inclusion of concepts from procedural justice and self-efficacy research. Participation is manipulated at three increasing levels: (1) no voice, (2) non-instrumental voice, and (3) instrumental voice. Research findings suggest that users' pre-experiment level of involvement with and attitude toward the present system are positively associated with their desire to participate in the development of the new system. Study results also indicate that users' a priori self-efficacy beliefs regarding their perceived ability to effectively contribute to the development process are positively related to desired participation. Pre-to post-experiment gains in psychological and behavioral variables are next assessed. In the instrumental voice condition, user involvement, user attitude, and performance gains are significantly highest; User attitude and involvement gains are significantly higher in the non-instrumental voice condition than in the no voice condition; however, gains in user performance are not significantly different between these treatment conditions. Research findings indicate that user participation can be effective, particularly when users perceive a noticeable degree of instrumental control over the decision outcome.
http://dx.doi.org/10.2307/249719

125.   Hunton, J.E., K.H. Price. **Effects of the user participation process and task meaningfulness on key information system outcomes**. Management Science, 1997. 43(6): p. 797-812.
In this study, 144 professional accounting data entry clerks took part in a fully randomized field experiment using a 4 (mode of participation) X 2 (task meaningfulness) design. Participants were full-time, mandatory users of payroll applications. The nature of the experiment engaged these users in hands-on activity (Hartwick and Barki 1994) regarding the development of a payroll input

screen. User mode of participation was manipulated by varying the extent of decision input used to execute hands-on activity in accordance with procedural justice theory. Perceptions of decision control, procedural justice, and outcome satisfaction, as well as objective levels of task performance escalated with corresponding increases in decision input. Task meaningfulness was manipulated by creating either high or low expectations of using the payroll input screen in the near future. As the development task became more meaningful, procedural justice, decision control, task commitment, and task performance responses also increased. An underlying theoretical model of treatment effects was tested using path analysis which supported the control-oriented theory of procedural justice. The strong attitudinal and behavioral results observed in this experiment enhance understanding of the user participation and involvement model proposed by Hartwick and Barki (1994) by incorporating process considerations from procedural justice theory into their framework. Implications of this research are discussed. http://dx.doi.org/10.1287/mnsc.43.6.797

126. Høstgaard, A.M., P. Bertelsen, C. Nøhr. **Methods to identify, study and understand end-user participation in HIT development**. BMC medical informatics and decision making, 2011. 11: p. 57. Experience has shown that for new health-information-technology (HIT) to be suc-cessful clinicians must obtain positive clinical benefits as a result of its implementation and joint-ownership of the decisions made during the development process. A prerequisite for achieving both success criteria is real end-user-participation. Experience has also shown that further research into developing improved methods to collect more detailed information on social groups participating in HIT development is needed in order to support, facilitate and improve real end-user participation. A case study of an EHR planning-process in a Danish county from October 2003 until April 2006 was conducted using process-analysis. Three social groups (physicians, IT-professionals and administrators) were identified and studied in the local, present perspective. In order to understand the interactions between the three groups, the national, historic perspective was included through a literature-study. Data were collected through observations, interviews, insight gathered from documents and relevant literature. In the local, present perspective, the administrator's strategy for the EHR planning process meant that there was no clinical workload-reduction. This was seen as one of the main barriers to the physicians to achieving real influence. In the national, historic perspective, physicians and administrators have had/have different perceptions of the purpose of the patient record and they have both struggled to influence this definition. To date, the administrators have won the battle. This explains the conditions made available for the physicians' participation in this case, which led to their role being reduced to that of clinical consultants--rather than real participants. In HIT-development the interests of and the balance of power between the different social groups involved are decisive in determining whether or not the end-users become real participants in the development process. Real end-user-participation is essential for the successful outcome of the process. By combining and developing existing theories and methods, this paper presents an improved method to collect more detailed information on social groups participating in HIT-development and their interaction during the development. This allows HIT management to explore new avenues during the HIT development process in order to support, facilitate and improve real end-user participation.

127. Iivari, J., M. Igbaria. **Determinants of user participation: A Finnish survey**. Behaviour & Information Technology, 1997. 16(2): p. 111-121.
The relationship between user participation and information systems success has intrigued researchers for two decades. Despite this history there is minimal research on the antecedents of

user participation. The tenet of the present paper is that the conditions of user participation are essentially changing. Especially, the European tradition of user participation has focused on blue collar workers rather than professionals and managers. Users are normally assumed to be computer illiterate. The North American tradition has almost exclusively focused on the impact of user participation on information systems success. The present paper examined the significance of organizational level of users, their task variety and computer experience as determinants of user participation including age, gender, education, computer training, organizational tenure and job tenure as control variables. The three determinants were found to have a significant positive effect on user participation, computer experience emerging as the most dominant factor. Gender, education and computer training were discovered to have significant effects mediated by organizational level, task variety and computer experience.
http://dx.doi.org/10.1080/014492997119950

128.   Jaffray, B. **Assessing public involvement programs in environmental decision making (Canada)**. Geoscope, 1981. 12(2): p. 7-10.
Outlines a four factor involvement program analytical framework, and presents an analysis of selected public involvement program evaluation efforts. This research focuses on involvement program evaluations, and is, in effect, an assessment of other researcher's involvement program evaluation frameworks, in order to determine the common threads in the current Canadian public involvement program involvement experience. -from Author

129.   Jansson, M., U. Ramberg. **Implementation and effects of user participation in playground management: A comparative study of two Swedish municipalities**. Managing Leisure, 2012. 17(1): p. 1-13.
This paper describes and analyses how customer orientation strategies, with the focus on user participation, are implemented in playground management and their effects on managers' attitudes and work with physical playgrounds. A comparative case study was conducted in two Swedish municipalities that involve users in different ways: through a manager-driven participation process and through informal user-initiated dialogue. The empirical material consisted of qualitative interviews with professionals in the management organisations and studies of local playgrounds. Implementation of strategies for user participation and tactical management activities appeared to be of importance. The manager-driven participation strategy was associated with a particularly positive attitude among managers, but also difficulties such as maintaining continuous dialogue with users. The small differences found in playground provision between the two municipalities give reason to question the physical effects of participation processes, and show the need for further research. © 2012 Copyright Taylor and Francis Group, LLC.
http://dx.doi.org/10.1080/13606719.2011.638204

130.   Jia, J., L.F. Capretz. <mark>Direct and mediating influences of user-developer perception gaps in requirements understanding on user participation</mark>. Requirements Engineering, 2017: p. 1-14.
User participation is considered an effective way to conduct requirements engineering, but user-developer perception gaps in requirements understanding occur frequently. Since user participation in practice is not as active as we expect and the requirements perception gap has been recognized as a risk that negatively affects projects, exploring whether user-developer perception gaps in requirements understanding will hinder user participation is worthwhile. This will help develop a greater comprehension of the intertwined relationship between user participation and perception gap, a topic that has not yet been extensively examined. This study

investigates the direct and mediating influences of user-developer requirements perception gaps on user participation by integrating requirements uncertainty and top management support. Survey data collected from 140 subjects were examined and analyzed using structural equation modeling. The results indicate that perception gaps have a direct negative effect on user participation and negate completely the positive effect of top management support on user participation. Additionally, perception gaps do not have a mediating effect between requirements uncertainty and user participation because requirements uncertainty does not significantly and directly affect user participation, but requirements uncertainty indirectly influences user participation due to its significant direct effect on perception gaps. The theoretical and practical implications are discussed, and limitations and possible future research areas are identified. © 2017 Springer-Verlag London
http://dx.doi.org/10.1007/s00766-017-0266-x

131. Joss, N., A. Cooklin, B. Oldenburg. <mark>A scoping review of end user involvement in disability research</mark>. Disability and Health Journal, 2016. 9(2): p. 189-196.
Background: Involving clients and consumers of health care in research, policy and health service development has been widely advocated for across a number of different fields and disciplines. Despite some promising evidence, 'end users' have not been meaningfully involved in all stages of the research process in the area of disability research. Objective: To conduct a scoping review on end user involvement in disability research, service and policy development. Methods: Literature was searched using electronic databases, hand searching reference lists of papers and grey literature. Electronic databases searched included the Cochrane Database of Systematic Reviews, MEDLINE, EMBASE, CINAHL, PsycINFO and Google Scholar. The search was restricted to articles published in English between January 2000 and April 2013. Results: Two clear themes emerged from a review of twenty-seven articles. Firstly, end users can benefit research as 'experts of experience' through their role as a co-researcher. Secondly, evidence suggests end users add value at different stages of the research process in this role. However, less is understood about end user involvement in the latter stages of the research process. Conclusions: This review suggests that end users can meaningfully contribute to the quality of disability research. End users are likely to engage in research with differing perspectives, desires to be involved at distinct stages of the process, differing roles and different abilities to participate in the research. Academic rigor, however, must be maintained by the researcher. (C) 2016 Elsevier Inc. All rights reserved.
http://dx.doi.org/10.1016/j.dhjo.2015.10.001

132. Kaasinen, E., M. Ainasoja, E. Vulli, H. Paavola, R. Hautala, P. Lehtonen, E. Reunanen, *User involvement in service innovations*, in *VTT Tiedotteita - Valtion Teknillinen Tutkimuskeskus*2010. p. 1-69.
The importance of user orientation in innovation activities is nowadays emphasized not only in business life but also in political and societal discussions. In today's competed and changing market situations, one promising way to support market success are innovations originating from the needs of the customers. The traditional division to product-oriented and service-oriented business is blurring as traditional products are equipped with service elements that bring additional value to customers. Service orientation in business changes the connection to the customers: it is not enough to be able to sell the product to the customer once but the service customer has to be kept satisfied every day. Service providers need to know their customers better and to offer them better possibilities to be involved in service development. In this report we present a review of the current state of the art in user involvement in service innovations. The

review is based on three different research viewpoints: marketing and business research, human-centred design and media research. In each of these research fields we can see a similar trend of changing the attitude towards users; from passive research object to an active design partner, potential resource and co-producer. The transition from product design to service design requires that design and usage should be more firmly connected - the design does not end when the service is launched but the design continues in use where the users are creating content for the service. The users shape usage practises in actual use and this may indicate needs to refine the service. That is why service providers should have good channels to monitor the users and to listen to their ideas and feedback. In addition to user involvement in the actual design process and during use, users should increasingly be involved also in early innovation phases, in ideating what kinds of services should be designed for them and with them. Different users can give different contributions to service innovation and their motivations and preferred ways to participate vary. Different roles in the innovation process should be available to user groups such as lead users, ordinary users, advanced users, critical users and non-users. User communities are increasingly important sources of innovations, either existing communities or new communities that are grown around the service. Customer interaction may shorten the development cycle and improve the quality of innovations. Successful user involvement, however, requires that the organisation has methods and processes to gather and analyse user data as well as to integrate user data in the design process. User involvement is especially useful in the early stages of service development processes due to their high uncertainty and low formalisation. Direct user-designer interaction helps in transferring user feedback and ideas to service innovations. Designers' direct interaction with users is also beneficial as it seems to change designers' mindset smoothly from technical features to user experience, thus boosting better designs. User experience of the service is improved when users themselves can contribute to developing the service. Copyright © VTT 2010.
Review

133.   Kallenbach-Herbert, B., Asme. **PUBLIC INVOLVEMENT ON CLOSURE OF ASSE II RADIOACTIVE WASTE REPOSITORY IN GERMANY**. Asme 2013 15th International Conference on Environmental Remediation and Radioactive Waste Management, Vol 2: Facility Decontamination and Decommissioning; Environmental Remediation; Environmental Management/Public Involvement/Crosscutting Issues/Global Partnering, 2013.
From 1967 to 1978, about 125,800 barrels of low-and intermediate level waste were disposed of - nominally for research purposes - in the former "Asse" salt mine which had before been used for the production of potash for many years. Since 1988 an inflow of brine is being observed which will cause dangers of flooding and of a collapse due to salt weakening and dissolution if it should increase. Since several years the closure of the Asse repository is planned with the objective to prevent the flooding and collapse of the mine and the release of radioactive substances to the biosphere. The first concept that was presented by the former operator, however, seemed completely unacceptable to regional representatives from politics and NGOs. Their activities against these plans made the project a top issue on the political agenda from the federal to the local level. The paper traces the main reasons which lead to the severe safety problems in the past as well as relevant changes in the governance system today. A focus is put on the process for public involvement in which the Citizens' Advisory Group "A2B" forms the core measure. Its structure and framework, experience and results, expectations from inside and outside perspectives are presented. Furthermore the question is tackled how far this process can serve as an example for a participatory approach in a siting process for a geological repository for high active waste which can be expected to be highly contested in the affected regions.

http://dx.doi.org/10.1115/icem2013-96090

134.   Kappelman, L.A. **Measuring user Involvement: A diffusion of innovation perspective**. ACM SIGMIS Database, 1995. 26(2-3): p. 65-86.
         User involvement is a need-based motivational attitude toward information systems and their development. As such, it has important implications for the successful creation and deployment of information systems in organizations. This paper reports on the development and validation of an instrument to determine if the distinction between a user's involvement in the process of information system diffusion can be measured independently of that user's involvement with the information system innovation itself. Utilizing previously-validated instruments from consumer behavior research, these two object-based categories of user involvement were operationalized. A longitudinal field study was conducted of users in a large financial institution during the implementation phase, in particular the later activities of the adaptation stage, of the information system diffusion process. During adaptation the information system product becomes available for use in the organization. Late adaptation stage activities include hardware installation, system conversion, and training. The instruments were pre-tested and assessed as to their content validity, internal consistency, convergent validity, unidimensionality, temporal stability, discriminant validity, predictive validity, and factorial validity. The evidence indicates that the measurement scales are reliable and valid. The primary question of scale independence was examined by discriminant validity. The empirical evidence supports the theoretical distinction between user process involvement and user system involvement. The implications of these findings to research and practice are discussed. © 1995, ACM. All rights reserved. http://dx.doi.org/10.1145/217278.217286

135.   Kappelman, L.A. **User training, user involvement, and IS implementation success**. Journal of Computer Information Systems, 1996. 36(3): p. 1-9.
         This paper examines some of the psychological outcomes of end-user training in the context of a field study conducted during the later implementation stages of a large-scale multisite information system (IS). The study tests the applicability of the behavioral-attitudinal theory of information system success (18, 19), and then expands the theory to include the distinction between attitudes toward the process of development and attitudes toward the IS product of development (15, 16, 17) utilizing instruments recently published in the Journal of Computer Information Systems (15). The evidence indicates that: (1) the behavioral-attitudinal theory is valid when applied to examining the role of user training in IS success; and (2) the theory is improved when expanded to include the distinction between the product/process objects of user involvement. Some of the implications of this to research and practice are discussed.

136.   Kara, H. <mark>Mental health service user involvement in research: Where have we come from, where are we going?</mark> Journal of Public Mental Health, 2013. 12(3): p. 122-135.
         – The aim of the research is to assess the extent and value of mental health service user (MHSU) involvement in research in England. – This is a knowledge review, including academic and "grey" literature, and documented testimonial evidence. – The involvement of MHSUs in mental health research has become mainstream. There is clear evidence that involving MHSUs in research adds value. Four gaps in the literature were identified. First, a lack of evidence from non-service-user researchers about their experience of working with MHSUs. Second, a lack of recognition that anyone involved in research may hold more than one role. Third, failure to treat carers as separate from MHSUs, or – often – to include them at all. Fourth, a lack of understanding that MHSUs may have a useful role to play in research on topics other than mental health. – The literature would

benefit from some evidence about non-service-user researchers' experiences of working with MHSU researchers. Carers should be recognised much more widely as different from MHSUs and with a valid role to play in mental health research from their own perspectives. MHSU researchers, and carer researchers, should be offered opportunities for involvement in research on topics other than mental health. – The evidence shows that involving service users in research can benefit everyone involved and the research itself. The process can be challenging for all concerned. However, there is now plenty of guidance about how to involve service users in research for maximum benefit to all (e.g. Faulkner, 2004b; SURGE, 2005; Morgan, 2006; Tew et al., 2006; Kotecha et al., 2007; Schrank and Wallcraft, 2008, pp. 243-247; Leiba, 2010, pp. 160-169; Armes et al., 2011; Morrow et al., 2012, p. 114). This guidance should be consulted by researchers, funders, ethics committees, and other stakeholders at the earliest possible stage of any relevant project. – It is essential to recognise and acknowledge that anyone involved in research may hold more than one role. Embracing multiple and mutable identities is not an easy process, as the literature shows, and attempts to do so are likely to produce resistance at every level. Nevertheless, the example of the survivor researchers suggests that doing this has the potential to enrich our individual and collective experience, and therefore society as a whole. – The paper is written by an independent researcher who is also a carer for people with mental health problems: a viewpoint which is rarely found in the literature. The literature suggests that power imbalances and identity issues are at the root of most difficulties and gaps. Social identity and categorisation theory offers a useful theoretical perspective. The paper will be of value to anyone interested in mental health research, whether as a student, service user/survivor, researcher or teacher. © 2013, Emerald Group Publishing Limited
http://dx.doi.org/10.1108/JPMH-01-2013-0001

137.   Karazivan, P., V. Dumez, L. Flora, M.P. Pomey, C. Del Grande, D.P. Ghadiri, . . . P. Lebel. **The patient-as-partner approach in health care: a conceptual framework for a necessary transition**. Academic medicine : journal of the Association of American Medical Colleges, 2015. 90(4): p. 437-441.
The prevalence of chronic diseases today calls for new ways of working with patients to manage their care. Although patient-centered approaches have contributed to significant advances in care and to treatments that more fully respect patients' preferences, values, and personal experiences, the reality is that health care professionals still hold a monopoly on the role of healer. Patients live with their conditions every day and are experts when it comes to their own experiences of illness; this expertise should be welcomed, valued, and fostered by other members of the care team. The patient-as-partner approach embodies the ideal of making the patient a bona fide member of the health care team, a true partner in his or her care. Since 2010, the University of Montreal, through the Direction of Collaboration and Patient Partnership, has embraced this approach. Patients are not only active members of their own health care team but also are involved in research and provide valuable training to health sciences students. Including patients as full partners in the health care team entails a significant shift in both the medical practice and medical education cultures. In this perspective, the authors describe this innovative approach to patient care, including the conceptual framework used in its development and the main achievements of patient partners in education, health care, and research.
http://dx.doi.org/10.1097/ACM.0000000000000603

138.   Kaur, P. **Underpinnings of User Participation in Service Provider-Hosted Online Communities**. Service Science, 2016. 8(3): p. 249-262.
The recent emergence of social media-based brand communities is seen as an effective channel

for practicing user-centric service innovation. However, user participation is the major hurdle in their sustainability. Despite the growing popularity of these brand communities, there has been only limited research examining the factors affecting user intention to continue using these communities. Teenagers represent an important demographic group, not only as the dominant users, but also in their value and potential in contributing toward successful business. To date, no previous research has investigated the participation behaviour of teenagers in these communities. To address this research gap, the present study examines the factors affecting teenagers' intention to continue participating in Facebook-based brand communities. The roles of social and individual factors in the formulation of their attitudes to participation are examined. The relationship between users' attitudes, activity levels, and continuation intentions are explored. The study findings suggest that self-efficacy, hedonic motivation, reciprocal benefit, and social influence have a positive impact on user attitude. Among these, self-efficacy has the strongest influence. Furthermore, attitude, continuation intention, and activity levels are significantly related. The findings have implications for organisations intending to use social media-based brand communities to practice user-centric service innovation.
http://dx.doi.org/10.1287/serv.2016.0136

139.   Khan, M.L. **Social media engagement: What motivates user participation and consumption on YouTube?** Computers in Human Behavior, 2017. 66: p. 236-247.
This study unearths the motives for YouTube user engagement that has been conceptualized as active participation and passive content consumption. In light of the Uses and Gratifications framework, a sample of 1143 registered YouTube users completed online surveys that helped gauge user behavior. Results showed that for participation on YouTube, the strongest predictor for liking and disliking videos was the relaxing entertainment motive; commenting and uploading being strongly predicted by social interaction motive; sharing being strongly predicted by information giving motive. Passive content consumption in the form of video viewing was most strongly predicted by relaxing entertainment motive, and reading comments predicted by information seeking motive. Greater YouTube experience negatively predicted liking, and anonymity played a role in sharing and uploading videos. Males were more likely to dislike YouTube videos in comparison with females. © 2016 Elsevier Ltd
http://dx.doi.org/10.1016/j.chb.2016.09.024

140.   Kim, H.S., S. Shyam Sundar. **Can online buddies and bandwagon cues enhance user participation in online health communities?** Computers in Human Behavior, 2014. 37: p. 319-333.
Individuals are more likely to obtain information and support from online health communities than offer help to other users (Fox & Jones, 2009; Preece, Nonnecke, & Andrews, 2004). The current study attempts to resolve this problem of under-contribution by proposing two theory-based persuasive strategies - a specific request in the form of an online buddy and collective community feedback in the form of bandwagon cues. A 2 (online buddy: absence vs. presence) by 2 (bandwagon cues: weak vs. strong) between-participants experiment tested the effects of these strategies on psychological outcomes, including perceived responsibility, social presence, sense of community, and perceived helpfulness, as well as their posting attitudes, posting intentions, and website attitudes, across two sessions. Contrary to expectations, we found that the assignment of online buddies in a health community forum leads to negative psychological and behavioral consequences, especially in the absence of strong community feedback. Furthermore, the online buddy feature interacts with bandwagon cues to activate different cognitive processes, leading to differential interpretation of the meanings of those bandwagon cues - either as compliments (in the presence of online buddy) or as unreliable

feedback (in the absence of online buddy). Theoretical and practical implications are discussed. ©
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http://dx.doi.org/10.1016/j.chb.2014.04.039

141. Kling, K.J., M.E. Hopkins. **Are we making the grade? Practices and reported efficacy measures of
primate conservation education programs**. American journal of primatology, 2015. 77(4): p.
434-448.
Conservation education is often employed alongside primate conservation efforts with the aim of
changing knowledge, attitudes, and behaviors toward non-human primates. Recommended
best-use practices include longevity, use of program incentives, collaboration among educators,
and adaptive program assessment, among others. This study surveys primate conservation
education programs (PCEPs) to assess the frequency of suggested best-use practices, and to
investigate impacts on program efficacy. Online surveys were collected from PCEPs in 2013-2014
(N = 43). The majority of programs reported lengths of 5-10 years, with participant involvement
ranging widely from a day to several years. Non-economic and economic incentives were
distributed by approximately half of all programs, with programs that provided economic
incentives reporting positive participant attitude changes more frequently than those that did not
(P = 0.03). While >70% of PCEPs consulted with community leaders, local teachers, and research
scientists, only 45.9% collaborated with other conservation educators and only 27% collaborated
with cultural experts such as cultural anthropologists. Programs that collaborated with other
conservation educators were more likely to report reductions in threats to primates, specifically to
bushmeat hunting and capture of primates for the pet trade (P = 0.07). Formal program
evaluations were employed by 72.1% of all programs, with the majority of programs using surveys
to assess changes to participant attitudes and knowledge. Formal evaluations of participant
behavior, community attitudes and behaviors, and threats to primate populations were less
common. While results indicate that PCEPs follow many suggested best-use practices, program
impacts may be enhanced by greater discussion of economic incentivization, increased
collaboration between conservation educators, and improved commitment to adaptive evaluation
of changes to behaviors in addition to attitudes and knowledge.
http://dx.doi.org/10.1002/ajp.22359

142. Klok, T., P.L. Brand, H. Bomhof-Roordink, E.J. Duiverman, A.A. Kaptein. **Parental illness perceptions
and medication perceptions in childhood asthma, a focus group study**. Acta Paediatrica,
International Journal of Paediatrics, 2011. 100(2): p. 248-252.
Aim: Asthma treatment according to guidelines fails frequently, through patients' nonadherence
to doctors' advice. This study aimed to explore how differences in asthma care influence parents'
perceptions to inhaled corticosteroids (ICS). Methods: We conducted six semistructured focus
groups, including 44 parents of asthmatic children (2-12 years of age, treated in primary or
specialist care). Verbatim transcripts were analysed with standard qualitative research methods.
Results: Parents decided deliberately whether ongoing ICS use was useful for their child. This
decision was based on their perceptions about illness and medication. In primary care, this issue
was hardly ever discussed with the health care provider because regular scheduled follow-up was
unusual. In specialist care, regular scheduled follow-up was usual, and parental perceptions about
illness and medication were discussed and modified when needed. Parent-reported adherence
was lower in primary care than in specialist care. Conclusion: This focus group study illustrates
how strongly parental perceptions of illness and medication influence adherence to health care
providers' advice and that such perceptions can be modified within a strong doctor-patient
partnership, improving adherence. © 2010 Foundation Acta Pædiatrica.

http://dx.doi.org/10.1111/j.1651-2227.2010.02024.x

143.   Kobayashi, E., T. Sakurada, S. Ueda, N. Satoh. Public involvement in pharmacogenomics research: A national survey on patients' attitudes towards pharmacogenomics research and the willingness to donate DNA samples to a DNA bank in Japan. Cell and Tissue Banking, 2011. 12(2): p. 71-80. To assess the attitude of Japanese patients towards pharmacogenomics research and a DNA bank for identifying genomic markers associated with adverse drug reactions (ADRs) and their willingness to donate DNA samples, we conducted a survey of 550 male and female patients. The majority of the respondents showed a positive attitude towards pharmacogenomics research (87.6%) and a DNA bank (75.1%). The willingness to donate DNA samples when experiencing severe ADRs (55.8%) was higher than when taking medications (40.4%). Positive attitudes towards a DNA bank and organ donation were significantly associated with an increased willingness to donate. Though the level of positive attitude in the patient population was higher than that in the general public in our former study (81.0 and 70.4%, respectively), the level of the willingness of patients to donate was 40.4% when taking medications and 55.8% when experiencing severe ADRs which was lower than that of the general public in our former study (45.3 and 61.7%). The results suggested that the level of true willingness in the patient population was lower than that of the general public considering the fictitious situation presented to the public (to suppose that they were patients receiving medication). It is important to assess the willingness of patients who are true potential donors, not the general public. © 2009 Springer Science+Business Media B.V. http://dx.doi.org/10.1007/s10561-009-9166-8

144.   Kobayashi, E., N. Satoh. Public involvement in pharmacogenomics research: a national survey on public attitudes towards pharmacogenomics research and the willingness to donate DNA samples to a DNA bank in Japan. Cell and Tissue Banking, 2009. 10(4): p. 281-291. To assess the attitudes of the Japanese general public towards pharmacogenomics research and a DNA bank for identifying genomic markers associated with ADRs and their willingness to donate DNA samples, we conducted a national survey for 1,103 Japanese adults from the general public, not a patient population. The response rate was 36.8%. The majority of the respondents showed a positive attitude towards pharmacogenomics research (81.0%) and a DNA bank (70.4%). Considering fictitious clinical situations such as taking medications and experiencing ADRs, the willingness to donate DNA samples when experiencing ADRs (61.7%) was higher than when taking medications (45.3%). Older generations were significantly associated with a decreased willingness to donate (OR = 0.45, CI 0.28-0.72 in 50s. OR = 0.49, CI: 0.31-0.77 in 60s). Positive attitudes towards pharmacogenomics research, a DNA bank, blood/bone marrow/organ donation were significantly associated with an increased willingness. However, the respondents had the following concerns regarding a DNA bank: the confidentiality of their personal information, the manner by which research results were utilized and simply the use of their own DNA for research. In order to attain public understanding to overcome these concerns, a process of public awareness should be put into place to emphasize the beneficial aspects of identifying genomic markers associated with ADRs and to address these concerns raised in our study. Further study is needed to assess the willingness of actual patients taking medications in real situations, since the respondents in our study were from the general public, not a patient population, and their willingness was assessed on the condition of assuming that they were patients taking medications. http://dx.doi.org/10.1007/s10561-009-9145-0

145.   Kok, B.N.E., K. Slegers, P. Vink. The amount of ergonomics and user involvement in 151 design

<mark>processes</mark>. Work-a Journal of Prevention Assessment & Rehabilitation, 2012. 41: p. 989-996. Ergonomics, usability and user-centered design are terms that are well known among designers. Yet, products often seem to fail to meet the users' needs, resulting in a gap between expected and experienced usability. To understand the possible causes of this gap the actions taken by the designer during the design process are studied in this paper. This can show whether and how certain actions influence the user-friendliness of the design products. The aim of this research was to understand whether ergonomic principles and methods are included in the design process, whether users are involved in this process and whether the experience of the designer (in ergonomics/user involvement) has an effect on the end product usability. In this study the design processes of 151 tangible products of students in design were analyzed. It showed that in 75% of the cases some ergonomic principles were applied. User involvement was performed in only 1/3 of the design cases. Hardly any correlation was found between the designers' experience in ergonomic principles and the way they applied it and no correlations were found between the designers' experience in user involvement and the users' involvement in the design process. http://dx.doi.org/10.3233/wor-2012-0275-989

146.   Kvarnstrom, S., B. Hedberg, E. Cedersund. **The dual faces of service user participation: Implications for empowerment processes in interprofessional practice**. Journal of Social Work, 2013. 13(3): p. 287-307.
         This article reports on an empirical research study exploring and describing variations in how front-line practitioners perceive service user participation (SUP), specifically in interprofessional practice. The settings comprised three Swedish health and social care organizations where the professionals worked in interprofessional teams: a program for chronic pain rehabilitation, a program for surgical treatment of obesity, and a short-term municipal home for older adults. The qualitative study design was informed by a phenomenographic approach and conducted as semi-structured individual interviews with 15 professionals representing nine professions, including social work. Findings: The main findings show seven qualitative variations in understanding of SUP: 1) inclusion in activities and social events, 2) obtaining guidance, 3) having self-determination and choice, 4) getting confirmation from and contact with professionals, 5) negotiating for adjustment, 6) personal responsibility through insight, and 7) circumstance surrounding SUP. Applications: The interprofessional dimensions discerned in the meaning attributed to SUP are mainly described in terms of amplified opportunities for participation. An interesting aspect of the findings is that in all the variations of perceptions of SUP, there are potentials to reverse to their opposites, that is, paradoxes that can be termed 'the dual faces of service user participation'. These aspects stress the need for continuing reflection on practices among both front-line practitioners and managers in empowering and paternalistic processes and on constantly improving organizational and policy conditions to facilitate SUP. http://dx.doi.org/10.1177/1468017311433234

147.   Kyle, G.T., D.L. Kerstetter, F.B. Guadagnolo. **Market Segmentation Using Participant Involvement Profiles**. Journal of Park & Recreation Administration, 2002. 20(1): p. 1-21.
         Research using participant involvement profiles for market segmentation has illustrated the procedure's utility both in terms of its managerial applicability as well as its legitimacy as a research tool for academic inquiry into consumer behavior. This study builds upon previous efforts that have noted how varying levels and types of involvement affect human behavior and attempts to classify participants of a 10K road race into homogenous segments based on their involvement profiles. The three objectives that guided this study were: (1) to construct profiles of participants based on their level and type of involvement; (2) to identify distinct market segments

using participants' involvement profiles; and (3) to profile selected market segments based on their socio-demographic characteristics, self-reported behaviors, and participants' perceptions of important service elements as well as evaluations of the organizing agency's performance in providing those service elements. Three distinct segments emerged from the analysis and were profiled using self-reported behavioral measures consisting of past participation in the event, annual participation in similar events, running magazine subscription, perceptions of important service attributes, and evaluations of agency performance in providing service attributes. The results demonstrate the complexity of the involvement construct by highlighting that in addition to varying across leisure activities, the type and level of involvement also varies across segments of participants. Future research examining involvement in this manner will enhance our understanding of the construct in addition to providing agencies with valuable marketing tools. While problems remain concerning the measurement of risk in the context of the leisure experience, these results suggest that distinct and meaningful target markets can still be identified through the use of involvement profiles. Further, target markets can be differentiated on the basis of self-reported behavioral characteristics, service preferences and service evaluations. Implications related to the pricing, promotion, programming, and distribution of the service are discussed. Segmentation using consumer involvement profiles provides managers with insights concerning their clients' underlying motives for participation. Used in conjunction with traditional market categorizations (e.g., socio-demographic variables, psychographic variables, benefits derived from participation), managers of leisure services are then in a better position to improve service delivery and provide greater participant satisfaction. [ABSTRACT FROM AUTHOR]

148.   Lakhani, M. **Patient and public involvement in quality improvement**. Journal of Clinical Governance, 2001. 9(4): p. 165-166.

149.   Lander, J., T. Hainz, I. Hirschberg, S. Bossert, D. Strech. **Do Public Involvement Activities in Biomedical Research and Innovation Recruit Representatively? A Systematic Qualitative Review**. Public Health Genomics, 2016. 19(4): p. 193-202.
Background: Public involvement activities (PIAs) may contribute to the governance of ethically challenging biomedical research and innovation by informing, consulting with and engaging the public in developments and decision making processes. For PIAs to capture a population's preferences (e.g. on issues in whole genome sequencing, biobanks or genome editing), a central methodological requirement is to involve a sufficiently representative subgroup of the general public. While the existing literature focusses on theoretical and normative aspects of 'representation', this study assesses empirically how such considerations are implemented in practice. It evaluates how PIA reports describe representation objectives, the recruitment process and levels of representation achieved. Methods: PIA reports were included from a systematic literature search if they directly reported a PIA conducted in a relevant discipline such as genomics, biobanks, biotechnology or others. PIA reports were analyzed with thematic text analysis. The text analysis was guided by an assessment matrix based on PIA-specific guidelines and frameworks. Results: We included 46 relevant reports, most focusing on issues in genomics. 27 reports (59%) explicitly described representation objectives, though mostly without adjusting

eligibility criteria and recruiting methods to the specific objective. 11 reports (24%) explicitly reported to have achieved the intended representation; the rest either reported failure or were silent on this issue. Conclusion: Representation of study samples in PIAs in biomedical research and innovation is currently not reported systematically. Improved reporting on representation would not only improve the validity and value of PIAs, but could also contribute to PIA results being used more often in relevant policy and decision-making processes. (C) 2016 S. Karger AG, Basel
http://dx.doi.org/10.1159/000444478

150. Lander, J., T. Hainz, I. Hirschberg, D. Strech. **Current practice of public involvement activities in biomedical research and innovation: A systematic qualitative review**. PLoS ONE, 2014. 9(12).
Background: A recent report from the British Nuffield Council on Bioethics associated 'emerging biotechnologies' with a threefold challenge: 1) uncertainty about outcomes, 2) diverse public views on the values and implications attached to biotechnologies and 3) the possibility of creating radical changes regarding societal relations and practices. To address these challenges, leading international institutions stress the need for public involvement activities (PIAs). The objective of this study was to assess the state of PIA reports in the field of biomedical research. Copyright: Methods: PIA reports were identified via a systematic literature search. Thematic text analysis was employed for data extraction. Results: After filtering, 35 public consultation and 11 public participation studies were included in this review. Analysis and synthesis of all 46 PIA studies resulted in 6 distinguishable PIA objectives and 37 corresponding PIA methods. Reports of outcome translation and PIA evaluation were found in 9 and 10 studies respectively (20% and 22%). The paper presents qualitative details. Discussion: The state of PIAs on biomedical research and innovation is characterized by a broad range of methods and awkward variation in the wording of objectives. Better comparability of PIAs might improve the translation of PIA findings into further policy development. PIA-specific reporting guidelines would help in this regard. The modest level of translation efforts is another pointer to the "deliberation to policy gap". The results of this review could inform the design of new PIAs and future efforts to improve PIA comparability and outcome translation. © 2014 Lander et al.
http://dx.doi.org/10.1371/journal.pone.0113274

151. Langaro, D., P. Rita, M. de Fátima Salgueiro. **Do social networking sites contribute for building brands? Evaluating the impact of users' participation on brand awareness and brand attitude**. Journal of Marketing Communications, 2015.
Social networking sites (SNSs) have attracted increasing attention from brands, which look at the platform as a privileged communication channel to reach their audiences. Despite their growing adoption, few research efforts have been devoted to evaluate SNSs' concrete implications for the brands. The current study addresses this opportunity, proposing a model that evaluates the impact of users' participation in SNSs on brand awareness and brand attitude, the two main pillars of brand knowledge. The study focuses on brand like pages in Facebook, the most used SNSs platform for brands. An online quantitative survey with brand like page users of leading brands in Facebook was implemented. Confirmatory factor analysis was used to estimate the measurement model and structural equation modelling was used to test the proposed research hypotheses. The results identify a significant, positive and direct impact of users' participation on brand awareness. Brand attitude also substantially benefits from users' participation, but this relationship is mediated by brand awareness. The findings help to validate SNSs' significant role on building brand knowledge and to position users' participation at the core of brands' SNSs objectives. Furthermore, the study provides a practical research framework, easily adapted for

monitoring purposes and managerial guidance. Future research directions are discussed. © 2015 Taylor & Francis
http://dx.doi.org/10.1080/13527266.2015.1036100

152. L'Astorina, A., I. Tomasoni, A. Basoni, P. Carrara. Beyond the dissemination of Earth Observation research: Stakeholders' and users' involvement in project co-design. Journal of Science Communication, 2015. 14(3).
Modern technology and innovation research needs to analyse and collect users' requirements from the outset of the project's design, according to the Responsible Research and Innovation (RRI) approach. Bringing in new services without involving end-users in the whole research process does not make for optimal results in terms of scientific, technological and economic impact. This commentary reports on research experience of stakeholder involvement and co-production in Italy, implemented in Earth Observation downstream services at regional level. It reports the participative approach and method adopted and the impacts and benefits derived.

153. Lee, C., R. Myrick, D. Asai, J.F. Coughlin, O.L. De Weck, *LEARNING FROM A DESIGN EXPERIENCE: CONTINUOUS USER INVOLVEMENT IN DEVELOPMENT OF AGING-IN-PLACE SOLUTION FOR OLDER ADULTS,* in *Design for Harmonies, Vol 7: Human Behaviour in Design*, U. Lindemann, et al., Editors. 2013.

154. Lee, J.H., T.C. Li. Supporting user participation design using a fuzzy analytic hierarchy process approach. Engineering Applications of Artificial Intelligence, 2011. 24(5): p. 850-865.
There are three fundamental problems that may occur in the process of user participation design: first, the participants/users may not be able to express their requirements clearly; second, they have little knowledge about design; and third, they are generally unfamiliar with the software that designers use. Based on this understanding, a method that considers design rationale is proposed in this work to support the process of user participation design. In addressing the user participation process, a fuzzy analytic hierarchy process (AHP) approach is applied to grasp people's ideas, in the initial design phase. A case study on creating house layout design is employed to illustrate the proposed approach. In this regard, to help participants/users create layout designs, it is proposed that a 3D generative system is used, which integrates navigational concepts, direct manipulation, and the design rationale theory. In a nutshell, this research proposes a system to implement a design rational model and improve design communication in the user participation process. To demonstrate the effectiveness of the proposed prototype system, a user test is performed and we put forward some findings and research questions for further research and industry practices. (c) 2011 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.engappai.2011.01.008

155. LeGris, J., R. Weir, G. Browne, A. Gafni, L. Stewart, S. Easton. Developing a model of collaborative research: the complexities and challenges of implementation. International journal of nursing studies, 2000. 37(1): p. 65-79.
While the benefits of collaborative research have been well documented, fewer publications exist regarding the complex, problematic issues involved in these undertakings. This paper offers an integrated collaborative research model to depict the complexities and challenges of initiation and implementation of a 2 1/2 year joint research project between a community hospital and a university school of nursing in Southern Ontario, Canada. A sampling of the experiences of the researchers are analyzed to clarify the dynamic and often competing issues and interactions involved in encouraging hospital-wide research involvement during periods of organizational growth and change. The model reflects the simultaneous interaction of organizational, change

and collaborative processes while maintaining the rigor of the research (RCT), and ensuring minimal disruption to the service agency. Quantitative outcomes of this collaboration are presented through an analysis of participant involvement on multiple organizational levels. Recommendations for future collaborative research, including design and methodological issues and collaborative and change strategies are offered. The complexity of balancing the necessary trade-offs required of successful collaborative research are highlighted and will be useful to those considering and planning future collaborations.

156.   Leung, T.T.F. **The welfare service practitioners' perception of their power position in the user participation imperative**. Asia Pacific Journal of Social Work and Development, 2016. 26(4): p. 231-244.
        In the popular user participation rhetoric of social work practice, and amid the outcry for sharing power with the welfare service users when providers make service decisions, much research attention has been put on the circumstances that impeded the users' voices, presuming that the service practitioners actually have de facto power over the service users. Based on the findings of a participatory research project conducted in Hong Kong, this paper scrutinises this presumed position of power from the service providers' own perspective. Drawn from interviews of 47 service practitioners individually or in group, this phenomenological account is important for deciphering the conscious experiences that influence the service practitioners' actions and reactions within participative spaces.
        http://dx.doi.org/10.1080/02185385.2016.1201432

157.   Levy, S., R. Aiton, J. Doig, J.P.L. Dow, S. Brown, L. Hunter, R. McNeil. **Outcomes focused user involvement in social work education: applying knowledge to practice**. Social Work Education, 2016. 35(8): p. 866-877.
        This paper discusses an innovative approach connecting service user and carer involvement (SUCI) in social work education to social work practice. The research team, comprised service users, carers, social work students and module leader, worked collaboratively democratising the research process. At the University of Dundee, a core social work module facilitates students to spend 15 h with a service user and/or carer (host) gaining a unique insight into their everyday lives. During this time, hosts and students discuss two policy practice questions, responses to these questions are generating annual qualitative data, with study findings being disseminated at local and national level. The experiential learning students acquire from spending time with their host becomes the site of knowledge creation through involvement that is applied to practice. This paper reports on the narratives emerging from the longitudinal data (20122015, n = 90) on the changing landscape of social care in Scotland and the dissemination of project findings. We explore the intersection where the voices of service users and carers, student learning and social work practice coalesce. A model of outcomes focused SUCI is introduced as a template for meaningful, sustainable and outcomes-focused SUCI in social work education.
        http://dx.doi.org/10.1080/02615479.2016.1240160

158.   Li, K.K., J. Abelson, M. Giacomini, D. Contandriopoulos. **Conceptualizing the use of public involvement in health policy decision-making**. Social Science and Medicine, 2015. 138: p. 14-21.
        The concept of public involvement use is not well-defined in the literature. Previous research studies have provided brief accounts of how public involvement may influence health policy, but have not detailed the internal dynamics and process through which it is actually used in the policy process. The study objective is to examine and clarify the concept and process of public involvement use in health policy decision-making. Using qualitative concept analysis methods, we

reviewed the literature on the use of public involvement and conducted semi-structured interviews with key informants who have theoretical and/or practical insights on public involvement and its use in policy decision-making. Our findings are organized around interrelated questions that animate how the concept of use is understood, interpreted, and operationalized. In asking, "How is 'use' perceived in relation to health policy decision-making?" meanings are constructed for the concept by identifying differences and drawing connections between "use" and related terms. In asking "How would one know if public involvement was used in health policy decision-making?" our findings weigh in on the act of listening as a precursor to use, the ways in which use is mediated, and responses to the input obtained from public involvement processes as signals of use. These findings are a first step toward improving conceptual clarity about what public involvement use means, how it is understood and interpreted by relevant actors in the public involvement and public policy fields, and how it might be operationalized. We expect our findings to be particularly useful for public involvement practitioners who are often confronted with questions from public involvement participants regarding how their input will be used in health policy decision-making. © 2015 Elsevier Ltd.
http://dx.doi.org/10.1016/j.socscimed.2015.05.023

159.   Lichon, M., M. Kavcic, D. Masterson. **A comparative study of contemporary user involvement within healthcare systems across England, Poland and Slovenia**. Journal of Health Organization and Management, 2015. 29(5): p. 625-636.
Purpose - The purpose of this paper is to explore how healthcare-users' engagement is perceived, how it occurs and how these perceptions differ between three European countries: England, Poland and Slovenia, using the concepts of voice, choice and coproduction.
Design/methodology/approach - This comparative, qualitative study is based on a review of legal documents, academic literature and semi-structured interviews conducted in October and November 2011. A research sample consisted of 21 interviewees representing various stakeholders including healthcare-users, doctors and managers. Primary and secondary data were analysed using theoretical thematic analysis. Emerging themes were identified from the interviews and related to the indicators describing healthcare-users' involvement in the voice, choice and coproduction model. Findings - Results of the comparative qualitative research suggest that the healthcare-users' influence is strongly grounded in England where the healthcare system and professionals are prepared to include healthcare-users in the decision-making process. In Slovenia, cultural development of healthcare-users' involvement seems to proceed the institutional development. In Poland, institutions are ready to involve healthcare-users in decision-making process although the cultural desirability of involving users among doctors and patients is lacking. Originality/value - The notion of user involvement is increasingly gaining importance and research attention, yet there is still little known about the way cultural, political, historical differences between various European countries influence it. This paper explores this little known area using the original approach of user involvement (Dent et al., 2011) with input from various stakeholders including patients, healthcare representatives and academics.
http://dx.doi.org/10.1108/jhom-05-2014-0088

160.   Lin, W.T., B.B.M. Shao. **The relationship between user participation and system success: a simultaneous contingency approach**. Information & Management, 2000. 37(6): p. 283-295.
The relationship between user participation and information system (IS) success has drawn attention from researchers for some time. It is assumed that strong participation of future users in the design of IS would lead to successful outcomes in terms of more IS usage, greater user acceptance, and increased user satisfaction. However, in spite of this, much of the empirical

research so far has been unable to demonstrate its benefits. This paper examines the participation-success relationship in a broader context, where the effects of user participation and two other factors, user attitudes and user involvement, on system success occur simultaneously. Other contingency variables considered here are: system impact, system complexity, and development methodology. The theoretical framework and the associated hypotheses are empirically tested by a survey of 32 organizations. Empirical results corroborate the positive link between user participation and user satisfaction and provide evidence on the interplay between user attitudes and user involvement. (C) 2000 Elsevier Science B.V. All rights reserved.
http://dx.doi.org/10.1016/s0378-7206(99)00055-5

161.   Lindenmeyer, A., H. Hearnshaw, J. Sturt, R. Ormerod, G. Aitchison. ==Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: a qualitative case study==. Health Expectations, 2007. 10(3): p. 268-277.
Objective To assess the benefits of involving health-care users in diabetes research. Design and participants For this qualitative case study, semi-structured interviews were conducted with researchers who had worked extensively with the group. During regular meetings of the Research User Group, members discussed their views of the group's effectiveness as part of the meeting's agenda. Interviews and discussions were transcribed, coded using N-Vivo software and analysed using constant comparative methods. Results Involvement of users in research was generally seen as contributing to effective and meaningful research. However, the group should not be considered to be representative of the patient population or participants of future trials. An important contributor to the group's success was its longstanding nature, enabling users to gain more insight into research and form constructive working relationships with researchers. The user-led nature of the group asserted itself, especially, in the language used during group meetings. A partial shift of power from researchers to users was generally acknowledged. Users' main contribution was their practical expertise in living with diabetes, but their involvement also helped researchers to remain connected to the 'real world' in which research would be applied. While the group's work fulfilled established principles of consumer involvement in research, important contributions relying on personal interaction between users and researchers were hard to evaluate by process measures alone. Conclusions We demonstrated the feasibility, acceptability and effectiveness of this longstanding, experienced, lay-led research advisory group. Its impact on research stems from the continuing interaction between researchers and users, and the general ethos of learning from each other in an on-going process. Both process measures and qualitative interviews with stakeholders are needed to evaluate the contributions of service users to health research.
http://dx.doi.org/10.1111/j.1369-7625.2007.00451.x

162.   Lindgren, I., *Stakeholder Involvement in Public e-Service Development - Broadening the Scope of User Involvement*, in *Electronic Government and Electronic Participation*, M. Janssen, et al., Editors. 2014. p. 84-92.
163.   Litva, A., J. Coast, J. Donovan, J. Eyles, M. Shepherd, J. Tacchi, . . . K. Morgan. =='The public is too subjective': Public involvement at different levels of health-care decision making==. Social Science and Medicine, 2002. 54(12): p. 1825-1837.
There are a number of impulses towards public participation in health care decision making including instrumentalist, communitarian, educative and expressive impulses and the desire for increased accountability. There has, however, been little research looking systematically at the public's preferences for being involved in particular types of rationing decisions, nor indeed, has there been a critical examination of the degree of involvement desired by the public. The research

reported here uses findings from focus groups and in-depth interviews to explore these questions. Eight focus groups were conducted with a total of 57 informants, four amongst randomly selected members of the public and four with informants from health and non-health related organisations. Nineteen interviews were conducted to allow the elaboration of focus group comments, to probe views more deeply and to pursue emerging themes. The findings show variations in the willingness of members of the public to be involved in health care decisions and consistency across the different forms of the public as represented by the focus groups with randomly selected citizens and pre-existing organisations. There was a strong desire in all the groups for the public to be involved both at the system and programme levels, with much less willingness to be involved at the individual level. At the system and programme levels informants generally favoured consultation, without responsibility for decisions, but with the guarantee that their contribution would be heard and that decisions taken following consultation would be explained. At the patient level informants felt that the public should participate only by setting criteria for deciding between potential beneficiaries of treatment. The public has much to contribute, particularly at the system and programme levels, to supplement the inputs of health care professionals. © 2002 Elsevier Science Ltd. All rights reserved.
http://dx.doi.org/10.1016/S0277-9536(01)00151-4

164.   Locock, L., A.M. Boylan, R. Snow, S. Staniszewska. **The power of symbolic capital in patient and public involvement in health research**. Health Expectations, 2017. 20(5): p. 836-844.
BackgroundPolicy-makers and health research funders increasingly require researchers to demonstrate that they have involved patients in the design and conduct of research. However, the extent to which patients and public have the power to get involved on an equal footing is dependent on their economic, cultural, social and symbolic capital. ObjectiveTo explore power relations in patient and public involvement (PPI) in research, particularly how patients may wield symbolic capital to develop a more equal relationship. MethodsNarrative interviews with a maximum variation sample of 38 people involved as patients, carers or public in health research, analysed thematically. FindingsSymbolic capital may be demonstrated in a range of ways (sometimes alongside or in the absence of other forms of capital): illness experience, technical illness knowledge and the challenging outsider. Symbolic capital is unstable and dependent on others for recognition and legitimacy. Nonetheless, participants identify a gradual shift in power relations over time. Discussion and conclusionsResearch into PPI has been conceptually and theoretically poor, limiting our understanding of its mechanisms and wider contextual elements. Our findings demonstrate the importance of reflecting on the forms of power and capital wielded by the health research community, and of acknowledging the way in which PPI is challenging the status quo. As one of the first papers to conceptualize how different forms of symbolic capital operate and their critical role in challenging the balance of power, our findings may help researchers better plan their PPI activities and reflect on their own power.
http://dx.doi.org/10.1111/hex.12519

165.   Long, L. **User involvement in student selection**. Practising Midwife, 2010. 13(10): p. 26-27.

166.   MacInnes, D., D. Beer, P. Keeble, D. Rees, L. Reid. **Service-user involvement in forensic mental health care research: Areas to consider when developing a collaborative study**. Journal of Mental Health, 2011. 20(5): p. 464-472.
Background: Although service-users are increasingly involved in the conduct of research in mental health settings, involvement in forensic mental health settings is limited. Aims: This paper looks at the factors perceived by professionals and service-users as important for developing collaborative

research in forensic mental health settings. Method: Following a collaborative research project undertaken in three forensic mental health units, the researchers involved in the project (professionals and service-users) reviewed factors perceived as important for developing service-user research in secure settings. Results: Three broad themes were identified. The main issues considered within these themes were detailed. Conclusions: Service-users in forensic mental health settings are able to have full involvement in research. http://dx.doi.org/10.3109/09638231003728109

167.   Mackrill, J., P. Marshall, S.R. Payne, E. Dimitrokali, R. Cain. <mark>Using a bespoke situated digital kiosk to encourage user participation in healthcare environment design</mark>. Applied Ergonomics, 2017. 59: p. 342-356.
Involving users through participation in healthcare service and environment design is growing. Existing approaches and toolkits for practitioners and researchers are often paper based involving workshops and other more traditional design approaches such as paper prototyping. The advent of digital technology provides the opportunity to explore new platforms for user participation. This paper presents results from three studies that used a bespoke situated user participation digital kiosk, engaging 33 users in investigating healthcare environment design. The studies, from primary and secondary care settings, allowed participant feedback on each environment and proved a novel, engaging "21st century" way to participate in the appraisal of the design process. The results point toward this as an exciting and growing area of research in developing not just a new method of user participation but also the technology that supports it. Limitations were noted in terms of data validity and engagement with the device. To guide the development of user participation using similar situated digital devices, key lessons and reflections are presented. © 2016
http://dx.doi.org/10.1016/j.apergo.2016.08.005

168.   Maconochie, H., F. McNeill. **User involvement: children's participation in a parent-baby group**. Community practitioner : the journal of the Community Practitioners' & Health Visitors' Association, 2010. 83(8): p. 17-20.
According to the National Service Framework, children have a right to participate in the development of healthcare services and yet research suggests that young children are at risk of exclusion from user involvement initiatives. This paper outlines the findings of a participatory action research project conducted with families attending a health visitors' parent-baby group. A combination of participatory research methods were used to ascertain the infants' perspectives of the service and this led to a number of changes in terms of professional attitudes, service provision and working practices. Changes in professional attitudes included acknowledging the importance of social interaction to the children, recognising young children's views as embodied and produced within social interactions, and respecting children as active contributors and not simply as passive recipients of healthcare services. Changes in service provision resulted in redistributing resources, structures and spaces to take account of children's perspectives. Finally, reciprocity and responsiveness were seen as key components in enhancing young children's participation.

169.   Magal, S.R., K.C. Snead. **The Role of Causal Attributions in Explaining the Link Between User Participation and Information System Success**. Information Resources Management Journal (IRMJ), 1993. 6(3): p. 8-20.
Understanding the factors influencing information system (IS) effectiveness has been of considerable concern to IS researchers, with the role of user participation (UP) in IS success

receiving much attention. The inconclusive and often contradictory research results in this area of inquiry have been attributed to a lack of rigor in method and to the lack of consideration of various intervening mechanisms between UP and IS success. This paper develops a model to explain a potential link of UP with IS success; the model is based upon a synthesis of UP and IS success research coupled with principles of attribution theory. Attribution theory is the study of the process by which people associate causes to outcomes or events. This theory implies the need to consider IS users' causal attributions for the IS-related outcomes they experience, as the nature of these attributions will likely influence users' evaluation of the IS. In synthesizing IS and attribution theory, this paper proposes that users' causal attributions of success and failure subsequent to IS use, is one factor explaining the linkages between UP, beliefs, and IS success. It is argued that UP is a critical determinant of IS success to the extent that it influences beliefs that lead to users' attributions for IS related outcomes, and ultimately to their subjective evaluation and future use of the IS. Consequently, a model is proposed that permits a more meaningful examination of the role of UP in IS success. © 1993, IGI Global. All rights reserved. http://dx.doi.org/10.4018/irmj.1993070101

170. Magnusson, P.R., J. Matthing, P. Kristensson. **Managing User Involvement in Service Innovation: Experiments With Innovating End Users**. Journal of Service Research, 2003. 6(2): p. 111-124.
Although user involvement is frequently practiced in companies, the research findings regarding its benefits for innovation are contradictory. This article experimentally assesses the contributions made by users in comparison with professional service developers and examines how the implementation of user involvement affects the outcome. During periods of 12 days, three different groups were assigned the task of generating ideas for end user telecom services. One group consisted of professional de signers, whereas the other two consisted of ordinary users. The users in one of the groups coped with idea creation by themselves, whereas the other group consulted a service design expert at two controlled meetings who provided feedback regarding technical feasibility. Involving users makes the ideas more original, holding a higher perceived user value, but the users'ideas are less producible on aver-age. The outcome was also affected by how user involvement was implemented. Scholarly and managerial implications conclude the article. © 2003, SAGE Publications. All rights reserved. http://dx.doi.org/10.1177/1094670503257028

171. Maguire, K., E. Jones, B. Williams-Yesson, S. Stevens. <mark>Valuing patient and public involvement in research</mark>. Nursing Times, 2014. 110(45): p. 22-23.
Patient and public involvement is now mandatory in funding applications for most health sciences research. This article offers a snapshot of views from patients and the public on their role in the research process.

172. Majumdar, S.R. **The case of public involvement in transportation planning using social media**. Case Studies on Transport Policy, 2017. 5(1): p. 121-133.
Public involvement in transportation planning using social media is gaining much popularity in an open government era that emphasizes transparency and engagement of the public in meaningful ways. The recent advancements in communications technology have made it possible for many local government agencies, like regional transportation planning organizations, to use social media tools like Facebook, Twitter, Flickr, YouTube, and others to provide information to the public, educate them, and seek their inputs and ideas for meaningful decision making in transportation projects. This exploratory study has tried to gauge the extent of social media use in transportation planning among local government agencies and identify the challenges

encountered in its use. Using the survey instrument, data has been collected from the regional councils of government in the state of Texas. From the analysis of data, it is evident that fifty percent of local government agencies use social media for public involvement in transportation planning. Those who use social media, use it in a one way communication with people which often precludes their scope of participation. Among the non-users of social media, digital divide, absence of organizational policies and lack of knowledge on best practices serve as impediments. To make use of social media as a supplemental tool to traditional modes of public involvement in transportation planning, local governments need to develop distinct policies and invest resources. © 2016 World Conference on Transport Research Society
http://dx.doi.org/10.1016/j.cstp.2016.11.002

173. Martikainen, S., M. Korpela, T. Tiihonen. User participation in healthcare IT development: A developers' viewpoint in Finland. International Journal of Medical Informatics, 2014. 83(3): p. 189-200.

Background and purpose: Recent research showed that physicians in Finland were highly critical of their information technology (IT) systems. They were also critical of the methods of collaboration with the developers of the health IT systems (HITS) in use at the time of the questionnaire. This study turned the set-up around and asked systems developers the same questions about collaboration. What is developers' view on end user participation in HITS development at the moment? How would developers wish end users to participate in systems development? Do the developers' views differ from the physicians' (end users') views of the current state of collaboration in developing IT systems? Methods: A web-based questionnaire study was conducted in one of the major HITS provider companies in Finland among all developers, including software developers and customer support and sales personnel. Both quantitative and free-text questions of a previous study were adapted for the purpose. The responses were analyzed with qualitative and basic quantitative methods. Results: The response rate of the questionnaire was 37% and 136 responses were received. The developers who responded were experienced workers; 81% of the respondents had 6 years or more of work experience in IT systems development and 35% of them had 6 years or more of work experience in the healthcare domain. Almost three-quarters (72%) of the respondents agreed with the statement 'I work with users'. Almost all the developers (90%) thought that they are interested in user feedback and also 81% thought that they take the end users' opinions and experiences into account when developing software. A majority of the developers (57%) considered that corrections and modifications are currently not implemented quickly enough. The most popular means of user participation were that 'users would present their work and needs related to it in their workplace' (76%), followed by user groups (75%). The developers suggested many traditional user-centered and usability design methods, too. The developers' views were compared to the views of the physicians who primarily used the case company's products. The views were in direct opposition on whether developers are interested in end users' views (90% of the developers agreed, vs. 60% of the physicians disagreed) and take them into account (81% of the developers agreed, vs. 63% of the physicians disagreed), as well as on user groups (favored by 75% of the developers vs. 14% of the physicians). The majority of the respondents, both developers (57%) and physicians (74%), were dissatisfied with the pace of implementation of corrections and modifications. Conclusions: Both physicians and developers seem to be "willing but not able" to collaborate with each other. Possible reasons for the differences in views include the fact that there is no return channel of communication on what happened to the end users' feedback, and that developers collaborate with customer representatives who are not end users. It is obvious that there are one or more spots along the route between the "end developers" and

end users where there is a breakdown of the information flow. (C) 2013 Elsevier Ireland Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ijmedinf.2013.12.003

174.   Maslin-Prothero, S. <mark>Developing user involvement in research</mark>. Journal of Clinical Nursing, 2003. 12(3): p. 412-421.
        User involvement is central to the UK government's modernization agenda for the National Health Service (NHS). This paper represents work undertaken for the NHS National Cancer Research and Development Programme and NHS Executive Trent. It includes reflection on the experience of user involvement in health care research drawing on current UK health policy documents and an examination of the factors affecting recruitment to breast cancer clinical trials, and contributes to the debate on recruitment to clinical trials. Reference to UK policy documents is made throughout as well as real life experience of involving users in research. It summarizes key issues that nurses and midwives must consider to ensure effective user participation in research and practice.
        http://dx.doi.org/10.1046/j.1365-2702.2003.00755.x

175.   Masood, E. Britain opens biotech regulation to greater public involvement. Nature, 1999. 399(6734): p. 287-288.
                http://dx.doi.org/10.1038/20482

176.   Mathisen, V., G.F. Lorem, A. Obstfelder, P. Maseide. Whose decision is it anyway? A qualitative study of user participation and how clinicians deal with the patient perspective in mental healthcare. Mental Health Review Journal, 2016. 21(4): p. 249-260.
        Purpose - The concept of user participation is well accepted internationally. Nevertheless, studies show that both patients and health professionals find it challenging to maintain patient-centred ideals in the context of severe mental illness. The purpose of this paper is to explore how professionals deal with the ideals in light of patients' right to participate in planning and decision making regarding milieu therapeutic measures and activities. Design/methodology/approach - This is a qualitative study with an interactionist approach based on fieldwork at three district psychiatric centres in Norway during 2011-2012. The observations focused on patient-staff interaction in milieu therapeutic activities. Interviews were based on observed situations. Findings - Adherence to treatment, rules and routines restricted patient autonomy. The professionals' practical orientation towards routines overrode the ideals of patients' rights. The staff regarded user participation primarily as participation in organised and mandatory activities. Refusal to comply was met with different sanctions, e.g. the prospect of being discharged. Originality/value - Although user participation calls for patient-centred approaches, there is some debate about the challenges and premises for cooperation with persons suffering from severe mental conditions. This study adds insight into the everyday organisational context that facilitates or impedes user participation. It helps to explain why the user perspective can be overlooked, thus providing important information to both clinicians and policy makers who aim to fulfil the patient's right to participate in planning and decision making regarding treatment and care.
        http://dx.doi.org/10.1108/mhrj-01-2016-0003

177.   McAndrew, S., G.A. Samociuk. Reflecting together: Developing a new strategy for continuous user involvement in mental health nurse education. Journal of Psychiatric and Mental Health Nursing, 2003. 10(5): p. 616-621.
        This paper explores the first issues encountered when establishing a method of service user

involvement in the preparation of a cohort of mental health nursing students during their branch programme. The method involved the creation of a group of service users and students whose purpose was to jointly reflect upon mental health issues. To do this students are expected to use their experience from practice placements and the service users to use their experiences as recipients of mental health services. This approach is being investigated through research utilizing an evaluative case study with features of action research incorporated into the design. The findings to date, which concern the process of negotiation, pre-study attitudinal survey and the first group process, will be presented. This will offer mental health professionals the opportunity to gain insight into one approach of actively involving service users in programmes of higher education over a sustained period of time. Reflection on practice themes will include: collaborative strategy, evaluative case study, education, mental health nursing, reflection on practice, and service-user involvement.
http://dx.doi.org/10.1046/j.1365-2850.2003.t01-1-00609.x

178. McNichol, E., P. Grimshaw. <mark>An innovative toolkit: increasing the role and value of patient and public involvement in the dissemination of research findings</mark>. International Practice Development Journal, 2014. 4(1): p. 1-14.
Background: Evidence of patient and public involvement (PPI) in health research dissemination is weak and the development of mechanisms to assist the adoption and diffusion of PPI outcomes into research findings, patient experience and clinical practice is at an early stage. Aim: This paper seeks directly to address this weakness by increasing researchers' awareness and understanding of the potential value of PPI in dissemination and identifying practical strategies that could improve the quality and impact of PPI by connecting the process with the wider innovation literature on adoption and diffusion. The toolkit: Guidance for these strategies is provided in the form of a toolkit that elevates the importance of PPI in dissemination of research and blends it with good practice in diffusion of innovations. It highlights how planning for PPI and dissemination at each stage of the research cycle facilitates the diffusion of research findings, while generating a culture of knowledge exchange with important stakeholders. Conclusions: Establishing and improving PPI dissemination in the research process has similarities with introducing any new innovation into a social context. Therefore, understanding and integrating insights from the literature on adoption and diffusion and linking them to PPI and the research cycle provides a different frame of reference for developing our approach in healthcare. Here we connect PPI to the adoption literature and suggest that a strong focus on the social nature of innovation will increase the reach and impact of research dissemination. This challenges the traditional research culture and suggests a need for a more open and continuous web of PPI relationships that are characterised by well balanced, timely contact and consist of appropriate and flexible interactions, planned into the whole research cycle. Implications for practice: This paper highlights the value of taking a structured approach to PPI and the importance of investing time in developing productive PPI relationships at the beginning of a project. Similarly, dissemination should be planned for and undertaken at key points and in different ways throughout the process in order to maximise its potential impact. The key implications are the value of: • Widening the scope of PPI dissemination into the whole research cycle • Opening up routes to improved research impact through better quality patient involvement • Challenging the stereotypical relationship between researcher and patient • Introducing innovation adoption concepts into PPI dissemination [ABSTRACT FROM AUTHOR]

179.   Messina, J., D.L. Grainger. **A pilot study to identify areas for further improvements in patient and public involvement in health technology assessments for medicines**. Patient, 2012. 5(3): p. 199-211.
Background: Patient and public participation in health technology assessment (HTA) of medicines has been cited as an important component of the decisionmaking structure; however, how to actually achieve meaningful involvement is less understood. Objectives: Our objectives were to conduct a pilot study to form the basis of future research and to gain insight into how to practically and meaningfully advance patient and public input in HTAs for medicines. Methods: Semi-structured interviews (n = 13) with informants in Australia (n = 7), Canada (n = 3), and the UK (n = 3) were conducted across agencies and experts (n = 9), as well as patient and advocacy groups (n = 4). Results: This pilot study identified through structured interviews three areas for further consideration. Advancement area 1 indicates that industry could help bring the patient perspective into the HTA process through incorporating patient experiences early in the drug development process and by including qualitative research on patient experiences in HTA dossiers. Advancement area 2 involves recognizing and supporting the role of patient advocacy groups, and making use of their access to the genuine patient perspective and experience of living with the condition in question. Finally, advancement area 3 is the continuous development of HTA systems and processes to better facilitate involvement, increasing transparency and feedback, exploring new options for reaching patients, and focusing on creating an active and informed health consumer. Conclusions: The HTA process is becoming increasingly transparent to patients and the public; however, more effort is required to fully engage patients in the decision-making processes for medicine HTAs. This pilot study identified three key areas for further advancement in this field, and recognized a need for further research in the areas of measuring the impact of patient engagement on decision making in medicine HTAs, as well as the best methods to better prepare patient advocacy groups through HTA education and training. These research recommendations will form the basis of a future study with a larger, more comprehensive sample.© 2012 Springer International Publishing AG. All rights reserved. http://dx.doi.org/10.2165/11597080

180.   Miglarese, J.V., R.H. Boyles, *The Charleston Bump: Policy context and public involvement*, in *Island in the Stream: Oceanography and Fisheries of the Charleston Bump*, G.R. Sedberry, Editor 2001. p. 235-240.

181.   Milewa, T. **User participation in service planning. A qualitative approach to gauging the impact of managerial attitudes**. Journal of management in medicine, 1997. 11(4): p. 238-245.
It is often suggested that professional and managerial attitudes significantly delimit the impact of new structures for enhancing the role and influence of service users in health and social care planning. Considers the existence and clarity of such managerial attitudes in the context of one attempt to involve users in mental health care planning. The existence of latent and explicit managerial parameters to the role played by users in the planning of services was confirmed by the research at a very general level. Perhaps inevitably though, even in relation to a very specific user participation project, these parameters became less uniform as more detailed issues were considered. This suggests that an investigative focus on the "process" oriented attitudes and assumptions of managers and professionals, although important, should not be allowed to detract from a concern with gauging the demonstrable outcomes of user participation.

182.   Millar, S.L., M. Chambers, M. Giles. Service user involvement in mental health care: an evolutionary concept analysis. Health Expectations, 2016. 19(2): p. 209-221.
BackgroundThe concept of service user involvement is an evolving concept in the mental health-care literature. ObjectiveThis study sought to explore and analyse the concept of service user involvement as used in within the field of mental health care. Methodological approachAn evolutionary concept analysis was conducted using a literature-based sample extracted from an electronic database search. One hundred and thirty-four papers met the inclusion criteria and were analysed to discover key attributes, antecedents and consequences of service user involvement and to produce a definition of the concept. FindingsFive key attributes of service user involvement within the context of mental health care were identified: a person-centred approach, informed decision making, advocacy, obtaining service user views and feedback and working in partnership. Discussion and conclusionsClarity of the attributes and definition of the concept of service user involvement aims to promote understanding of the concept among key stakeholders including mental health professionals, service users and community and voluntary organizations. The findings of the research have utility in the areas of theory and policy development, research on service user involvement in mental health care and service user involvement in mental health practice. Directions for further research regarding the concept are identified.
http://dx.doi.org/10.1111/hex.12353

183.   Minogue, V., J. Boness, A. Brown, J. Girdlestone. The impact of service user involvement in research. International Journal of Health Care Quality Assurance, 2005. 18(2): p. 103-112.
Purpose - There are many examples of consumer involvement in NHS research but few studies have examined the impact of this on service development or the research process. This study, involving service user and carer researchers working alongside professional researchers, aimed to examine the development of one service user and carer research group in a mental health Trust. Dersign/methodology/approach - The research involved a review of existing literature on consumer involvement in research, a review of user involvement in research in South West Yorkshire Mental Health NHS Trust, a survey of consumers and NHS staff in the Trust, and a skills audit and training needs analysis of consumers. Findings - The study identified the range and extent of consumer involvement and the impact of this on consumers and the Trust. Service users and carers were involved in a range of projects, mainly on the level of consultation or collaboration. The benefits for consumers were principally on a personal level and included gaining knowledge and experience, improved sense of well-being, self esteem, and confidence. The benefit for the Trust was in having a service user perspective and focus. However, there is a tendency to omit service users from planning and setting priorities. Practical implications - The study pointed to the need to build the evidence base on consumer involvement in research, particularly in terms of how consumers can impact on setting research priorities and selecting appropriate methods. It identifies the need for more training for consumers and for NHS staff and for a more coherent strategy. Originality/value - This article will be of value to anyone who is at the start or in the early stages of their journey of consumer involvement. It identifies some of the practical issues faced by consumers and staff in working collaboratively, but also points to the benefits for all the stakeholders. © Emerald Group Publishing Limited.
http://dx.doi.org/10.1108/09526860510588133

184.   Mjosund, N.H., M. Eriksson, G.A. Espnes, M. Haaland-Overby, S.L. Jensen, I. Norheim, . . . H.F. Vinje. Service user involvement enhanced the research quality in a study using interpretative phenomenological analysis - the power of multiple perspectives. Journal of Advanced Nursing,

2017. 73(1): p. 265-278.

AimThe aim of this study was to examine how service user involvement can contribute to the development of interpretative phenomenological analysis methodology and enhance research quality. BackgroundInterpretative phenomenological analysis is a qualitative methodology used in nursing research internationally to understand human experiences that are essential to the participants. Service user involvement is requested in nursing research. DesignWe share experiences from 4years of collaboration (2012-2015) on a mental health promotion project, which involved an advisory team. MethodsFive research advisors either with a diagnosis or related to a person with severe mental illness constituted the team. They collaborated with the research fellow throughout the entire research process and have co-authored this article. We examined the joint process of analysing the empirical data from interviews. Our analytical discussions were audiotaped, transcribed and subsequently interpreted following the guidelines for good qualitative analysis in interpretative phenomenological analysis studies. ResultsThe advisory team became the researcher's helping hand'. Multiple perspectives influenced the qualitative analysis, which gave more insightful interpretations of nuances, complexity, richness or ambiguity in the interviewed participants' accounts. The outcome of the service user involvement was increased breadth and depth in findings. ConclusionService user involvement improved the research quality in a nursing research project on mental health promotion. The interpretative element of interpretative phenomenological analysis was enhanced by the emergence of multiple perspectives in the qualitative analysis of the empirical data. We argue that service user involvement and interpretative phenomenological analysis methodology can mutually reinforce each other and strengthen qualitative methodology.
http://dx.doi.org/10.1111/jan.13093

185. Moffat, M., J. Cleland, T. van der Molen, D. Price. **Poor communication may impair optimal asthma care: A qualitative study**. Family Practice, 2007. 24(1): p. 65-70.
Background. Despite asthma being primarily managed in general practice and primary care, there is little research into the issues and tools which may impact on managing poorly controlled asthma in this setting. Objective. To explore the views of health care professionals (HCPs) towards asthma guidelines and self-management plans (SMPs) to identify why these are not used routinely in general practice. Methods. Data from 54 HCPs [GPs and practice nurses (PNs)] in north-east Scotland were collected via qualitative interviews and focus groups. Participant views and experience of asthma guidelines and SMPs were explored. Results. Participants had mainly positive attitudes towards guidelines and SMPs, although both were used only when deemed suitable by the individual. Suitability depended on individual patient issues (e.g. psychosocial factors, level of control) and/or professional issues (e.g. ease of use, time available, job roles). Patient issues were viewed as impacting on asthma control directly and, indirectly, as the main reason for not using guidelines or SMPs with a patient. HCPs reported lacking necessary communication skills for dealing with patient asthma control issues, particularly where these were non-medical. Professional and organizational issues such as training and communication were also perceived as impairing asthma management. Conclusion. Our findings indicate that guidelines are seen as providing the 'why' of helping asthma patients' self-manage but not the 'what to... or 'how to...' communicate. Poor professional-patient communication seems largely to explain the poor uptake of SMPs and guideline use in general practice and primary care. This limitation is more obvious to professionals when they are working with patients with poorly controlled asthma. There is a need to identify key communication skills for effective professional-patient partnership in adult asthma management, and to develop robust strategies for effectively training GPs and PNs in enhancing these skills. © 2007 Oxford University Press.

http://dx.doi.org/10.1093/fampra/cml062

186.   Molin, J.F., C.C. Konijnendijk van den Bosch. <mark>Between Big Ideas and Daily Realities - The roles and perspectives of Danish municipal green space managers on public involvement in green space maintenance</mark>. Urban Forestry and Urban Greening, 2014. 13(3): p. 553-561.
Public involvement (PI) in green space maintenance activities has increased during the past decades. The various (potential) benefits of PI have been recognised. Denmark, however, has no established tradition for such activities, despite its well-established tradition of volunteering. Local authorities have traditionally been the sovereign entity within public green space management, reflecting a hierarchical mode of governance. Yet, an increased call for new forms of local democracy and for new governance modes has resulted in growing attention for PI practices. Hence more knowledge is needed, for example on ongoing changes in governance arrangements regarding municipal green space.This paper thus aims to gain insight into (a) current governance arrangements with respect to municipal green space maintenance as well as temporal changes in these and (b) the consequences of the former for governmental actors and municipal managers in particular. An analytical framework based on governance theory and the Policy Arrangement Approach was developed to meet these aims. Data was collected by means of selected semi-structured interviews with green space managers from ten Danish municipalities.Findings show that green space PI occurred in all ten municipalities and thus that governance arrangements had started to include non-government actors, signalling a possible shift to co-governance from more common hierarchical governance modes. Green space managers felt themselves often ill-prepared for new governance arrangements and PI, e.g. in terms of lack of training and expertise. They based themselves strongly on their own experiences and preferences. More responsibility had been allocated to citizens, but often only to a select group of those who were already organised and/or had good connections with local authorities (i.e. closed co-governance). Green space managers listed a number of benefits of PI, generally adhering to the prevailing discourse of more co-governance. However, they also noted a number of challenges, including discrepancies between current maintenance practices and more PI. These, as well as a wider understanding of changing governance arrangements in green space management and maintenance, need to be addressed in future research. © 2014 Elsevier GmbH. http://dx.doi.org/10.1016/j.ufug.2014.03.006

187.   Morrow, E., F. Ross, P. Grocott, J. Bennett. <mark>A model and measure for quality service user involvement in health research</mark>. International Journal of Consumer Studies, 2010. 34(5): p. 532-539.
In the UK, researchers across the health professions are increasingly being encouraged by policymakers and research commissioners to 'involve' service users in research. A recent review shows there is some evidence that involving patients, carers, relatives, social or community groups directly and actively as part of the research process can improve the conduct of research studies and the impact of the findings. Yet, little is known about how involvement is played out within research studies and there is a need for more critical and consistent assessment of what constitutes quality involvement. The overall purpose of this paper is to support learning about quality service user involvement in health care research. The aim is to provide service users and researchers with a structured and consistent way to reflect and report on their experiences. A range of philosophical and social theories of power and empowerment were reviewed and synthesized to create a model of quality involvement. The analysis encompassed both service user factors (what a person feels able to do, whether they feel their potential is being fulfilled and their sense of being valued) alongside research factors (research relationships, ways of doing research,

research structures). A model is presented (Quality Involvement Framework), which contributes theoretically informed perspectives about the meaning and assessment of quality service user involvement in research. The model is developed as a practical measure (a Quality Involvement Questionnaire) for researchers and service users to be more reflective about the constraints and possibilities of involvement. The tools presented here could help research teams to examine personal factors and the research contexts that influence the nature and quality of service user involvement in research. They may also help to identify reoccurring issues about quality which could inform future policy, practice and research.
http://dx.doi.org/10.1111/j.1470-6431.2010.00901.x

188.   Moule, P., R. Davies. **A devolved model for public involvement in the field of mental health research: case study learning**. Health Expectations, 2016. 19(6): p. 1302-1311.
The article offers information on a case study on public involvement in mental health research. Topics discussed include usage of knowledge of local people for implementation of personalized budgets, supporting recruitment and experience of working on devolved model with user-led organizations and challenges faced while implementing the model.
http://dx.doi.org/10.1111/hex.12426

189.   Muresan, M., E. Gogu, *SMEs' Public Involvement in the Regional Sustainable Development*, in *World Conference on Business, Economics and Management*, A.I. Lacob, G.A. Baskan, and H. Uzunboylu, Editors. 2012. p. 253-257.

190.   Nembhard, I.M., A.L. Tucker. **Applying Organizational Learning Research to Accountable Care Organizations**. Medical Care Research and Review, 2016. 73(6): p. 673-684.
To accomplish the goal of improving quality of care while simultaneously reducing cost, Accountable Care Organizations (ACOs) need to find new and better ways of providing health care to populations of patients. This requires implementing best practices and improving collaboration across the multiple entities involved in care delivery, including patients. In this article, we discuss seven lessons from the organizational learning literature that can help ACOs overcome the inherent challenges of learning how to work together in radically new ways. The lessons involve setting expectations, creating a supportive culture, and structuring the improvement efforts. For example, with regard to setting expectations, framing the changes as learning experiences rather than as implementation projects encourages the teams to utilize helpful activities, such as dry runs and pilot tests. It is also important to create an organizational culture where employees feel safe pointing out improvement opportunities and experimenting with new ways of working. With regard to structure, stable, cross-functional teams provide a powerful building block for effective improvement efforts. The article concludes by outlining opportunities for future research on organizational learning in ACOs.
http://dx.doi.org/10.1177/1077558716640415

191.   Nyborg, I., L.J. Danbolt, M. Kirkevold. **User participation is a family matter: A multiple case study of the experiences of older, hospitalised people and their relatives**. Journal of Clinical Nursing, 2017.
Aims and objectives: The purpose of this multiple case study was to compare and contrast older people's and their relatives' experiences of participation in decision-making processes regarding the planning of everyday life after discharge from hospital. Background: Internationally, patient involvement in health services is established to benefit patient health and to improve quality of the services. The literature shows that at hospital discharge, older people would benefit from better communication and more active participation of relatives in the discharge planning. Little research has been carried out on the experiences of patients and relatives as a family in this

context, and even less has investigated their participation. Design: This study used a qualitative design with a comparative multicase approach. Participants were recruited from two hospitals in Norway using a purposive sampling strategy. Methods: Semi-structured interviews were conducted with five patients and with six of their relatives. Results: Three patterns of experiences were identified: contradicting experiences; consistent experiences of nonpreferred participation; similar, but separate experiences of user participation. Conclusions: User participation in the planning of everyday life following discharge appeared to be random and limited for both patients and their relatives, and conflicting for the families as a whole. The decision-making processes seemed to be limited to the hospital context and did not include the broader context of everyday life following discharge. Relevance to clinical practice: The results underscore the importance of taking a family perspective when caring for older people. Family meetings might be a useful tool to ensure systematic assessment and integration of the perspectives of both older people and their family in the planning of follow-up care. © 2017 John Wiley & Sons Ltd. http://dx.doi.org/10.1111/jocn.13765

192.   Obeid, A. **Perceptions of user participation in health care**. Journal of Community Nursing, 2000. 14(4): p. XIII-XIV.
In the first of three articles Amira Obeid describes her grounded theory study on health visitors perceptions of user participation in health care. © PTM Publishers Limited.

193.   Oeye, C., A.K. Bjelland, A. Skorpen, N. Anderssen. **User participation when using milieu therapy in a psychiatric hospital in Norway: A mission impossible?** Nursing Inquiry, 2009. 16(4): p. 287-296.
User participation when using milieu therapy in a psychiatric hospital in Norway: a mission impossible? In the past decade, the Norwegian government has emphasized user participation as an important goal in the care of mentally ill patients, through governmental strategic plans. At the same time, the governmental documents request normalization of psychiatric patients, including the re-socialization of psychiatric patients back into society outside the psychiatric hospital. Milieu therapy is a therapeutic tool to ensure user participation and re-socialization. Based on an ethnographic study in a long-term psychiatric ward in a psychiatric hospital, we identified how staff tried to implement user participation in their milieu-oriented therapy work. We have identified three major tensions and challenges in implementing user participation in milieu-therapeutic work. First, it is difficult to implement individual-based user participation and at the same time take collective house rules and codes of conduct into consideration. Second, user participation proved a difficulty when patients' viewpoints challenged staff judgements on proper conduct and goals for which patients might aim. Third, user participation becomes a challenge when trying to establish relationships based on equality when using milieu therapy in a biomedical hierarchical hospital structure. These tensions and challenges are seen in light of paradoxical political frames and demands on one side, and milieu therapy as a complex tradition anchored in different ideologies on the other. © 2009 Blackwell Publishing Ltd. http://dx.doi.org/10.1111/j.1440-1800.2009.00463.x

194.   Oguz, F., M. Holt. **Library blogs and user participation: A survey about comment spam in library blogs**. Library Hi Tech, 2011. 29(1): p. 173-188.
Purpose: The purpose of this research is to identify and describe the impact of comment spam in library blogs. Three research questions guided the study: current level of commenting in library blogs; librarians' perception of comment spam; and techniques used to address the comment spam problem. Design/methodology/approach: A quantitative approach is used to investigate research questions. Informal interviews were conducted with four academic and three public

libraries with active blogs to develop a better understanding of the problem and then to develop an appropriate data collection instrument. Based on the feedback received from these blog administrators, a survey questionnaire was developed and then distributed online via direct e-mailing and mailing lists. A total of 108 responses were received. Findings: Regardless of the library type with which blogs were affiliated with and the size of the community they served, user participation in library blogs was very limited in terms of comments left. Over 80 percent of libraries reported receiving five or fewer comments in a given week. Comment spam was not perceived to be a major problem by blog administrators. Detection-based techniques were the most commonly used approaches to combat comment spam in library blogs. Research limitations/implications: The research focuses on the comment spam problem in blogs affiliated with libraries where the library is responsible for content published on the blog. The comment spam problem is investigated from the library blog administrator's perspective. Practical implications: Results of this study provide empirical evidence regarding level of commenting and the impact of comment spam in library blogs. The results and findings of the study can offer guidance to libraries that are reconsidering whether to allow commenting in their blogs and to those that are planning to establish a blog to reach out to their users, while keeping this online environment engaging and interactive. Originality/value: The study provides empirical evidence that level of commenting is very limited, comment spam is not regarded as an important problem, and it does not interfere with the communication process in library blogs. © Emerald Group Publishing Limited.
http://dx.doi.org/10.1108/07378831111116994

195.   Okamoto, M., Y.I. Nakano, T. Nishida, *Toward enhancing user involvement via empathy channel in human-computer interface design*, in *Intelligent Media Technology for Communicative Intelligence*, L. Bolc, Z. Michalewicz, and T. Nishida, Editors. 2004. p. 111-121.

196.   Oliver, S., D.G. Armes, G. Gyte. **Public involvement in setting a national research agenda: A mixed methods evaluation**. Patient, 2009. 2(3): p. 179-190.
Background: A growing body of literature supports the inclusion of patients, other service users, and the wider public in guiding health technology assessment, particularly in relation to interventions and outcomes for evaluative studies. Objective: To describe the input and influence of public involvement in setting the agenda for a national research program. Methods: The data source was the commissioned research of the UK National Health Service Health Technology Assessment (HTA) program, 1999?2004. The study consisted of a mixed methods evaluation employing document analyses, key informant interviews, and structured non-participant observations. Routine management records of the HTA program were examined for public influence on research topics. The nature and influence of contributions from the public were compared with those of other experts. Structured observations of advisory panel meetings investigated how discussion and decisions related to patient and public perspectives and how panel members responded to public input to the program. Semi-structured interviews gathered the perceptions of staff and advisory panel members. Results: The public provided unique contributions both as external experts and as panel members. The value and influence of many of these contributions were acknowledged by staff and panel members. Input from external public experts was least where recruitment was passive (through a website) and where contributions were required in a research question format that may have been unfamiliar to non-researchers. However, public influence at this stage was at least of the same order as that of professional suggestions. Input was most where recruitment effort was greater, where contributions could be made in an open format, and where the responsibility for integrating these into a research question format lay with research program staff. Public experts contributing at this stage often

influenced research plans. Their contributions resulted in some important changes, including making patient and carer perspectives explicit, changing the focus of the research, adding new outcomes, refuting the need for the planned research, providing up-to-date prevalence data, and providing plain English background text. At their best, public members of advisory panels were seen as providing useful comment and encouraging greater sensitivity to patient perspectives among other panel members. At their worst, they were seen as lobbying for particular patient groups. Conclusions: Public involvement has influenced decisions about research commissioned by the HTA program with only relatively minor changes to the procedures and resources for managing the program required. This results in outcomes research that incorporates patient and public preferences and values, and that is freely available for evidence-informed health services. © 2009 Adis Data Information BV. All rights reserved.
http://dx.doi.org/10.2165/11314860

197. Oliver, S., K. Liabo, R. Stewart, R. Rees. ==Public involvement in research: making sense of the diversity==. Journal of Health Services Research & Policy, 2015. 20(1): p. 45-51.
This paper presents a coherent framework for designing and evaluating public involvement in research by drawing on an extensive literature and the authors' experience. The framework consists of three key interrelated dimensions: the drivers for involvement; the processes for involvement and the impact of involvement. The pivotal point in this framework is the opportunity for researchers and others to exchange ideas. This opportunity results from the processes which bring them together and which support their debates and decisions. It is also the point at which research that is in the public interest is open to public influence and the point at which the interaction can also influence anyone directly involved. Judicious choice of methods for bringing people together, and supporting their debate and decisions, depends upon the drivers of those involved; these vary with their characteristics, particularly their degree of enthusiasm and experience, and their motivation.
http://dx.doi.org/10.1177/1355819614551848

198. Oliver, S.R., R.W. Rees, L. Clarke-Jones, R. Milne, A.R. Oakley, J. Gabbay, . . . G. Gyte. **A multidimensional conceptual framework for analysing public involvement in health services research**. Health Expectations, 2008. 11(1): p. 72-84.
Objective: To describe the development of a multidimensional conceptual framework capable of drawing out the implications for policy and practice of what is known about public involvement in research agenda setting. Background: Public involvement in research is growing in western and developing countries. There is a need to learn from collective experience and a diverse literature of research, policy documents and reflective reports. Methods: Systematic searches of research literature, policy and lay networks identified reports of public involvement in research agenda setting. Framework analysis, previously described for primary research, was used to develop the framework, which was then applied to reports of public involvement in order to analyse and compare these. Findings: The conceptual framework takes into account the people involved; the people initiating the involvement; the degree of public involvement; the forum for exchange; and methods used for decision making. It also considers context (in terms of the research focus and the historical, geographical or institutional setting), and theoretical basis. Conclusions: The framework facilitates learning across diverse experiences, whether reported in policy documents, reflections or formal research, to generate a policy- and practice-relevant overview. A further advantage is that it identifies gaps in the literature which need to be filled in order to inform future research about public involvement. © 2008 The Authors.
http://dx.doi.org/10.1111/j.1369-7625.2007.00476.x

199.   Omeni, E., M. Barnes, D. MacDonald, M. Crawford, D. Rose. <mark>Service user involvement: Impact and participation: A survey of service user and staff perspectives</mark>. BMC Health Services Research, 2014. 14(1).
Background: Over the last 20 years governments around the world have promoted user involvement in an effort to improve the quality of health services. Despite the growing emphasis placed on user involvement in England, there is a paucity of recent studies looking at how service users and professionals perceive the outcomes of user involvement policies. This study aimed to examine the overall levels of participation in service user involvement in mental health services among professionals and service users and ascertain their views on the impact of involvement activity on various areas of service delivery. Methods: A cross-sectional survey of service users and providers within community mental health services. The sampling was carried out across three mental health Trusts, two serving people living in inner-city areas and a third covering a mixed rural/urban population. A questionnaire with closed and open ended questions was used to gather the responses of service users and frontline professionals. As a mixed methods study, the analysis consisted of both quantitative and qualitative approaches. Results: Three hundred and two service users responded to the survey with a response rate of 48%. One hundred and forty three frontline mental health professionals, 26.8% of those approached submitted questionnaires. Almost half of service users (N=138, 45.7%,) and healthcare professionals (N=143, 55.9%) reported having been involved in some form of user involvement activity. Although there were some differences in the responses of service users and frontline professionals, both groups reported that service user involvement was having a positive impact. Conclusions: The findings show that, within the three mental health trusts examined in this study, service user involvement has become widespread and is perceived by both staff and service users to be a good policy. The study had some important limitations. The questionnaire used was based on existing literature, however it was not subjected to psychometric testing. In addition, response rates were low, particularly among professionals. Despite the limitations, the findings are encouraging, offering important of insight into views and experiences of service users and healthcare staff. Further studies are needed to assess and investigate the topic on a national level. © 2014 Omeni et al. http://dx.doi.org/10.1186/s12913-014-0491-7

200.   Owens, C., G. Owen, H. Lambert, J. Donovan, J. Belam, F. Rapport, K. Lloyd. **Public involvement in suicide prevention: Understanding and strengthening lay responses to distress**. BMC Public Health, 2009. 9.
Background. The slogan "Suicide prevention is everyone's business" has been used in a number of campaigns worldwide in recent years, but most research into suicide prevention has focused on the role of medical professionals in identifying and managing risk. Little consideration has been given to the role that lay people can play in suicide prevention, or to the resources they need in order to do so. The majority of people who take their own lives are not under the care of specialist mental health services, and around half have not had recent contact with their general practitioner. These individuals are not known to be 'at risk' and there is little or no opportunity for clinical intervention. Family members and friends may be the only ones to know that a person is troubled or distressed, and their capacity to recognise, assess and respond to that distress is therefore vitally important. This study aims to discover what the suicidal process looks like from the point of view of relatives and friends and to gain insight into the complex and difficult judgements that people have to make when trying to support a distressed individual. Methods/Design. The study uses qualitative methods to build up a detailed picture of 15-20 completed suicides, aged 18-34. Data are gathered by means of in-depth interviews with relatives,

friends and others who knew the deceased well. In each case, as many informants as possible are sought using a purposive snowballing technique. Interviews focus on the family and social network of the deceased, the ways in which relatives and friends interpreted and responded to his/her distress, the potential for intervention that may have existed within the lay network and the knowledge, skills and other resources that would have helped members to support the distressed individual more effectively. Discussion. The study will inform interventions to promote public mental health awareness and will provide a basis on which to develop community-focussed suicide prevention strategies.
http://dx.doi.org/10.1186/1471-2458-9-308

201.   Patterson, S., T. Weaver, K. Agath, E. Albert, T. Rhodes, D. Rutter, M. Crawford. 'They can't solve the problem without us': A qualitative study of stakeholder perspectives on user involvement in drug treatment services in England. Health and Social Care in the Community, 2009. 17(1): p. 54-62.
Providers of public health care are under pressure to involve service-users in service development. This pressure emanates from legislators and the public who promote user involvement (UI), as a 'means to an end' and/or 'an end in itself'. Case studies in six English commissioning areas explored the process and purpose of UI in drug treatment services. In-depth interviews with 139 respondents who commission, manage, deliver or use services were conducted. We identified 'non-', 'passive-' and 'active participant' users. Active users were commonly motivated by a desire for social justice, a social conscience and personal development. UI was evidently influenced by multiple social organizational and personal factors. Some 'generic' factors have been reported in other settings. However, the illegality of drug use powerfully affects all stakeholders creating a context unique to drug treatment settings. Stigma and power imbalances were pervasive, and strong tensions concerning the goal and purpose of UI were apparent. Within the UK context, we identified five organizational approaches to UI. Based on rationale and objectives of UI, and the scope of influence accorded users, organizations could be characterised as protagonists, pragmatists, sceptics, abstainers or avoiders. We conclude that many tensions apparent in local level UI have roots in UI policy, which is ambiguous about: (1) benefit and rights, and (2) the promotion of healthcare objectives within a UK drug strategy driven by a crime reduction agenda. This duality must be resolved for UI to flourish at local level. © 2008 Blackwell Publishing Ltd.
http://dx.doi.org/10.1111/j.1365-2524.2008.00797.x

202.   Patterson, S., T. Weaver, M. Crawford. Drug service user groups: Only a partial solution to the problem of developing user involvement. Drugs: Education, Prevention and Policy, 2010. 17(1): p. 84-97.
Aims: To investigate and describe the role of drug service user groups in local service user involvement (UI). Method: Mixed-method study involving cross-sectional survey of commissioners, providers and users of drug treatment services and qualitative in-depth case studies in samples of drug action teams in England. Findings: User groups experience problems with sustainability. While the majority of sites reported current or past involvement with user groups, active groups were identified in only a third of sites. These groups varied widely in form and function. Generally groups provided solidarity for users and access to expert opinion for agencies. There was evidence of conflict between user and agency expectations that was exacerbated by power imbalance, role ambiguity and inadequate infrastructure. While the transience of groups was viewed pragmatically by some, others perceived such problems as confirmation that people who use drugs are unable to form effective groups. Conclusions: User groups are fundamental to UI, but are only a partial solution to the challenge of developing UI. Clarity of purpose and process and appropriate support are crucial. Further research should focus

on factors that enable groups to function interdependently and contribute to UI without being seen as the exclusive mechanism for it.
http://dx.doi.org/10.3109/09687630802225495

203.   Perry, J., M. Watkins, A. Gilbert, J. Rawlinson. **A systematic review of the evidence on service user involvement in interpersonal skills training of mental health students**. Journal of Psychiatric and Mental Health Nursing, 2013. 20(6): p. 525-540.
Accessible Summary: • This review looks at the involvement of people who have experienced mental health difficulties in teaching mental health students communication skills. • A systematic review of the English language publications from 1990-2010 was carried out using a wide range of sources including online databases such as the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO and MEDLINE (Ovid). • The overall goal was to assess the quality of existing evidence in this area and synthesis of findings on the effect of teaching involving people who have experienced mental health problems on students' ability to communicate. The conclusions of the review were: 1 Overall this type of teaching was acceptable to students and of value. 2 When service users teach about communication there is a move in student's practice towards improved attitudes towards people with mental health difficulties. 3 Some students were concerned that the people teaching them were not sufficiently representative of most people with mental health difficulties. 4 This type of teaching made professionals reflect more deeply on the way they communicate. Recommendations were also made to improve future research: 1 Researchers should use a clear definition of what constitutes good communication. 2 If skill in communication is being measured tried and tested measures should be used to do this and an experimental approach should be adopted. 3 A mixture of methods that both measure changes in skills and behaviour and elicit peoples actual experience of this type of teaching seems to be the best way of researching this area. Service user involvement has become a common feature of education programmes for mental health students. However, little is known about the effects of this type of education on the interpersonal skills of students taking part. This paper reports findings from a systematic review that formed part of a wider investigation into service user involvement in teaching interpersonal skills. The review aimed to locate and assess the quality of the published evidence relating to the effects of service user involvement on mental health students interpersonal skills and to synthesize results, using a definition of interpersonal skill that includes attitudes, empathy and skills as its key components. Results from this study indicate that the quality of evidence in this area is poor. However, sufficient synthesis of the evidence base was possible to allow conclusions and recommendations for both research and practice. Conclusions were that the involvement of service users in this area is both acceptable and valuable for students and had specific impacts on attitudes, empathy and skills. Some difficulties and reservations about the style of involvement are discussed. Recommendations for the conduct of future research are also made. © 2012 John Wiley & Sons Ltd.
http://dx.doi.org/10.1111/j.1365-2850.2012.01955.x

204.   Petersen, K., T. Borg, L. Hounsgaard, C.V. Nielsen. <mark>Learning via participation - a user perspective on user involvement in mental health rehabilitation</mark>. Scandinavian Journal of Disability Research, 2012. 14(2): p. 97-112.
AbstractThe aim of the study is to gain insight into the user's perspective on user involvement in mental health rehabilitation. The study was designed as a field study lasting 15 months in two supported housing schemes. An ethnographic approach by James Spradley was employed, involving participant observation, informal conversations, and individual- and group-interview. A phenomenological-hermeneutic approach inspired by Paul Ricoeur's theory on text interpretation

was used, including theories of situated learning. The results of the study show that the users experienced their involvement in rehabilitation to be associated with learning processes in interaction with residents as well as professionals. Learning took place via legitimate peripheral participation, via support from and negotiations with professionals and support from peer residents. Both opportunities for and limitations for learning were experienced. The transferability of knowledge and skills to life in a community was questioned, as limited access to participation was experienced. © 2012 Copyright Nordic Network on Disability Research. http://dx.doi.org/10.1080/15017419.2010.540927

205. Pilemalm, S., T. Timpka. **Third generation participatory design in health informatics-Making user participation applicable to large-scale information system projects**. Journal of Biomedical Informatics, 2008. 41(2): p. 327-339.
Participatory Design (PD) methods in the field of health informatics have mainly been applied to the development of small-scale systems with homogeneous user groups in local settings. Meanwhile, health service organizations are becoming increasingly large and complex in character, making it necessary to extend the scope of the systems that are used for managing data, information and knowledge. This study reports participatory action research on the development of a PD framework for large-scale system design. The research was conducted in a public health informatics project aimed at developing a system for 175,000 users. A renewed PD framework was developed in response to six major limitations experienced to be associated with the existing methods. The resulting framework preserves the theoretical grounding, but extends the toolbox to suit applications in networked health service organizations. Future research should involve evaluations of the framework in other health service settings where comprehensive HISs are developed. © 2007 Elsevier Inc. All rights reserved. http://dx.doi.org/10.1016/j.jbi.2007.09.004

206. Pilgrim, D., L. Waldron. **User involvement in mental health service development: How far can it go?** Journal of Mental Health, 1998. 7(1): p. 95-104.
The principle of user involvement in mental health services is now advocated by central government, encouraged by service commissioners and accepted as a feature of service development by provider managers. In the wake of the 1990 NHS and Community Care Act, most localities have witnessed one or more consultation exercises which have informed mental health strategy documents produced by NHS and social service commissioners. This paper reports a piece of action research about user involvement in one locality, which attempted to take users beyond the role of passive suppliers of opinion and encouraged their role as active negotiators of change. In order to understand both the achievements and limits of success of this exercise, the socio-political context of user involvement in British mental health service development is considered. http://dx.doi.org/10.1080/09638239818373

207. Plugge, E., N. Douglas, A.R. Fitzpatrick. **Imprisoned women's concepts of health and illness: The implications for policy on patient and public involvement in healthcare**. Journal of Public Health Policy, 2008. 29(4): p. 424-439.
In the United Kingdom (UK), government policy urges involvement of patients in their care and in health-related research. Women prisoners have considerable health needs and constitute an important patient group. This study explores women prisoners' perceptions of health and illness to consider the extent to which they differed from those of lay people. Thirty-seven women participated in six focus groups across two prisons in England. They spoke about their views of

health and what it was to be healthy. Women prisoners' concepts of health and well-being were similar to those of lay people and they demonstrated a good understanding of the key health issues faced by women prisoners. This group have much to contribute to the research process and researchers should attempt to overcome the existing barriers in order to involve prisoners more fully in line with UK Government policy. © 2008 Palgrave Macmillan. http://dx.doi.org/10.1057/jphp.2008.32

208.   Pollard, K., A.L. Donskoy, P. Moule, C. Donald, M. Lima, C. Rice. Developing and evaluating guidelines for patient and public involvement (PPI) in research. International journal of health care quality assurance, 2015. 28(2): p. 141-155.
        PURPOSE: A growing literature reports the benefits and challenges of patient and public involvement (PPI) in research; nevertheless, understanding PPI in research design remains under-developed. The purpose of this paper is to report learning experiences from involving service users as research partners in two projects that developed and evaluated guidelines for good practice in this regard. The main objective was to evaluate these guidelines.
DESIGN/METHODOLOGY/APPROACH: PPI research guidelines were developed through five workshops involving service users/patients, carers, health and social care professionals/managers and academics. Using a participatory qualitative approach, these guidelines were evaluated through mapping them against the two service user research partners' experience within another project.
FINDINGS: The guidelines were found to be fit for purpose, as they allowed problems to be easily identified and reassurance that required standards were being met. Both academic and service user research partners learned and gained relevant skills. Two service user research partners also found their daily living skills unexpectedly enhanced by project participation.
ORIGINALITY/VALUE: The PPI guidelines, the authors developed were produced by consensus involving several stakeholders. Service users involved as research partners in the project experienced unanticipated personal benefits.
        http://dx.doi.org/10.1108/IJHCQA-01-2014-0001

209.   Pollock, A., P. Campbell, G. Baer, P.L. Choo, J. Morris, A. Forster. User involvement in a Cochrane systematic review: Using structured methods to enhance the clinical relevance, usefulness and usability of a systematic review update. Systematic Reviews, 2015. 4(1).
        Background: This paper describes the structured methods used to involve patients, carers and health professionals in an update of a Cochrane systematic review relating to physiotherapy after stroke and explores the perceived impact of involvement. Methods: We sought funding and ethical approval for our user involvement. We recruited a stakeholder group comprising stroke survivors, carers, physiotherapists and educators and held three pre-planned meetings during the course of updating a Cochrane systematic review. Within these meetings, we used formal group consensus methods, based on nominal group techniques, to reach consensus decisions on key issues relating to the structure and methods of the review. Results: The stakeholder group comprised 13 people, including stroke survivors, carers and physiotherapists with a range of different experience, and either 12 or 13 participated in each meeting. At meeting 1, there was consensus that methods of categorising interventions that were used in the original Cochrane review were no longer appropriate or clinically relevant (11/13 participants disagreed or strongly disagreed with previous categories) and that international trials (which had not fitted into the original method of categorisation) ought to be included within the review (12/12 participants agreed or strongly agreed these should be included). At meeting 2, the group members reached consensus over 27 clearly defined treatment components, which were to be used to categorise interventions within the review (12/12 agreed or strongly agreed), and at meeting 3, they agreed

on the key messages emerging from the completed review. All participants strongly agreed that the views of the group impacted on the review update, that the review benefited from the involvement of the stakeholder group, and that they believed other Cochrane reviews would benefit from the involvement of similar stakeholder groups. Conclusions: We involved a stakeholder group in the update of a Cochrane systematic review, using clearly described structured methods to reach consensus decisions. The involvement of stakeholders impacted substantially on the review, with the inclusion of international studies, and changes to classification of treatments, comparisons and subgroup comparisons explored within the meta-analysis. We argue that the structured approach which we adopted has implications for other systematic reviews. © 2015 Pollock et al. licensee BioMed Central.
http://dx.doi.org/10.1186/s13643-015-0023-5

210. Poulton, B.C. **User involvement in identifying health needs and shaping and evaluating services: Is it being realised?** Journal of Advanced Nursing, 1999. 30(6): p. 1289-1296.
The rhetoric of user involvement has featured in health policy documents for over a decade. However, there is mixed evidence as to the extent to which it is being achieved. This paper explores what is meant by user involvement, proposing that it exists at a series of levels ranging from information giving to true empowerment. Examples are presented from two practice development projects. The first sought to develop multidisciplinary audit in primary care, attempting to involve users in defining health needs and determining services. Although the project co-ordinators were highly committed to user involvement this was only achieved to a limited extent. It was concluded that there was a resistance to user involvement grounded in the fear that such involvement would increase user expectations and add to the pressures of overworked primary care teams. The second project used interviews with service users to assess the effectiveness of a team building initiative. Users were found to be knowledgeable about practitioner roles and how to access the care they required. The overall conclusion is that there needs to be a shift from rhetoric to reality at governmental and practitioner level if true user involvement is to be achieved.
http://dx.doi.org/10.1046/j.1365-2648.1999.01224.x

211. Pound, P., R. Blaug. **Transparency and public involvement in animal research**. ATLA Alternatives to Laboratory Animals, 2016. 44(2): p. 167-173.
To be legitimate, research needs to be ethical, methodologically sound, of sufficient value to justify public expenditure and be transparent. Animal research has always been contested on ethical grounds, but there is now mounting evidence of poor scientific method, and growing doubts about its clinical value. So what of transparency? Here we examine the increasing focus on openness within animal research in the UK, analysing recent developments within the Home Office and within the main group representing the interests of the sector, Understanding Animal Research. We argue that, while important steps are being taken toward greater transparency, the legitimacy of animal research continues to be undermined by selective openness. We propose that openness could be increased through public involvement, and that this would bring about much needed improvements in animal research, as it has done in clinical research.

212. Pries-Heje, L. **Time, attitude, and user participation: How prior events determine user attitudes in ERP implementation**. International Journal of Enterprise Information Systems, 2008. 4(3): p. 48-65.
Assimilation of a standard ERP system to an organization is difficult. User involvement seems to be the crux of the matter However even the best intentions for user involvement may come to nothing A case study of a five-year ERP inplementation process reveals that a main reason may be

that the perception of usefulness of the system in any given phase of the implementation is heavily dependent on preceding events - the process. A process model analysis identifies eight episodes and nine encounters in the case showing that the user's attitude towards the ERP system changes between acceptance, equivocation, resistance and rejection depending on three things: (1) the dynamic between user and consultants, (2) the dynamic between different user groups, and (3) the understanding of technical, organizationat and socio-technical options. When relating the empirical findings to existing theory on user participation, it is argued that the changes could be explained as a slide from influential user participation toward pseudo participation and back to influential participation, and that user participation in the context of ERP implementations raises new issues regarding user participation. Thus further research regarding new approaches and/or new techniques and tools for user participation in the context of ERP implementations is needed. Copyright © 2008, IGI Global.

213.   Quaddus, M., A. Lau, Uiu, *Impact of user participation on Web-based information system: The Hong Kong experience*. Proceedings of 10th International Conference on Computer and Information Technology2007. 349-354.

214.   Rahimi, B., R. Safdari, M. Jebraeily. ==Development of hospital information systems: User participation and factors affecting it.== Acta Informatica Medica, 2014. 22(6): p. 398-401.
Introduction: Given the large volume of data generated in hospitals, in order to efficiently management them; using hospital information system (HIS) is critical. User participation is one of the major factors in the success of HIS that in turn leads Information needs and processes to be correctly predicted and also their commitment to the development of HIS to be augmented. The purpose of this study is to investigate the participation rate of users in different stages of HIS development as well as to identify the factors affecting it. Method and materials: This is a descriptive-cross sectional study which was inducted in 2014.The study population consists of 140 HIS users (from different types of job including physicians, nurses, laboratory, radiology and HIM staffs) from Teaching Hospitals Affiliated to Urmia University of Medical Sciences. Data were collected using a ==self-structured questionnaire== which was estimated as both reliable and valid.The data were analyzed by SPSS software descriptive statistics and analytical statistics (t-test and chi-square). Results: The highest participation rate of users in the four-stage development of the HIS was related to the implementation phase (2.88) and the lowest participation rate was related to analysis (1.23).The test results showed that the rate of user participation was not satisfactory in none of the stages of development ($P<0.05$).The most important factors in increasing user participation include established teamwork from end-users and the support of top managers from HIS development. Conclusion: According to the results obtained from the study, it seems that health care administrators must have a detailed plan for user participation prior to the development and purchase of HIS so that they identify the real needs as well as increase their commitment and motivations to develop, maintain and upgrade the system, and in this way, the success of the system will be assured. © AVICENA 2014.
http://dx.doi.org/10.5455/aim.2014.22.398-401

215.   Rees, C.E., L.V. Knight, C.E. Wilkinson. **"User involvement is a sine qua non, almost, in medical education": Learning with rather than just about health and social care service users**. Advances in Health Sciences Education, 2007. 12(3): p. 359-390.
Despite the General Medical Council emphasising the value of service users to medical students' education, there is scant literature about service user involvement in medical education. Although some research has outlined the effectiveness of service users as teachers, none has explored social issues surrounding how medical students learn 'with' rather than just 'about' service users.

Incorporating insights from contemporary socio-cultural learning theory, this study examines the views and experiences of 47 stakeholders (comprising 19 service users, 13 medical students and 15 medical educators) concerning service user involvement in medical education. Eight audiotaped focus group discussions were convened and the audiotapes were transcribed. The transcripts and audiotapes were independently analysed by multiple researchers using Framework analysis. Seven content- and five process-orientated themes emerged from the analysis. Content-related themes included the costs and benefits of service user involvement in medical education and process-related themes included the use and function of humour and metaphor. In this paper, we focus primarily on the content-related themes. We discuss these findings in light of the existing service user involvement literature and contemporary socio-cultural learning theory and provide implications for further research and educational practice. We encourage educators to involve service users in medical education but only in a considered way. © 2006 Springer Science+Business Media, Inc.
http://dx.doi.org/10.1007/s10459-006-9007-5

216.   Rhodes, C.A. **Service user involvement in pre-registration children's nursing education: the impact and influence on practice: a case study on the student perspective**. Issues in comprehensive pediatric nursing, 2013. 36(4): p. 291-308.
This article reports on a study that aimed to conduct an in-depth investigation into the impact of user involvement on student learning and subsequent influence on practice as a qualified nurse. This was undertaken through a single case study that followed a narrative inquiry approach. UK policy has recommended user involvement in healthcare education for a number of years; this has in turn increased requirements for involvement from Professional, Statutory and Regulatory Bodies. The Nursing and Midwifery Council (NMC, 2010) now requires program providers to clearly demonstrate how service users and carers contribute to program design, delivery and assessment. Although the literature base is expanding there remains limited evidence of the impact of involvement on student learning and improved outcomes for patients. Narratives were collected from a children's nursing student on completion of her 3-year nurse education program and again after practicing as a qualified children's nurse for 1 year. Taking part in the research enabled the participant to consider and reflect on her experience of user involvement in her education and training. Analysis followed an interpretive approach utilizing "The Listening Guide" (Doucet & Mauthner 2008) with the researcher's interpretation of how the experience was conveyed with clear acknowledgement of reflexivity.The findings identified central themes of authenticity, knowledge of self, resilience and coping, professional relationships, personalization of care, and influence on practice. This demonstrates transformative learning and support to practice, with preparation for situations and ideas on how to respond with empathy and compassion. This article contributes to the emerging evidence base specifically from a children's nursing perspective, an area with a dearth of published material. Further research with a range of students is required to explore the lasting impact on practice.
http://dx.doi.org/10.3109/01460862.2013.830161

217.   Richards, J. **Supervision of midwives-making maternity user involvement a reality**. Practising Midwife, 2010. 13(10): p. 28-29.

218.   Rise, M.B., H. Grimstad, M. Solbjør, A. Steinsbekk. **Effect of an institutional development plan for user participation on professionals' knowledge, practice, and attitudes. A controlled study**. BMC Health Services Research, 2011. 11.
Background: Governments in several countries attempt to strengthen user participation through

instructing health care organisations to plan and implement activities such as user representation in administrational boards, improved information to users, and more individual user participation in clinical work. The professionals are central in implementing initiatives to enhance user participation in organisations, but no controlled studies have been conducted on the effect on professionals from implementing institutional development plans. The objective was to investigate whether implementing a development plan intending to enhance user participation in a mental health hospital had any effect on the professionals' knowledge, practice, or attitudes towards user participation. Methods. This was a non-randomized controlled study including professionals from three mental health hospitals in Central Norway. A development plan intended to enhance user participation was implemented in one of the hospitals as a part of a larger re-organizational process. The plan included i.e. establishing a patient education centre and a user office, purchasing of user expertise, appointing contact professionals for next of kin, and improving of the centre's information and the professional culture. The professionals at the intervention hospital thus constituted the intervention group, while the professionals at two other hospitals participated as control group. All professionals were invited to answer the ==Consumer Participation Questionnaire (CPQ)== and additional questions, focusing on knowledge, practice, and attitudes towards user participation, two times with a 16 months interval. Results: A total of 438 professionals participated (55% response rate). Comparing the changes in the intervention group with the changes in the control group revealed no statistically significant differences at a 0.05 level. The implementation of the development plan thus had no measurable effect on the professionals' knowledge, practice, or attitudes at the intervention hospital, compared to the control hospitals. Conclusion: This is the first controlled study on the effect on professionals from implementing a development plan to enhance user participation in a mental health hospital. The plan had no effect on professionals' knowledge, practice, or attitudes. This can be due to the quality of the development plan, the implementation process, and/or the suitability of the outcome measures. © 2011 Rise et al; licensee BioMed Central Ltd.
http://dx.doi.org/10.1186/1472-6963-11-296

219.   Rise, M.B., M. Solbjør, M.C. Lara, H. Westerlund, H. Grimstad, A. Steinsbekk. **Same description, different values. How service users and providers define patient and public involvement in health care**. Health Expectations, 2013. 16(3): p. 266-276.
Background Patient and public involvement in health care is important, but the existing definitions of the concept do not integrate the stakeholders' own perceptions. Objective To investigate and compare service users' and service providers' own definitions of patient and public involvement and their implications. Design, setting and participants Qualitative study with mainly individual in-depth semi-structured interviews conducted between June 2007 and June 2009. Data were analysed using a grounded theory approach. Results A total of 20 patients, 13 public representatives and 44 health service providers/managers in both somatic and mental health care were interviewed. A common definition of patient and public involvement emerged: It is founded on mutual respect, carried out through dialogue aiming at achieving shared decision making. Nevertheless, users and providers assigned different values to the core aspects: Respect was imperative for service users and implied for providers, dialogue was a way to gain respect for service users and to achieve good outcome for providers, and both worried that the other party wanted to make sole decisions. Conclusions Users and providers need to consider that although they have a common definition of involvement in health care, they assign different values to its aspects. Increasing and improving patient and public involvement therefore requires knowledge on and dialogue between the parties about these differences. © 2011 John Wiley & Sons Ltd.
http://dx.doi.org/10.1111/j.1369-7625.2011.00713.x

220.   Rise, M.B., M. Solbjør, A. Steinsbekk. **Experiences from the implementation of a comprehensive development plan for user involvement in a mental health hospital: A qualitative case study**. International Journal of Social Psychiatry, 2014. 60(4): p. 387-395.
        Background: Few studies have investigated user involvement initiatives in whole organizations. The aim was to explore the experiences of professionals and user representatives taking part in the implementation of a user involvement plan. Materials: A qualitative study in a mental health hospital included interviews and observational data. Discussion: Three different stories emerged. The first described the implementation as a success. The second described the implementation as a success, but after overcoming several obstacles. The third described that the development plan had limited impact. Conclusions: Close attention should be made to decision-making and resource allocation when implementing user involvement. © The Author(s) 2013. http://dx.doi.org/10.1177/0020764013491739

221.   Rise, M.B., A. Steinsbekk. **Does implementing a development plan for user participation in a mental hospital change patients' experience? A non-randomized controlled study**. Health expectations : an international journal of public participation in health care and health policy, 2015. 18(5): p. 809-825.
        BACKGROUND: Governments in several countries attempt to strengthen user participation through instructing health-care organizations to implement user participation initiatives. There is, however, little knowledge on the effect on patients' experience from comprehensive plans for enhancing user participation in whole health service organizations.
OBJECTIVE: To investigate whether implementing a development plan intending to enhance user participation in a mental hospital had any effect on the patients' experience of user participation.
DESIGN, SETTING AND PARTICIPANTS: A non-randomized controlled study including patients in three mental hospitals in Central Norway, one intervention hospital and two control hospitals.
INTERVENTIONS: A development plan intended to enhance user participation was implemented in the intervention hospital as a part of a larger reorganizational process. The plan included establishment of a patient education centre and a user office, purchase of user expertise, appointment of contact professionals for next of kin and improvement of the centre's information and the professional culture.
MAIN OUTCOME MEASURES: Perceptions of Care, Inpatient Treatment Alliance Scale and questions made for this study.
RESULTS: A total of 1651 patients participated. Implementing a development plan in a mental hospital intending to enhance user participation had no significant effect on the patients' experience of user participation.
DISCUSSIONS AND CONCLUSIONS: The lack of effect can be due to inappropriate initiatives or challenges in implementation processes. Further research should ensure that initiatives and implementation processes are appropriate to impact the patients' experience. http://dx.doi.org/10.1111/hex.12105

222.   Robinson, A. <mark>Patient and public involvement: In theory and in practice</mark>. Journal of Laryngology and Otology, 2014. 128(4): p. 318-325.
        Background: You've probably heard of patient and public involvement by now. You may even have 'involved' people in your research. But why involve patients, carers and members of the public at all? Is it just another hoop to jump through when preparing a research funding application for submission, or could it actually add something to your research? Could involving patients and members of the public even help you to design and deliver better research, with

outcomes focused directly on the needs of your patient group? Objective: This article aims to answer some of these questions. It considers the theory underpinning patient and public involvement. This is followed by practical suggestions and advice to help you develop (or further develop if you already involve people!) patient and public involvement within your own research. There is also a case study to illustrate some of the main points, and extracts written by members of Research Design Service North East Consumer Panels. Copyright © JLO (1984) Limited 2014. http://dx.doi.org/10.1017/S0022215114000735

223.   Rose, D. **Partnership, co-ordination of care and the place of user involvement**. Journal of Mental Health, 2003. 12(1): p. 59-70.
Background: The context for this paper is current UK policy emphasis on both 'partnership' and 'user involvement' and discussion on the system of Care Programme Approach (CPA). Aims: To investigate whether increasing co-ordination of care at a structural level is associated with greater user involvement. Method: Social survey techniques were adapted in order to be user-focused and the work was prepared and carried out by service users. Results: Service users tend to be unaware of the major way in which their care is co-ordinated but even less involved in it. On the rare occasions that service users are involved in their care and other elements of empowerment are in place, they are more satisfied overall with the services they receive. Conclusion: Increasing co-ordination of care at a managerial level does not necessarily lead to greater awareness or involvement amongst individual users of CPA. This may be linked to the way service users are perceived by their mental health workers and it is argued that this should change if users are to be full 'partners'. Declaration of interest: None.
http://dx.doi.org/10.1080/09638230021000058300

224.   Rose, D. <mark>Patient and public involvement in health research: Ethical imperative and/or radical challenge?</mark> Journal of Health Psychology, 2014. 19(1): p. 149-158.
Patient and public involvement in health research, including mental health research, is promoted by research funders in England. However, it is poorly conceptualised. One argument is that patient and public involvement in research is an ethical imperative because those who research is for should have a stake in how it is done. This could be developed through concepts of citizenship and democratic science. More strongly, it can be argued that changing the knowledge producers will change knowledge itself. Starting with feminist standpoint epistemology, it is argued that a political conceptualisation best captures the new knowledge that marginalised health groups can produce. © The Author(s) 2013.
http://dx.doi.org/10.1177/1359105313500249

225.   Rose, D., P. Fleischmann, P. Schofield. **Perceptions of user involvement: A user-led study**. International Journal of Social Psychiatry, 2010. 56(4): p. 389-401.
Background: User involvement in health services has been a priority for government since 1990. In mental health, concern has been expressed that involved service users (activists) are not representative of 'ordinary' patients. Aims: (i) To investigate service users' perceptions of the outcomes of user involvement in two London boroughs. (ii) To determine whether the perceptions of outcomes differ between activists and non-activists. Method: The study was user-led. The user-researchers compiled a semi-structured interview schedule which they then administered to a sample of 40 people; 20 were defined as activists and 20 as non-activists. There were also 20 participants in each borough. Results: Activists were aware of more user groups and forms of user involvement than non-activists. However, in terms of perceptions of the outcomes of user involvement, there was little difference between the activists and non-activists. Discussion:

There is very little extant work on the outcomes of user involvement in mental health services. This study examined this and, contrary to reservations often expressed, there was little difference between activists and non-activists. Conclusion: This is a pilot study. Further work should examine perceptions of the outcomes of user involvement by other stakeholders, for example, front-line workers, managers, carers and commissioners. © 2010 The Author(s). http://dx.doi.org/10.1177/0020764009106618

226. Rostami, A. **User Participation in Social Networks: The Case of Balatarin An online Persian-language social bookmarking system**. Proceedings of the 2013 10th International Conference on Information Technology: New Generations, 2013: p. 445-449.
The raise of social Web brought new ways of disseminating information, news and published content over the Web. Social news aggregator Web sites such as Digg and Reddit are already known for their role in promoting user-based content by utilizing story submission and voting system. Balatarin, the first and one of the most famous news aggregator in Persian language, is a social bookmarking Web site, which is developed by combining the underlying idea of Reddit, Digg, Newsvine and Del.icio.us. Although Balatarin is among popular and influential Web sites in the Middle East, there has not been any analytical research on it. Here, we studied the user activity to see whether it is dominated by few users' participation, or social incidents can motivate users and influence their contribution. For our study, we collected data representing user activity over the course of three years. We carried out some computational analysis on user participation under social circumstances, such as blockade and election in Iran. The evaluation of the results shows that such social factors can motivate users to break the tyranny of the minority submitters by contributing more.
http://dx.doi.org/10.1109/itng.2013.68

227. Rouibah, K., H.I. Hamdy, M.Z. Al-Enezi. **Effect of management support, training, and user involvement on system usage and satisfaction in Kuwait**. Industrial Management and Data Systems, 2009. 109(3): p. 338-356.
Purpose - The purpose of this paper is to investigate the organizational factors and human motivations affecting information systems and information technology (IS/IT) usage and user's satisfaction in an Arabic country. Design/methodology/approach - The study develops a research model that links three organizational factors (top management support - TMS, availability of training, and user's involvement) to IS/IT usage and end-user's satisfaction via the mediation of TAM beliefs (usefulness and ease-of-use) by 382 IS users. The model was examined through the LISREL. Findings - The results indicate that IS/IT usage and user satisfaction is largely influenced by perceived usefulness. Among the organizational factors, TMS was found to have the strongest effect on IS/IT usage and user's satisfaction, followed by availability of training and user involvement. Research limitations/implications - This study focuses on perceptions of respondents from public organizations who have had high experience with IS/IT. These perceptions are based on a one-time survey. For better validity, a longitudinal study with additional variables is needed. Practical implications - This study is useful for practitioners who want to increase and boost system usage and user's atisfaction in the Arab region. Originality/value - This paper highlights the motives of IS/IT usage and user's satisfaction in the Arab world and to educate researchers about how IS/IT is perceived by end-users in Kuwait. © 2009 Emerald Group Publishing Limited. All rights reserved.
http://dx.doi.org/10.1108/02635570910939371

228. Rowa-Dewar, N., W. Ager, K. Ryan, I. Hargan, G. Hubbard, N. Kearney. <mark>Using a rapid appraisal</mark>

approach in a nationwide, multisite public involvement study in Scotland. Qualitative Health Research, 2008. 18(6): p. 863-869.

This article reflects on the use of a multisite rapid appraisal (RA) approach with reference to the (to-date) largest qualitative study gathering the views of cancer and cancer care in a cross-section of the Scottish population. A series of ten RAs were conducted in ten communities across Scotland, reflecting the geographical and socioeconomic spread of the Scottish population and involving 507 members of the public, including the views of people who are often termed "hard to reach." The research method is evaluated with reference to principles of RA approaches: the inductive approach, triangulation, assessment and response, and participation. Presentation of the methods adopted in this study demonstrates the value of the rapid appraisal approach in engaging with members of the public in health-related issues, which belies the "quick and dirty" reputation of RA approaches and offers a model for future public involvement work in health care. This makes the reflections on the method utilized particularly relevant to policy makers and researchers wishing to achieve meaningful public involvement and/or consider a method not previously used in this context. © 2008 Sage Publications.
http://dx.doi.org/10.1177/1049732308318735

229.   Rudman, M.J. User involvement in the nursing curriculum: Seeking users' views. Journal of Psychiatric and Mental Health Nursing, 1996. 3(3): p. 195-200.

This qualitative study considers the views of users of mental health services on a pre-registration nursing curriculum. Semistructured group interviews were used to gain the (illustrative) views of twenty members of two user groups on nursing knowledge, skills and qualities. Interest in users' views has generally been belated or reluctant. In more recent literature, statements emerge about the need to develop a climate of respect, acceptance and sensitivity. While nurses have a central role in mental health care, a detailed examination from the user's perspective has been lacking. Despite the rhetoric of involvement, commentaries on nursing practice suggest little has changed. Findings suggest an eclectic knowledge base that respects individual differences and the user's experience, knowledge of local communities, and better recognition of physical illness is required. 'Knowledge of life' is seen as important. An emphasis on interpersonal skills is suggested, including flexible responses, information-giving, and sensitive handling of tense situations. This should be balanced against 'practical' nursing. Traditional teaching in relation to 'psychotic' experiences is challenged. It is suggested that caring should be emphasized as much as 'rational knowledge'. Developing responsive qualities that minimize 'distancing' may demand a reevaluation of boundaries between user and professional. © 1996 Blackwell Science Ltd.

230.   Rui, S. Transport policy and public involvement: Concertation between mobilization and frustration. Innovation, 2004. 17(2): p. 129-144.

This paper examines the possibility of establishing a public space of deliberation concerning transport policy. It deals with the question of whether it is possible to envisage instances of concertation that deflect conflict. Based mostly on French experience with public inquiries on transport infrastructure, it discusses the relevance and applicability of the sociology of collective action, as well as theories of deliberative democracy. The paper's main argument is that concertation does not occur in a vacuum but is instead structured by power relations. It is, therefore, first and foremost an opportunity to express dissatisfaction and frustration. At the same time, public debate represents-perhaps for the same reason-an opportunity to criticize forms of social domination. It thus may give rise to citizen mobilization rather than help contain it, as is often naively expected by its promoters within the public policy administration. Conflict is thus always the actual subject of public debate. © 2004 Interdisciplinary Centre for Comparative

Research in the Social Sciences.
http://dx.doi.org/10.1080/1351161042000238652

231.   Rutter, D., C. Manley, T. Weaver, M.J. Crawford, N. Fulop. **Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London**. Social Science and Medicine, 2004. 58(10): p. 1973-1984.
       User or patient involvement (UI) in the planning and delivery of health services is an aspiration of many industrialized economies, and has been promoted by United Kingdom (UK) governments for over two decades. This paper reports the findings of qualitative case studies of UI in two mental health provider Trusts in London. Semi-structured interviews were conducted with a variety of stakeholders, including Trust staff at all levels and user group members, to compare the expectations of diverse stakeholders and the extent to which these were achieved. We found that UI remained in the gift of provider managers: providers retained control over decision making, and expected users to address Trust agendas and conform to Trust management practices. Users wanted to achieve concrete changes to policies and services, but had broader aspirations to improve the status and condition of people with mental health problems. Suggestions are made about the direction of future strategies to improve UI. © 2003 Elsevier Ltd. All rights reserved.
       http://dx.doi.org/10.1016/S0277-9536(03)00401-5

232.   Saebjornsen, S.E.N., E. Willumsen. **Service user participation in interprofessional teams in child welfare in Norway: vulnerable adolescents' perceptions**. Child & Family Social Work, 2017. 22: p. 43-53.
       Children's participation has been a requirement in the Norwegian child welfare system for decades and children's effective participation has the potential to benefit children's outcomes. However, research suggests that effective user participation is still relatively rare and that user participation is seen as 'difficult' by both service users and professionals. One way to ensure children's rights to participation in Norway is to include adolescent service users in the interprofessional team formed around the child. Knowledge about experiences of adolescents in this kind of participation may provide important insights. This study explores five adolescents' perceptions about participating in such teams. Qualitative interviews and qualitative content analysis was used. We found that adolescents' participation in interprofessional teams may constitute one way to achieve effective participation. Both facilitating factors and impediments to effective user participation were found. The study suggests new ways to facilitate positive circles of participation and to increase the likelihood of improved child welfare outcomes from processes which secure more effective interprofessional help and support.
       http://dx.doi.org/10.1111/cfs.12242

233.   Samorinha, C., M. Lichon, S. Silva, M. Dent. **User involvement in assisted reproductive technologies: England and Portugal**. Journal of Health, Organisation and Management, 2015. 29(5): p. 582-594.
       Purpose – The purpose of this paper is to compare user involvement in the case of assisted reproductive technologies in England and Portugal through the concepts of voice, choice and co-production, assessing the implications for user empowerment. Design/methodology/approach – This qualitative study draws primarily on policy review and uses exploratory semi-structured interviews with key informants as a way of illustrating points. Data on the following themes was compared: voice (users' representativeness on licensing bodies and channels of communication between users and doctors); choice (funding and accessibility criteria; choice of fertility centres, doctors and level of care); and co-production (criteria through which users actively engage with

health professionals in planning the treatment). Findings – Inter- and intra-healthcare systems variations between the two countries on choice and co-production were identified. Differences between funding and accessibility, regions, public and private sectors and attitudes towards doctor-patient relationship (paternalistic/partnership) were the key issues. Although consumer choice and indicators of co-production are evident in treatment pathways in both countries, user empowerment is not. This is limited by inequalities in accessibility criteria, dependence on doctors' individual perspectives and lack of genuine and formal hearing of citizens' voice. Originality/value – Enhancing users' involvement claims for individual and organizational cultures reflecting user-centred values. Effective ways to incorporate users' knowledge in shared decision making and co-design are needed to empower patients and to improve the delivery of care. © 2015, Emerald Group Publishing Limited.
http://dx.doi.org/10.1108/JHOM-12-2014-0202

234. Samudre, S., R. Shidhaye, S. Ahuja, S. Nanda, A. Khan, S. Evans-Lacko, C. Hanlon. **Service user involvement for mental health system strengthening in India: A qualitative study**. BMC Psychiatry, 2016. 16(1).
Background: There is a wide recognition that involvement of service users and their caregivers in health system policy and planning processes can strengthen health systems; however, most evidence and experience has come from high-income countries. This study aimed to explore baseline experiences, barriers and facilitators to service user-caregiver involvement in the emerging mental health system in India, and stakeholders' perspectives on how greater involvement could be achieved. Methods: A qualitative study was conducted in Sehore district of Madhya Pradesh, India. In-depth interviews (n = 27) and a focus group discussion were conducted among service users, caregivers and their representatives at district, state and national levels and policy makers, service providers and mental health researchers. The topic guide explored the baseline situation in India, barriers and facilitators to service user and caregiver involvement in the following aspects of mental health systems: policy-making and planning, service development, monitoring and quality control, as well as research. Framework analysis was employed. Results: Respondents spoke of the limited involvement of service users and caregivers in the current Indian mental health system. The major reported barriers to this involvement were (1) unmet treatment and economic needs arising from low access to mental health services coupled with the high burden of illness, (2) pervasive stigmatising attitudes operating at the level of service user, caregiver, community, healthcare provider and healthcare administrators, and (3) entrenched power differentials between service providers and service users. Respondents prioritised greater involvement of service users in the planning of their own individual-level mental health care before considering involvement at the mental health system level. A stepwise progression was endorsed, starting from needs assessment, through empowerment and organization of service users and caregivers, leading finally to meaningful involvement. Conclusions: Societal and system level barriers need to be addressed in order to facilitate the involvement of service users and caregivers to strengthen the Indian mental health system. Shifting from a largely 'provider-centric' to a more 'user-centric' model of mental health care may be a fundamental first step to sustainable user involvement at the system level.
http://dx.doi.org/10.1186/s12888-016-0981-8

235. Scammell, J., V. Heaslip, E. Crowley. **Service user involvement in preregistration general nurse education: a systematic review**. Journal of clinical nursing, 2016. 25(1-2): p. 53-69.
AIMS AND OBJECTIVES: A systematic review of published studies on service user involvement in undergraduate, preregistration general nursing education (excluding mental health-specific

programmes). The objective is to examine how students are exposed to engagement with service users.

BACKGROUND: The requirement of service user involvement in all nurse education is policy expectation of health professional education providers, in response to the increased public and political expectations. Previous literature reviews have focused solely on mental health.

DESIGN: Systematic review using the Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines; timeframe 1997-2014; published in English.

METHODS: Search of CINAHL, Cochrane Review, Education Research Complete, Internurse, MEDLINE, PsychINFO, Scopus, SocINDEX and Web of Science yielded 229 citations; 11 studies met the review eligibility criteria.

RESULTS: Seven studies used qualitative methodology, two quantitative and two mixed methods. Studies from the United Kingdom dominated (n = 9), the remainder from South Africa and Turkey. The results are described using four themes: benefits and limitations of service user involvement; nursing student selection; education delivery; practice-based learning and assessment. Most studies were small scale; nine had less than 30 participants. Overall the evidence suggests that student, lecturers and service users valued service user involvement in nurse education, to provide an authentic insight into the illness experience. Logistical considerations around support and student cohort size emerged.

CONCLUSIONS: This is the first systematic review to focus on service user involvement in general nurse education. It reveals that service user involvement commenced later and is more limited in general programmes as compared to equivalent mental health education provision. Most of the evidence focuses on perceptions of the value of involvement. Further research is required to more clearly establish impact on learning and clinical practice.

RELEVANCE TO CLINICAL PRACTICE: Service user involvement in nurse education is valued by stakeholders but preparation and support for those involved, including mentors is underestimated.
http://dx.doi.org/10.1111/jocn.13068

236.   Schon, U.K. **User Involvement in Social Work and Education-A Matter of Participation?** Journal of Evidence-Informed Social Work, 2016. 13(1): p. 21-33.
        The increase in user involvement in social work practice and education can be explained by incentives toward an evidence-based practice, such as those offered by legislation and from the user movement, and those related to professional development. Still, the clients' involvement in research and practice is highlighted as a gap that needs to be filled. The aim of the author in this article is to study the presence of user involvement in social work practice, research, and education, and the level of influence of users and carers within these activities. The results reflect an expanding user involvement in social work practice. Still, projects of user involvement in social work practice are often developed on an ad hoc and inconsistent basis, and knowledge about the effects of these efforts is still limited. User involvement is not to be understood as something that is self-evidently good. On the contrary, the results present a rather complex concept that is bound up with changing and contested understandings of the role of the social worker, academia, and the users themselves.
        http://dx.doi.org/10.1080/15433714.2014.939382

237.   Seekamp, E., C.C. Harris, T.E. Hall, T.Y. Craig. **A mixed methods approach to measuring depth of group information processing in the context of deliberative public involvement**. Journal of Mixed Methods Research, 2010. 4(3): p. 222-247.
        This article presents a mixed methods procedure for evaluating information processing and the

role of social influences in deliberative public involvement groups. Specifically, it describes an interpretive, qualitative coding scheme for analyzing group discussions to quantitatively assess how group differences in information processing and social influences affect decision judgments. To substantiate the need for this new approach, the contributions of social psychology for better understanding persuasive influences in groups and individual information processing are described in relation to participatory public involvement contexts. The approach is then described using examples from a deliberative public involvement process. The article concludes with a discussion of the challenges associated with the proposed technique and suggestions for research to advance the technique and assess its contribution to mixed methods research. © The Author(s) 2010.
http://dx.doi.org/10.1177/1558689810370601

238. Shepherd, S., A.C. Kay. **When government confidence undermines public involvement in modern disasters**. Social Cognition, 2014. 32(3): p. 206-216.
As our global community increases in complexity, crises and disasters-such as global financial meltdowns and natural disasters-increasingly have the ability to impact millions of lives. Because of the scale and complexity of these issues, they are seemingly beyond comprehension and personal control. As such, people may rely on the government as a psychological crutch, thus undermining their own engagement with and understanding of crises and disasters. In the context of the present economic crisis (Study 1) and the 2010 BP oil crisis in the Gulf of Mexico (Study 2) the current research provides evidence for the idea that when perceptions of government competency and agency are high, people become less inclined to learn about and become engaged in crises and disasters. © 2014 Guilford Publications, Inc.

239. Sherman, S., C. Latkin. **A qualitative exploratory study of injection drug users' participation in a long-term epidemiological study of HIV**. AIDS and Behavior, 1999. 3(4): p. 289-299.
An exploratory study was conducted with 15 current or former injecting drug users to gain an understanding of the motivations for and reactions to participating in ALIVE (AIDS Link to Intravenous Experiences), a longitudinal natural history study of HIV among urban drug users in Baltimore, Maryland. Semistructured qualitative interviews explored participants' perceptions of ALIVE and of its benefits and the factors that might influence accuracy of self-report. Participants described benefiting from the study in many tangible and intangible ways. ALIVE was the sole source of health care for many, as only a third of the participants had health insurance. Participants' biggest challenge in the ALIVE survey were questions related to sexuality, which were perceived as too personal or elicited shame. Results indicate the importance of qualitative research in understanding how and why people are motivated to participate in epidemiological studies and how these perceptions might relate to their responses in survey research.
http://dx.doi.org/10.1023/A:1025433317367

240. Shiau, W.L., M.M.L. Luo. **Continuance intention of blog users: the impact of perceived enjoyment, habit, user involvement and blogging time**. Behaviour & Information Technology, 2013. 32(6): p. 570-583.
The purpose of this study is to understand factors that affect continuance intention of a popular hedonic information system, blogs. The expectation-confirmation theory (ECT) is adapted with perceived enjoyment, habit and user involvement. Data was collected via an online survey. A total of 430 valid responses were collected. The research model was assessed by structural equation modelling (SEM). The results show that continuance intention of blog use was predicted collectively by user involvement, satisfaction and perceived enjoyment. Habit, however, exhibited

no strong relationship with satisfaction and use intention. Users' satisfaction with blog use was predicted primarily by perceived enjoyment, followed by users' confirmation of expectation and user involvement. Perceived enjoyment was predicted by users' involvement and users' confirmation of expectation. Blogging time significantly moderates the effect of habit on perceived enjoyment, but not on satisfaction and continuance intention. The integrated model explains 65% of the satisfaction and 57% of continuance intention. The results suggest that integrating perceived enjoyment and user involvement into the ECT provides better insights into continuous use in the blog context.
http://dx.doi.org/10.1080/0144929x.2012.671851

241. Simmons, R., J. Birchall, A. Prout. <mark>User Involvement in Public Services: 'Choice about Voice'.</mark> Public Policy and Administration, 2012. 27(1): p. 3-29.
Processes of involvement and representation are particularly important in UK public services if users' interests are adequately to be taken into account. Yet there are several different, sometimes competing ways for users' views to be represented, and their interaction is not well understood. This article reports on research exploring these issues in relation to three public services - housing, social care and leisure services. We asked, how do public service users experience and evaluate the alternative ways in which their interests may be represented, and what factors guide their 'choice about voice'? Mechanisms available for users to express their views can be categorised as 'hierarchical' (e.g. contacting elected officials); individualistic (e.g. complaints procedures); or group-based (e.g. user forums). Users make assumptions about what channel is appropriate for particular issues in a particular context. However, their ability to communicate via their chosen channel is dependent on viable opportunities to do so. This idea of viability (or lack of it) goes beyond the simple provision of a full range of channels. It relates to the prospects of users' views being recognised and accepted - and to the sense of disconnection and withdrawal that often accompanies low expectations or disappointing experiences. © The Author(s) 2011.
http://dx.doi.org/10.1177/0952076710384903

242. Small, W., L. Maher, J. Lawlor, E. Wood, K. Shannon, T. Kerr. Injection drug users' involvement in drug dealing in the downtown eastside of Vancouver: Social organization and systemic violence. International Journal of Drug Policy, 2013. 24(5): p. 479-487.
Background: Illicit drug markets are a key component of the risk environment surrounding injection drug use. However, relatively few studies have explored how injection drug users' (IDUs) involvement in drug dealing shapes their experiences of drug market-related harm. This exploratory qualitative study aims to understand IDUs' dealing activities and roles, as well as the perceived benefits and risks related to participation in illicit drug markets, including experiences of drug market violence. Methods: Ten IDUs with extensive involvement in drug dealing activities were recruited from the Vancouver Injection Drug User Study (VIDUS) and participated in semi-structured qualitative interviews, which elicited discussion of experiences dealing drugs, perceived benefits and hazards related to dealing, and understandings of drug market violence. Results: Participant's involvement in drug market activities included corporate sales, freelance or independent sales, and opportunistic sales termed "middling" as well as drug market-related hustles entailing selling bogus drugs and robbing dealers. Participants primarily dealt drugs to support their own illicit drug use, and we found that arrest and criminal justice involvement, hazards stemming from drug debts, and drug market-related violence were key risks related to dealing activities. Conclusion: The challenges of managing personal consumption while selling drugs exacerbates the hazards associated with drug dealing. Efforts to address drug dealing among IDUs should consider both drug dependency and the material conditions that propel drug

users towards dealing activities. Interventions should explore the potential of combining enhanced drug treatment programs with low threshold employment and alternative income generation opportunities. © 2013 .
http://dx.doi.org/10.1016/j.drugpo.2013.03.006

243.   Smith, E., F. Ross, S. Donovan, J. Manthorpe, S. Brearley, J. Sitzia, P. Beresford. <mark>Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice</mark>. International Journal of Nursing Studies, 2008. 45(2): p. 298-315.
Objectives: In the UK policy recommends that service users (patients, carers and the public) should be involved in all publicly funded health and social care research. However, little is known about which approaches work best in different research contexts and why. The purpose of this paper is to explain some of the theoretical limitations to current understandings of service user involvement and to provide some suggestions for theory and methods development. This paper draws upon findings from a review of the research 'evidence' and current practice on service user involvement in the design and undertaking of nursing, midwifery and health visiting research. Design: A multi-method review was commissioned by the NHS Service Delivery and Organisation (SDO) Research and Development Programme. The timeframe was April 2004-March 2005. The full report (Ref: SDO/69/2003) and supplementary bibliography are available from: http://www.sdo.ishtm.ac.uk. Review methods/data: Initial searches of the health and social care literature and consultations with researchers were used to develop a broad definition of the topic area. A service user reference group (26 members) worked with the project team to refine the scope of the review, to set inclusion criteria and develop a framework for the analysis. Systematic searches of the literature were undertaken online and through library stacks (345 relevant documents were identified). Ongoing and recently completed studies that had involved service users were identified through online databases (34 studies) and through a national consultation exercise (17 studies). Selected studies were followed up using <mark>telephone interviews</mark> (n = 11). Members of the service user reference group worked with the research team to advise on key messages for dissemination to different audiences. Results: Information was gained about contextual factors, drivers, concepts, approaches and outcomes of service user involvement in nursing, midwifery and health visiting research, as well as developments in other research fields. Synthesis of this information shows that there are different purposes and domains for user involvement, either as part of researcher-led or user-led research, or as part of a partnership approach. A number of issues were identified as being important for future research. These include: linking different reasons for service user involvement with different outcomes; understanding the relationship between research data and service user involvement, and developing conceptualisations of user involvement that are capable of accommodating complex research relationships. Suggestions for the development of practice include: consideration of diversity, communication, ethical issues, working relationships, finances, education and training. Conclusions: Because research is undertaken for different reasons and in different contexts, it is not possible to say that involving service users will, or should, always be undertaken in the same way to achieve the same benefits. At a research project level uniqueness of purpose is a defining characteristic and strength of service user involvement. (C) 2006 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ijnurstu.2006.09.010

244.   Smith, E., F.M. Ross. Service user involvement and integrated care pathways. International Journal of Health Care Quality Assurance, 2007. 20(3): p. 195-214.
Purpose - Understanding patients' experiences of their interactions with health services is an important step in building quality from within. The purpose of this article is to look at the

possibilities for involving service users in the development of the National Health Service in England through the structure of integrated care pathways (ICPs). Design/methodology/approach - A systematic literature review was undertaken to identify how patient experiences have been attained and used in three clinical areas: cataract care, hip replacement and knee arthroscopy. The information was weighted according to methodological criteria and synthesized according to the typical stages of each pathway. Key issues were summarised thematically across each pathway. Findings - The findings relate to the use of patient views and experiences within organisational structures, service development, methodological research, education and training. The article identifies important issues of practical significance for involving service users in the planning and development of patient focused ICPs: such as the diversity of patients, perspectives of continuity, information and patient support and the need for methodological research. Research limitations/implications - The review is limited in that the literature across all three pathways tends to report findings of small studies undertaken in one clinical service or setting and most studies are not randomised or controlled. Originality/value - The literature identified by the review contains important messages for both NHS policy and future research to involve service users in the planned expansion and plurality of NHS care. © Emerald Group Publishing Limited. http://dx.doi.org/10.1108/09526860710743345

245. Smith, H.B., C. Porteous, C. Bunce, K. Bonstein, J. Hickey, C.M. Dayan, . . . D.G. Ezra. **Description and evaluation of the first national patient and public involvement day for thyroid eye disease in the United Kingdom**. Thyroid, 2014. 24(9): p. 1400-1406.
Background: To ensure appropriate patient-focused outcomes, the National Institute for Health Research (NIHR) in the United Kingdom has made consultation with patients, caregivers, and the public a prerequisite to providing research funding. One method of encouraging engagement with research is through patient and public involvement (PPI) events. We describe the planning and implementation of a PPI day for thyroid eye disease (TED) and evaluate our own event using feedback from delegates. Methods: The Moorfields NIHR Biomedical Research Centre, in partnership with TED charities, arranged the first national PPI day for TED in the United Kingdom. The event included didactic lectures; pre-event and postevent questionnaires; an exhibition with stalls, posters, and an interactive voting wall to determine research priorities; focus group sessions to explore patient experiences and perceptions of research; and one-on-one interviews recording individual patient stories. Results: Of 100 attendees, 70 completed questionnaires. When asked whether the day had provided what they wanted, 48 of 52 (92%) said yes; 3 of 52 (6%) said no. Overall 6 of 52 (12%) rated the event as good; 28 of 52 (54%), very good; and 18 of 52 (34%), excellent. Thirty-six patients registered to participate in further research, identifying "finding the cause for TED," "improving psychological support," and "achieving a better cosmetic outcome" as key priorities. A poor understanding of TED among medical professionals was a common complaint. Conclusions: The event received positive feedback and achieved its key objective of engaging patients, researchers, and clinicians in a two-way discussion about research priorities and improved study design. An invaluable insight was gained into patients' needs for a better quality of life, and we have demonstrated that important data can be captured from such events, providing an evidential basis consistent with the NIHR principles of patient-centered research. © Mary Ann Liebert, Inc.
http://dx.doi.org/10.1089/thy.2014.0200

246. Snape, D., J. Kirkham, N. Britten, K. Froggatt, F. Gradinger, F. Lobban, . . . A. Jacoby. Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: A modified Delphi study. BMJ Open, 2014. 4(6).

Objective: To explore areas of consensus and conflict in relation to perceived public involvement (PI) barriers and drivers, perceived impacts of PI and ways of evaluating PI approaches in health and social care research. Background: Internationally and within the UK the recognition of potential benefits of PI in health and social care research is gathering momentum and PI is increasingly identified by organisations as a prerequisite for funding. However, there is relatively little examination of the impacts of PI and how those impacts might be measured. Design: Mixed method, three-phase, modified Delphi technique, conducted as part of a larger MRC multiphase project. Sample: Clinical and non-clinical academics, members of the public, research managers, commissioners and funders. Findings: This study found high levels of consensus about the most important barriers and drivers to PI. There was acknowledgement that tokenism was common in relation to PI; and strong support for the view that demonstrating the impacts and value of PI was made more difficult by tokenistic practice. PI was seen as having intrinsic value; nonetheless, there was clear support for the importance of evaluating its impact. Research team cohesion and appropriate resources were considered essential to effective PI implementation. Panellists agreed that PI can be challenging, but can be facilitated by clear guidance, together with models of good practice and measurable standards. Conclusions: This study is the first to present empirical evidence of the opinions voiced by key stakeholders on areas of consensus and conflict in relation to perceived PI barriers and drivers, perceived impacts of PI and the need to evaluate PI. As such it further contributes to debate around best practice in PI, the potential for tokenism and how best to evaluate the impacts of PI. These findings have been used in the development of the Public Involvement Impact Assessment Framework (PiiAF), an online resource which offers guidance to researchers and members of the public involved in the PI process.
http://dx.doi.org/10.1136/bmjopen-2014-004943

247. Solbjør, M., A. Steinsbekk. **User involvement in hospital wards: Professionals negotiating user knowledge. A qualitative study**. Patient Education and Counseling, 2011. 85(2): p. e144-e149.
Objective: To investigate how health professionals in hospital wards that have voluntarily initiated user involvement negotiate user knowledge into their professional knowledge. Methods: Qualitative interviews were conducted with 18 health professionals from 12 hospital wards in Central Norway. Results: The main value to health professionals of initiating user involvement was gaining access to user knowledge. Two functions of user knowledge were identified - user knowledge as an alternative to professional knowledge and user knowledge as support for professional knowledge. The need for good professional practice was used as an argument for closing professional fields to user involvement. Professionals were also under scrutiny from other discourses, such as scientific-bureaucratic medicine, which had a strong impact on how user involvement was carried out. Conclusion: Health professionals saw knowledge transfer as valuable, but ultimately valued professional knowledge above user knowledge. Practice implications: Even health personnel who embrace user involvement limit the influence of user knowledge on their own professional work. It seems necessary that user involvement be included in health policy and practice guidelines at hospital wards, if it is desirable that user knowledge influence professional knowledge and everyday work. © 2011 Elsevier Ireland Ltd.
http://dx.doi.org/10.1016/j.pec.2011.02.009

248. Soneryd, L. **Public involvement in the planning process: EIA and lessons from the Örebro airport extension, Sweden**. Environmental Science and Policy, 2004. 7(1): p. 59-68.
Environmental impact assessment (EIA) has been developed to include techniques for involving the public in environmental decision making. Although there is evidence from the evaluation of EIA in many countries that these ambitions often fail, little research has been done on EIA from

the viewpoint of the public or from a deliberative democracy perspective (a deliberative democracy creates high demands for participation and argumentation for all concerned). This paper discusses public involvement from the perspective of local residents and their possibilities for engaging in deliberative processes in varying arenas. A case study on an airport extension in Sweden is used as an illustrative example of more general questions of public objectives, means, strategies and influence that are raised in relation to public involvement in planning. When local residents find that the EIA process does not provide them with the tools necessary to make an impact, they may find other creative ways of acting, outside as well as within formal arrangements for public involvement. As shown by this case study EIA opens up an arena for deliberation between concerned parties, but which may then be closed by mechanisms that restrict public involvement and impact. However, there are many arenas for deliberation, both within the traditional representative system and through local protests-an important issue to address if we want to understand involvement (or non-involvement) in EIA from the viewpoint of the public as well as from a deliberative democracy perspective. © 2003 Elsevier Ltd. All rights reserved. http://dx.doi.org/10.1016/j.envsci.2003.10.007

249.   Sorebo, A.M., O. Sorebo, M.K. Sein, *The Influence of User Involvement and Personal Innovativeness on User Behavior*, in *Proceedings of World Academy of Science, Engineering and Technology, Vol 26, Parts 1 and 2, December 2007*, C. Ardil, Editor 2007. p. 98-103.

250.   Speers, J. **Service user involvement in the assessment of a practice competency in mental health nursing - Stakeholders' views and recommendations**. Nurse Education in Practice, 2008. 8(2): p. 112-119.
Competence in building therapeutic relationships is essential for student mental health nurses and therefore requires robust assessment. However, the assessment of such complex skills is problematic. Following policy directives exhorting increased service user involvement in general, there have been recent suggestions that service users could contribute to the assessment of practice. This paper outlines a research project which investigated the views of 24 stakeholders (service users, lecturers, mentors, ex-students and student nurses) about the potential involvement of service users in the assessment of student mental health nurses' competence in forming therapeutic relationships. The findings revealed that service users interviewed had a largely positive attitude towards this potential development. Nurse participants were more ambivalent. Despite citing several key advantages, nurses also expressed some important reservations about how such a proposal could be implemented in practice. Nevertheless, on balance, they were in favour in principle. Key recommendations for the implementation of this potential development included strategies to enable anonymity and freedom of choice for service users. A range of options for obtaining service user feedback were put forward, along with some ideas about how the fairness of the assessment might be protected. © 2007 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.nepr.2007.04.002

251.   Speers, J., J. Lathlean. **Service user involvement in giving mental health students feedback on placement: A participatory action research study**. Nurse education today, 2015. 35(9): p. e84-e89.
BACKGROUND: Although the drive to engage service users in service delivery, research and education has mainstream acceptance, it is not easy to achieve meaningful involvement. The contribution that could potentially be made by users whilst accessing services is often overlooked. OBJECTIVES AND PARTICIPANTS: This study involved stakeholders (mentors, service users and a lecturer) working together to design, evaluate and refine a system enabling students to seek feedback from service users. The feedback concerned mental health students' interpersonal skills and

occurred whilst on practice placement. This research aimed to explore the experiences of those concerned when nine students attempted to learn from rather than about service users.

DESIGN: A 2-year study, encompassing five cycles of participatory action research (PAR).

SETTING: A small island community in the British Isles, adopting UK standards for pre-registration nurse education.

METHODS: Data came from interviews with service users and mentors and a series of reflective group discussions with students who volunteered to try out the feedback mechanism. The deliberations of the PAR stakeholder group informed the research cycles and added to the data, which were subject to thematic analysis.

FINDINGS: Findings indicated that service users volunteering to give feedback had unanimously positive experiences. Students' experience lay on a continuum: those with a stronger sense of self were more willing and able to ask for feedback than less confident students. Cultural adjustment to the role change needed was challenging, requiring self-awareness and courage. Over time, all students achieved deep learning and, for some, learning appeared transformative.

CONCLUSION: Although contextual, the study concluded that the feedback initiative encouraged the development of more equitable relationships, in which mental health nurses respected the expertise of service users. This potentially benefits student development, recovery-orientated practice, service users and HEIs searching for meaningful ways to involve service users in learning and formative assessment.
http://dx.doi.org/10.1016/j.nedt.2015.07.004

252.   Spiers, S., K. Harney, C. Chilvers. **Service user involvement in forensic mental health: Can it work?** Journal of Forensic Psychiatry and Psychology, 2005. 16(2): p. 211-220.

In 2001 the Department of Health issued its Research Governance Framework for Health and Social Care and subsequent Research Governance Implementation Plan which outlined the steps toward full compliance with the framework by 2004. The Research Governance Framework says that service users and their representatives should wherever possible be involved in the design, conduct, analysis, and reporting of research. The benefits of involving service users in the research process have been highlighted in many research fields including cancer and mental health, where active partnership with service users has ensured that research is meaningful and relevant to their needs. Involvement of service users and carets can shape the research agenda through the provision of a valuable perspective which is shaped by people's own experiences. However, the many practical implications of the involvement of service users in research need to be addressed to ensure that their involvement is not tokenistic. Important issues of public protection and security further complicate service user involvement in forensic mental health research. The UK National Forensic Mental Health Research and Development Programme actively encourages the involvement of service users in its research commissioning processes and has taken some innovative steps to involve current forensic mental health service users in research prioritisation and commissioning. © 2005 Taylor & Francis Group Ltd.
http://dx.doi.org/10.1080/14789940500098137

253.   Staley, K., S.A. Buckland, H. Hayes, M. Tarpey. ==**'The missing links': understanding how context and mechanism influence the impact of public involvement in research**==. Health Expectations, 2014. 17(6): p. 755-764.

Introduction It is now more widely recognized that public involvement in research increases the quality and relevance of the research. However, there are also more questions as to exactly how and when involvement brings added value. The nature of the current evidence of impact Based on the findings of recent literature reviews, most reports of public involvement that discuss impact

are based on observational evaluations. These usefully describe the context, the type of involvement and the impact. However, the links between these factors are rarely considered. The findings are therefore limited to identifying the range of impacts and general lessons for good practice. Reflecting on the links between context, mechanism and outcome in these observational evaluations identifies which aspects of the context and mechanism could be significant to the outcome. Studies that are more in line with the principles of realistic evaluation can test these links more rigorously. Building on the evidence from observational evaluations to design research that explores the 'missing links' will help to address the question 'what works best, for whom and when'. Conclusions We conclude that a more intentional and explicit exploration of the links between context, mechanism and outcome, applying the principles of realistic evaluation to public involvement in research, should lead to a more sophisticated understanding of the factors that increase or decrease the likelihood of positive outcomes. This will support the development of more strategic approaches to involvement maximizing the benefits for all involved. http://dx.doi.org/10.1111/hex.12017

254.   Staley, K., V. Minogue. User involvement leads to more ethically sound research. Clinical Ethics, 2006. 1(2): p. 95-100.
Involving service users and carers in clinical research can help to improve its quality and relevance. By defining the limits of ethical acceptability, improving research design and management, ensuring information for participants is accessible and ensuring the views of participants are properly respected, user involvement can also improve the ethical conduct of research. But research proposals with good quality user involvement have experienced difficulties in obtaining ethical approval. Not all Research Ethics Committees (RECs) fully understand the active role of service user/carer researchers and the current review system can act as a barrier to involving service users and carers in research. This problem urgently needs to be addressed because it is actually in the interests of RECs to promote and support user involvement. This will require adapting the systems of ethical approval, providing further training for REC members and involving service users and carers in developing and implementing these changes. © 2006, Royal Society of Medicine Press. All rights reserved. http://dx.doi.org/10.1258/147775006777254489

255.   Staniszewska, S., K.L. Haywood, J. Brett, L. Tutton. **Patient and Public Involvement in Patient-Reported Outcome Measures Evolution Not Revolution**. Patient-Patient Centered Outcomes Research, 2012. 5(2): p. 79-87.
This paper considers the potential for collaborative patient and public involvement in the development, application, evaluation, and interpretation of patient-reported outcome measures (PROMs). The development of PROMs has followed a well trodden methodological path, with patients contributing as research subjects to the content of many PROMs. This paper argues that the development of PROMs should embrace more collaborative forms of patient and public involvement with patients as research partners in the research process, not just as those individuals who are consulted or as subjects, from whom data are sourced, to ensure the acceptability, relevance, and quality of research. We consider the potential for patients to be involved in a much wider range of methodological activities in PROM development working in partnership with researchers, which we hope will promote paradigmal evolution rather than revolution. http://dx.doi.org/10.2165/11597150-000000000-00000

256.   Staniszewska, S., N. Jones, M. Newburn, S. Marshall. **User involvement in the development of a**

research bid: Barriers, enablers and impacts. Health Expectations, 2007. 10(2): p. 173-183.

Objective: To involve users in the development of a research bid to examine parents' experiences of having a pre-term baby, and to examine the barriers, enablers and impacts of user involvement. Design: A mainly collaborative approach to user involvement was adopted, although different types of involvement were evident at different stages of the project. Users' experiences and perspectives provided the focus for the regular meetings which underpinned the writing of the research bid. The researcher acted as a facilitator in the development of the bid, with input from users and the wider advisory group. Main outcomes: User involvement had an important impact on the development of the research aims, methods and on ethical aspects. Through careful collaboration a research bid was produced which was rooted in users' experiences, whilst also addressing key research questions. Key enablers for involvement included good working relationships, funding for the lead researchers time. Barriers included lack of financial support for users, the time-consuming nature of involvement and the language of research. Conclusions: If user involvement remains an international policy imperative with little if any support at the vital stage of bid development, policy-makers, service user organizations, researchers, health service providers and commissioners will need to recognize the limited nature of involvement that may result and the impact this would have on the evidence base. Researchers will need to recognize the resource implications of involvement at this point, and user groups will need to decide whether to participate when there is the greatest chance of influencing research but little or no funding. © 2007 The Authors.
http://dx.doi.org/10.1111/j.1369-7625.2007.00436.x

257.   Stclair Tullo, E., L. Robinson, J. Newton. <mark>Comparing the perceptions of academics and members of the public about patient and public involvement in ageing research</mark>. Age & Ageing, 2015. 44(3): p. 533-536.

Background: public and patient involvement (PPI) in clinical research is increasingly advocated by funding and regulatory bodies. However, little is known about the views of either academics or members of the public about perceptions of the practical realities of PPI, particularly in relation to ageing research. Objective: to survey current levels of PPI in biomedical and clinical research relating to ageing at one institution. To compare and contrast the views of academics and the public about PPI relating to research about ageing. Design: electronic survey of senior academics, postgraduate students and members of a local user group for older people. Setting and participants: thirty-three academics (18 principal investigators and 15 PhD students) at a biomedical research institution. Fifty-four members of a local user group for older people. Results: thirty per cent (10/33) of projects described some PPI activity. Older adults were more positive about active involvement in research about ageing than academics. The perceived benefits of and barriers to involvement in research were similar among all groups, although older members of the public were more likely than academics to acknowledge potential barriers to involvement. Conclusion: academics and older people share some perceptions about PPI in ageing research, but members of the public are more optimistic about active involvement. Further correspondence between these groups may help to identify feasible involvement activities for older people and encourage collaborative research about ageing. [ABSTRACT FROM AUTHOR]

http://dx.doi.org/10.1093/ageing/afu193

258.   Stewart, E., M. Aitken. **Beyond NIMBYs and NOOMBYs: what can wind farm controversies teach us about public involvement in hospital closures?** BMC health services research, 2015. 15: p. 530. BACKGROUND: Many policymakers, researchers and commentators argue that hospital closures are necessary as health systems adapt to new technological and financial contexts, and as population health needs in developed countries shift. However closures are often unpopular with local communities. Previous research has characterised public opposition as an obstacle to change. Public opposition to the siting of wind farms, often described as NIMBYism (Not In My Back Yard), is a useful comparator issue to the perceived NOOMBYism (Not Out Of My Back Yard) of hospital closure protestors.

DISCUSSION: The analysis of public attitudes to wind farms has moved from a fairly crude characterisation of the 'attitude-behaviour gap' between publics who support the idea of wind energy, but oppose local wind farms, to empirical, often qualitative, studies of public perspectives. These have emphasised the complexity of public attitudes, and revealed some of the 'rational' concerns which lie beneath protests. Research has also explored processes of community engagement within the wind farm decision-making process, and the crucial role of trust between communities, authorities, and developers. Drawing on what has been learnt from studies of opposition to wind farms, we suggest a range of questions and approaches to explore public perspectives on hospital closure more thoroughly. Understanding the range of public responses to service change is an important first step in resolving the practical dilemma of effecting health system transformation in a democratic fashion.
http://dx.doi.org/10.1186/s12913-015-1172-x

259.   Stringer, B., B. Van Meijel, W. De Vree, J. Van Der Bijl. **User involvement in mental health care: The role of nurses. A literature review**. Journal of Psychiatric and Mental Health Nursing, 2008. 15(8): p. 678-683.
This literature review was carried out to examine the effects of user involvement in shared decision-making processes and the methods/tools available to psychiatric nurses to measure and encourage user involvement. A systematic literature review was then used in this study. Many studies indicate that an increased involvement of service users leads to better care, better treatment compliance, improved health outcomes and higher levels of patient satisfaction. The tools and methods described are designed to measure the ability to participate, the process of implementation and the evaluation of healthcare services. An adequate instrument to measure user involvement will be necessary to underpin the positive effects. Although care providers have a statutory duty to help shape user involvement, and the tools required are available, care providers are still insufficiently inclined to take up this duty. © 2008 Blackwell Publishing Ltd.
http://dx.doi.org/10.1111/j.1365-2850.2008.01285.x

260.   Subramanyam, R., F.L. Weisstein, M.S. Krishnan. ==User participation in software development projects==. Communications of the ACM, 2010. 53(3): p. 137-141.
Introduction It is commonly acknowledged that success in IT projects is difficult to achieve. A recent industry survey observed that only 34% of IT projects were considered successful. Of the several potential factors contributing to this hard-to-achieve success, user involvement was noted as the most important one. Consistent with this notion, both researchers and practitioners have viewed user participation as an important way of improving software quality and increasing user satisfaction and acceptance. Users/customers are often encouraged to participate and directly communicate with developers in the software development process. On the other hand, empirical

evidence shows that user participation in the development process can negatively influence project performance since it could make the process more difficult, lengthy, and less effective. Such contradictory findings raise the question of when user participation is actually helpful and when it might negatively impact project performance. Previous research tells only one side of the story since it has examined user participation or project performance by focusing primarily on user viewpoints. The findings give an incomplete picture since they have not thoroughly addressed developer viewpoints. Clearly, there is a need to investigate software project success from the perspective of developers given that not only are they at the core of development process but they also represent the largest single cost in software development. Developer satisfaction is imperative for systems development success. Dissatisfied developers would adversely affect the quality of software as well as the productivity of development teams. A high rate of developer turnover in projects (due to dissatisfaction) could lead to increasing costs for development firms as well as high user/customer dissatisfaction. Due to the differences in background and circumstance, developers and users often share different and sometimes conflicting interests during software development. Researchers have identified a large gap in perceptions and definitions of project success between developers and the software industry (for example, users/customers). For example, developers tend to be achievement-oriented and are intrinsically motivated to develop excellent software, while users/ customers emphasis more on meeting a schedule or maintaining a budget. Thus, the potential conflicting interests between users and developers might negatively affect the software development performance. This article addresses the question of the relative effectiveness of user participation by empirically examining the perceived software project performance (for example, satisfaction) from both user and developer perspectives simultaneously. We used survey data from 117 software development projects and 746 respondents at a large Fortune 100 manufacturing firm during a four-year time period to investigate the impact of user participation on the satisfaction of both developers and users. Our findings offer insights into the impact of user participation on generating higher levels of developer and user satisfaction and, at the same time, minimizing the perception gap between users and developers on project performance. In addition, we also study the role of software complexity (for example, whether projects involve new software development as opposed to maintenance of existing software) in user participation and its effect on satisfaction. ==Questionnaire== data was collected from 453 software developers and 293 users/customers working on 117 software projects (for details of the data collection process, see the sidebar "How the Survey was Conducted"). The average number of developer survey respondents per project (for example, team) was four and the average number of user/customer respondents per project was three. Our analysis was performed at project level, and satisfaction scores for developers and users were averaged for each project. Of the 117 software development projects, 45 (39% of our sample) were maintenance projects and 72 (61%) were new development projects. The average software development time of the 117 software projects was 126 days. Figure 1 outlines the project characteristics in our sample. The most common business domain for our software projects was the manufacturing and supply chain (41 projects, 35%) and most of the projects were Web-based applications (78 projects, 66%). © 2010 ACM.
http://dx.doi.org/10.1145/1666420.1666455

261. Sykes, C., W. Goodwin. **Assessing patient, carer and public involvement in health care**. Quality in Primary Care, 2007. 15(1): p. 45-52.
Involving patients and carers aims to be empowering and broaden participation in decision making. However, creating adequate structures and processes for involvement is still in its infancy. Clarity of the meaning of involvement can help to move patient, carer and public involvement

from rhetoric to reality. This paper presents a content analysis of NHS staff's, patients', carers' and the public's understanding of involvement. Six categories of involvement were identified (outcome-focused, patient-led, representative, variety of methods, feedback, those with power should be involved). The categories were used to pilot a questionnaire to measure involvement based on their understanding of involvement. A reliability analysis demonstrated good reliability. Further development is needed to assess construct validity. Feedback from those involved in piloting the questionnaire highlights that involvement is a complex process involving more than tangible outcomes. We recommend that further research is carried out to understand and assess the quality of the process of patient, carer and public involvement. © 2007 Radcliffe Publishing.

262. Syme, G.J., B.S. Sadler. **Evaluation of Public Involvement in Water Resources Planning: A Researcher-Practitioner Dialogue**. Evaluation Review, 1994. 18(5): p. 523-542.
This article identifies evaluation of decisions incorporating public involvement as an area where views might differ according to the role of the stakeholder. The two authors have had extensive interaction in a wide variety of public involvement programs related to water resources, but from the differing perspectives of research and practice. Because of increasing public interest in quality public involvement programs, valuation has a high priority for both authors. Based on theory and experience, six general criteria that are seen by both researcher and practitioner as requirements for adequate evaluation are presented in the context of a brief case study. © 1994, Sage Publications. All rights reserved.
http://dx.doi.org/10.1177/0193841X9401800501

263. Szmukler, G., K. Staley, T. Kabir. **Service user involvement in research**. Asia-Pacific Psychiatry, 2011. 3(4): p. 180-186.
Involving service users as research partners is likely to be one of the major developments in research management and conduct in the twenty-first century. We outline the reasons why we believe this will make for better research, citing examples. Some of the many ways in which service users can be involved are described, but there remains plenty of scope for innovation and creativity. There are significant challenges, but the evidence from experience in this field indicates they can be overcome. © 2011 Blackwell Publishing Asia Pty Ltd.
http://dx.doi.org/10.1111/j.1758-5872.2011.00145.x

264. Sølling, I.K., P. Carøe, K.S. Mathiesen. **Development and implementation of IT require focus on user participation, acceptance and workflow**. Studies in health technology and informatics, 2014. 201: p. 219-226.
The study "Online Care" follows a municipal project "Online Welfare" where a nurse's presence in the citizen's own home was replaced by online communication. The paper is based on a citizen's perspective and seeks to develop meaningful workflow for the benefit of citizens with medical problems. The study examines five citizens' opinions on whether online communication in a meaningful way supports the citizens in what they associate with a good life. In addition, relatives and the citizen's nurse were interviewed individually concerning the same issues as the citizens. The study has been approved by the Danish System of Ethics in Science and is conducted in collaboration with Aalborg University, Aalborg Municipality and DanAge, (NGO). The municipality's goal of efficiency and financial savings regarding "Online Welfare" was not honored due to insufficient network infrastructure and technical problems. An adoption barrier was that the municipality did not determine the efforts and the goal of the project, who could benefit from participating and the requirements of the professionals and the organization including ethical considerations. It was difficult to find citizens who were willing to participate. Citizens, who were

included in the study accepted and adopted the technology however, "Online Welfare" could not replace the care they used to receive. Therefore, the offer was perceived as an "appendix" which tended to meaninglessness by some of the citizens. The nurses' perception of nursing care and their limited IT skills was a barrier to acceptance, adoption and development of technology opportunities in nursing. The citizens' disability, the screen appearance, and the technology setup meant that the citizens perceived poor usability of the equipment. The study showed a change in workflow, as the cooperation between the citizen and the professional developed. New roles occurred for the professionals. The citizens had many ideas concerning the development of the technology and the study recommends that users are involved in the development and implementation of welfare technology and telemedicine. The relatively small sample size of the study shows findings that must be clarified by further research.

265.   Sørensen, E.W., L.S. Haugbølle. **Using an action research process in pharmacy practice research-A cooperative project between university and internship pharmacies**. Research in Social and Administrative Pharmacy, 2008. 4(4): p. 384-401.
Background: Action research (AR) is a common research-based methodology useful for development and organizational changes in health care when participant involvement is key. However, AR is not widely used for research in the development of pharmaceutical care services in pharmacy practice. Objectives: To disseminate the experience from using AR methodology to develop cognitive services in pharmacies by describing how the AR process was conducted in a specific study, and to describe the outcome for participants. Methods: The study was conducted over a 3-year period and run by a steering group of researchers, pharmacy students, and preceptors. The study design was based on AR methodology. The following data production methods were used to describe and evaluate the AR model: documentary analysis, qualitative interviews, and ==questionnaires.== Results: Experiences from using AR methodology and the outcome for participants are described. A set of principles was followed while the study, called the Pharmacy-University study, was being conducted. These principles are considered useful for designing future AR studies. Outcome for participating pharmacies was registered for staff-oriented and patient-oriented activities. Outcome for students was practice as project leaders and enhancement of clinical pharmacy-based skills. Outcome for researchers and the steering group conducting the study was in-depth knowledge of the status of pharmacies in giving advice to patient groups, and effective learning methods for students. Conclusion: Developing and implementing cognitive pharmaceutical services (CPS) involves wide-reaching changes that require the willingness of pharmacy and staff as well as external partners. The use of AR methodology creates a platform that supports raising the awareness and the possible inclusion of these partners. During this study, a set of tools was developed for use in implementing CPS as part of AR. © 2008 Elsevier Inc. All rights reserved. http://dx.doi.org/10.1016/j.sapharm.2007.10.005

266.   Tang, J.P.S., S. Tse, L. Davidson. **The big picture unfolds: Using photovoice to study user participation in mental health services**. The International journal of social psychiatry, 2016. 62(8): p. 696-707.
BACKGROUND: User participation is advocated on the basis that consumers know their own needs better than anyone else. Photovoice is a participatory research method that empowers the grass-root population to give voice on concerned issues for eliciting social change.
AIM: This study explores the experience and impact of user participation in mental health services (MHS) in Hong Kong through photovoice. It also examines the effects of this method in studying user participation.

METHOD: In this qualitative inquiry, authors, two peer researchers and three participants were involved in the various stages of research design, data collection and data analysis. Participants took photos showing their perception and experiences of being involved in different MHS systems. They shared their narratives through these images and reflected on the participatory experience of photovoice.

RESULTS: User participation was experienced as a gradual process of assuming control that involved personal responsibility, connection with peers, collaboration with staff, redefinition of boundaries and social inclusion. Meaningful participation gave rise to a sense of contribution, interpersonal connection and self-worth and transformed one's identity. Participants enjoyed the mutual interaction and derived benefit from the photovoice process. Issues such as consent and confidentiality arose in implementation.

CONCLUSION: Participation entails partnership among service users, providers and peers. Photovoice opens up new space for unfolding expert knowledge. Further application of this participatory approach with the local community is suggested in order to develop person-centered care.

267.   Tang, Z.J., J.H. Luo, U. Alfred, *Determinants of user participation during business-to-business information system development: a field study*. Sixth Wuhan International Conference on E-Business, Vols 1-4: Management Challenges in a Global World2007. 776-781.

268.   Tee, S., J. Lathlean, L. Herbert, T. Coldham, B. East, T.-J. Johnson. **User participation in mental health nurse decision-making: a co-operative enquiry**. Journal of Advanced Nursing, 2007. 60(2): p. 135-145.

Title. User participation in mental health nurse decision-making: a co-operative enquiry Aim. This paper is a report of a study to encourage participants to work together to identify strategies for increasing user participation in clinical decisions and to evaluate the value of co-operative inquiry as a vehicle for supporting learning in practice. Background. Service user participation in the clinical practice decisions of mental health nurses is considered essential for good practice. Methods need to be found which enable opportunities for shared learning, facilitate practice development and empower service users. Method. A co-operative inquiry design engaged all participants (n = 17) as co-researchers and involved repeated cycles of action and reflection, using multiple data collection methods. The research was conducted over a two year period in 2004–2005, with mental health nursing students collaborating with service users. Findings. Factors inhibiting participation included stigmatizing and paternalistic approaches, where clinical judgments were made solely on the basis of diagnosis. Enhancing factors were a respectful culture which recognized users''expertise' and communicated belief in individual potential. Inquiry benefits included insight into service users' perspectives, enhanced confidence in decision-making, appreciation of power issues in helping relationships and deconstruction of decision-making within a safe learning environment. Conclusion. Learning from novel approaches which enable nursing students to develop their reflective and reflexive ability is essential to avoid practice which disempowers and potentially harms service users' recovery. Co-operative inquiry is a valuable vehicle for developing professional practice in higher education and practice environments. [ABSTRACT FROM AUTHOR]

http://dx.doi.org/10.1111/j.1365-2648.2007.04345.x

269. Terry, J. **Service user involvement in pre-registration mental health nurse education classroom settings: A review of the literature**. Journal of Psychiatric and Mental Health Nursing, 2012. 19(9): p. 816-829.
Service user involvement is an important part of pre-registration nursing programmes, as it can give students the opportunity to learn from users about their experiences of health and illness, but so far there have been limited studies in this area. • This literature review provides an opportunity to explore how service user involvement in classroom settings can impact on student learning, and describes methods of best practice. • Further research is needed to understand the influence of service user involvement on student nurses' clinical practice. Service user involvement in pre-registration nurse education is now a requirement, yet little is known about how students engage with users in the classroom, how such initiatives are being evaluated, how service users are prepared themselves to teach students, or the potential influence on clinical practice. The aim of this literature review was to bring together published articles on service user involvement in classroom settings in pre-registration mental health nurse education programmes, including their evaluations. A comprehensive review of the literature was carried out via computer search engines and the Internet, as well as a hand search of pertinent journals and references. This produced eight papers that fitted the inclusion criteria, comprising four empirical studies and four review articles, which were then reviewed using a seven-item checklist. The articles revealed a range of teaching and learning strategies had been employed, ranging from exposure to users' personal stories, to students being required to demonstrate awareness of user perspectives in case study presentations, with others involving eLearning and assessment skills initiatives. This review concludes that further longitudinal research is needed to establish the influence of user involvement in the classroom over time. © 2012 Blackwell Publishing.
http://dx.doi.org/10.1111/j.1365-2850.2011.01858.x

270. Terry, J., C. Standing. **The value of user participation in E-commerce systems development**. Informing Science, 2004. 7: p. 31-45.
Many researchers and practitioners consider user participation in the development of an information system is essential to the success of the system. System designers have promoted development techniques that demand user participation, such as prototyping, rapid application development and joint application design. Interestingly, the research literature on the topic has not been conclusive about the value of user participation, although the perception of value has still existed. The importance of user participation in information systems could be seen as a myth. The time pressure to develop Web based e-commerce systems and the propagation of the view that e-commerce is different and subject to different rules has led developers to question the value of customer participation in the development process. Indeed, the notion of the "user" has become confused. No longer is a user necessarily found in-house, but may be a geographically remote customer unknown to an organization. This paper proposes and validates a model that examines the role of key users and stakeholders in e-commerce applications development. Despite the business need for remote, untrained users to quickly feel comfortable and satisfied in an e-commerce site encounter, it appears that many organisations are making little effort to engage users in e-commerce site developmental activities.

271. Terry, J.M. **The pursuit of excellence and innovation in service user involvement in nurse education programmes: Report from a travel scholarship**. Nurse Education in Practice, 2013. 13(3): p. 202-206.
The involvement of service users and carers in nurse education is increasing, with the new

standards for pre-registration nurse education in the UK, which require nurse education providers to demonstrate how they are involving users and carers in the planning, delivery, teaching and evaluation of nursing curricula (Nursing and Midwifery Council, 2010). A travel scholarship provided the opportunity to explore best practice in this area, focussing on identifying support systems and processes that enable user involvement.The scholarship was undertaken in the UK and Ireland during a 4 week study tour between June and July 2011, during which I visited 15 universities, and met with nurse education staff, users and carers involved in nurse education programmes. Prerequisite processes, the spectrum and variety of involvement activities, quality assurance and evaluation; and sustainability of user involvement in nurse education are reported in this paper. Service users and carers are an under-utilised resource, and as experts by experience have much to offer students and staff by increased involvement in nurse education programmes. The importance of values, enthusiasm and relationships, the cornerstones that strengthen user involvement; often sustain such partnerships. © 2012 Elsevier Ltd.
http://dx.doi.org/10.1016/j.nepr.2012.09.004

272. Terry, L.M. **Service user involvement in nurse education: A report on using online discussions with a service user to augment his digital story**. Nurse Education Today, 2012. 32(2): p. 161-166.
Service user involvement is a key element within current pre- and post-registration nurse education in the U.K. but achieving this is challenging. Most service user involvement is through classroom visits. Digital stories, film and audio are alternatives but lack the interactivity and development of reflection that can be achieved through face-to-face contact. This report reviews the background to service user involvement in healthcare professional education then provides a reflective account of a novel initiative whereby a spinal-injured patient was involved in creating a digital story around some of his in-hospital experiences and then engaged in online discussions with post-registration nursing (degree) and practice educator (masters) students. These discussions provided a richer experience for the students enabling them to reflect more deeply on how nursing care is delivered and perceived by service users. The report concludes that digital stories can be used with repeated groups to inspire discussion and reflection. Augmenting such digital stories with online discussions with the service user whose story is told helps practitioners develop greater empathy, insight and understanding which are beneficial for improving service delivery and nursing care. © 2011 Elsevier Ltd.
http://dx.doi.org/10.1016/j.nedt.2011.06.006

273. Thompson, J., R. Barber, P.R. Ward, J.D. Boote, C.L. Cooper, C.J. Armitage, G. Jones. <mark>Health researchers' attitudes towards public involvement in health research</mark>. Health Expectations, 2009. 12(2): p. 209-220.
Objective To investigate health researchers' attitudes to involving the public in research. Background Public involvement in research is encouraged by the Department of Health in the UK. Despite this, the number of health researchers actively involving the public in research appears to be limited. There is little research specifically addressing the attitudes of health researchers towards involving the public: how they interpret the policy, what motivates and de-motivates them and what their experiences have been to date. Design A qualitative research design, using semi-structured telephone interviews. Setting and participants Fifteen purposively sampled UK-based University health researchers were the participants. Interviews were conducted over the telephone. Findings The participants suggested varying constructions of public involvement in research. Arguments based on moral and political principles and consequentialist arguments for involving the public in research were offered and most participants highlighted the potential benefits of involving the public. However, feelings of apprehension expressed by some

participants imply that a number of researchers may still be uncomfortable with involving the public, as it presents a different way of working. © 2009 Blackwell Publishing Ltd.
http://dx.doi.org/10.1111/j.1369-7625.2009.00532.x

274.   Thompson, J., P. Bissell, C.L. Cooper, C.J. Armitage, R. Barber. **Exploring the Impact of Patient and Public Involvement in a Cancer Research Setting**. Qualitative Health Research, 2014. 24(1): p. 46-54.
An enduring theme in the literature exploring patient and public involvement (PPI) in research has been the focus on evaluating impact, defined usually in terms of participants' practical contribution to enhancing research processes. By contrast, there has been less emphasis on the perspectives and experiences of those involved in PPI. Drawing on qualitative data with people involved in the National Cancer Research Network in the United Kingdom, we report on what motivated participants to get involved and their experiences of involvement in this setting. We highlight how those involved in PPI often espoused the notion of the good citizen, with PPI in research being a natural extension of their wider civic interests. However, our findings also highlight how PPI was an important resource, utilized by participants to make sense of living with chronic illness. We suggest that PPI in research also offers spaces for the reconfiguration of self and identity.
http://dx.doi.org/10.1177/1049732313514482

275.   Thornicroft, G., M. Tansella. **Growing recognition of the importance of service user involvement in mental health service planning and evaluation**. Epidemiologia e Psichiatria Sociale, 2005. 14(1): p. 1-3.
Service user involvement in the planning and provision of mental health services has been growing over the last two decades, especially in countries and areas where institutional service provision has been changed to a community-orientated model of care. However, the material involvement of service users in mental health research is still in its infancy. The aim of this paper is to attempt to place these developments in a conceptual context, to summarise the ethics-based and evidence-based reasons why it has to be considered as necessary, and to illustrate some of the emerging evidence which shows the advantages to be gained from it. In particular the results of recent studies are briefly reported, showing that outcomes data rated by service users in some cases are more important than those rated by staff. The reduction in patient-rated unmet needs in the social domain was the strongest predictor of an increase in subjective quality of life. The importance of including service user preferences within the content of the research questions is exemplified by the results of a recent study that showed that joint crisis plans can significantly reduce the use of compulsory admission during crises and by a review that demonstrated that the use of an explicit service user perspective produced distinctive insights into the long-term effects of Electro-Convulsive Therapy (ECT).

276.   Thornton, H. **Patient and public involvement in clinical trials**. BMJ, 2008. 336(7650): p. 903-904.
http://dx.doi.org/10.1136/bmj.39547.586100.80

277.   Thorstensen, E. **Public Involvement and Narrative Fallacies of Nanotechnologies**. NanoEthics, 2014. 8(3): p. 227-240.
This paper analyzes a European research project called 'Deepening Ethical Engagement and Participation in Emerging Nanotechnologies' with the abbreviation DEEPEN. The DEEPEN's findings and conclusions on the narratives, public understandings and the lay ethics of nanotechnologies are examined in a critical manner. Through a criticism of the theoretical

framings of what constitutes a narrative and the application of a different theoretical framing of narratives, the paper argues that the findings and conclusion of the DEEPEN should be approached with caution as there are several unjustified claims concerning the contextualization of the findings. Such claims pertain to the theoretical framing of narratives, virtue ethics, modernity, lay attitudes, and earlier research. © 2014, Springer Science+Business Media Dordrecht.
http://dx.doi.org/10.1007/s11569-014-0202-1

278.   Townend, M., T. Braithwaite, *Mental health research–the value of user involvement,* in *Journal of Mental Health*2002, Routledge. p. 117-119.
        Editorial. Explores the role of service users in mental health research. Impact of the experience of distress among service users on the research; Importance of incorporating cultural change in service user research; Pros and cons with the activism of service users.
        Editorial

279.   Tovolgyi, S. **User involvement in the ergonomic development of a medical instrument: a longitudinal case study**. International Journal of Occupational Safety and Ergonomics, 2016. 22(2): p. 207-217.
        In this study the focus is on the continuous ergonomic-focused development of a medical instrument that is capable of performing blood group serological tests. Primarily, a medical device must be clinically effective and safe. At the same time it must also meet the needs of its users. This calls for consideration of numerous ergonomic aspects. The development process of the product line in question was supported by a longitudinal series of carefully designed focus groups. Altogether, the 23 focus groups conducted included 245 participants from 72 laboratories. The aim of the empirical research was to collect users' experiences, ideas and needs as inputs for the following phase of the product development process. During the mentioned focus group analyses, around 100 development proposals were conceived. Besides presenting more of the mentioned development proposals, the focus group analysis was shown as a proper methodology to involve end-users in the development and implementation of new technology or devices.
        http://dx.doi.org/10.1080/10803548.2015.1131072

280.   Tritter, J., V. Barley. **User involvement in Cancer Services**. Clinical Oncology, 2001. 13(1): p. 6-7.

281.   Trivedi, P., T. Wykes. **From passive subjects to equal partners: Qualitative review of user involvement in research**. British Journal of Psychiatry, 2002. 181(DEC.): p. 468-472.
        Background: The Department of Health and UK funding bodies have suggested that clinical academics work closely with mental health service users in research projects. Although there are helpful guidelines on the issues that have to be dealt with, there have been few examples of how this partnership research might be undertaken. Aims: To illustrate the challenges in joint research projects. Method: We subjected the process of user involvement to ten questions which arose in the development of a joint research project. The answers are an amalgamation of the user and clinical researcher considerations and are affected by hindsight. Results: The involvement of the user-researcher changed the focus of the study and its design and content. More attention was paid to the intervention itself and the way in which it was delivered. This process increased the amount of time taken to carry out and write up the project as well as incurring financial costs for user consultation payments and dissemination. Conclusions: This experience has clarified the contribution that users can make, for example by raising new research questions, by ensuring

interventions are kept 'user friendly', and the selection of outcome measures.
http://dx.doi.org/10.1192/bjp.181.6.468

282. Truman, C., P. Raine. **Experience and meaning of user involvement: some explorations from a community mental health project**. Health & social care in the community, 2002. 10(3): p. 136-143.
With an increased interest in and policy commitment to involving service users in the planning and delivery of health service provision, there is a clear need to explore both the rhetoric and realities of what user involvement entails. In the present paper, by drawing upon an evaluation of a community-based exercise facility for people with mental health problems, the authors explore ways in which the reality of user involvement is subject to a range of configurations within health services. The paper describes a piece of qualitative research that was undertaken within a participatory framework to explore the nature of user involvement within the facility. The data have been analysed using a grounded theory approach to provide insights into: the organisational context in which user involvement takes place; factors which encourage meaningful participation on the part of service users; perceived barriers to user involvement; and issues of sustainability and continuity. This research approach has enabled the authors to explore the views and experiences of users, service providers and referral agencies in relation to the nature and potential for user involvement. The findings illustrate ways in which user involvement may take place under both flexible and formal arrangements across a variety of activities. The present paper provides an account of some of the meanings and experiences of what 'successful' user participation may involve and the conditions which underpin 'success'. The authors conclude that successful and meaningful user involvement should enable and support users to recognise their existing skills, and to develop new ones, at a pace that suits their particular circumstances and personal resources. This process may require adaptation not only by organisations, but also by service providers and non-involved users.

283. Tullo, E.S.C., L. Robinson, J. Newton. **Comparing the perceptions of academics and members of the public about patient and public involvement in ageing research**. Age and Ageing, 2015. 44(3): p. 533-536.
Background: public and patient involvement (PPI) in clinical research is increasingly advocated by funding and regulatory bodies. However, little is known about the views of either academics or members of the public about perceptions of the practical realities of PPI, particularly in relation to ageing research.Objective: to survey current levels of PPI in biomedical and clinical research relating to ageing at one institution. To compare and contrast the views of academics and the public about PPI relating to research about ageing.Design: electronic survey of senior academics, postgraduate students and members of a local user group for older people.Setting and participants: thirty-three academics (18 principal investigators and 15 PhD students) at a biomedical research institution. Fifty-four members of a local user group for older people.Results: thirty per cent (10/33) of projects described some PPI activity. Older adults were more positive about active involvement in research about ageing than academics. The perceived benefits of and barriers to involvement in research were similar among all groups, although older members of the public were more likely than academics to acknowledge potential barriers to involvement.Conclusion: academics and older people share some perceptions about PPI in ageing research, but members of the public are more optimistic about active involvement. Further correspondence between these groups may help to identify feasible involvement activities for older people and encourage collaborative research about ageing.
http://dx.doi.org/10.1093/ageing/afu193

284.   Wai Michael Siu, K. User participation: quality assurance for user-fit design. International Journal of Quality and Service Sciences, 2010. 2(3): p. 287-299.
Purpose – The purpose of this paper is to discuss how the participatory approach should be considered and applied in research for the disabled. It aims to arouse the awareness of policymakers, professionals, researchers and the general public that disabled people must not only be considered, but also invited to participate in research actively in order to bring real benefit to disabled people. Design/methodology/approach – An in depth case study related to policy, implementation and management quality of tactile guide paths (TGP) was carried out in Hong Kong. Participatory approach was adopted to explore how to help visually impaired people (VIP) access places independently. The methods included group discussions, direct individual interviews, field studies and intensive observations. Findings – The quality of TGP is still unsatisfactory in policy, implementation and management aspects in that VIP still face a lot of difficulties in accessing places, in particular the places they have never gone before. Two of the major causes of poor quality of TGP are misunderstanding and neglect. VIP, as well as other disabled people, still face many difficulties arising from different sources; from the grant society policies to small objects in their daily lives. Practical implications – VIP should not be considered as a group of people with ills, trouble and problems in the society. Policymakers, professionals in design and implementation and management people must recognise that they should not impose their value judgments and preferences on VIP. Instead, user participation is a good and applicable approach to assure a high quality of design. Originality/value – The paper offers insights into quality assurance for user fit designs. © 2010, Emerald Group Publishing Limited http://dx.doi.org/10.1108/17566691011090035

285.   Valentine, G., B. Jamieson, A.M. Kettles, M. Spence. User's involvement in their care: A follow-up study. Journal of Psychosocial Nursing and Mental Health Services, 2003. 41(4): p. 18-25.

286.   Walker, D.-M., R. Pandya-Wood. Can research development bursaries for patient and public involvement have a positive impact on grant applications? A UK-based, small-scale service evaluation. Health Expectations, 2015. 18(5): p. 1474-1480.
The article presents the study that investigates the implications of research development bursaries, for use in patient and public involvement (PPI), on the applications of grants in Great Britain. The topics discussed include the concept of PPI, the effectiveness of the bursary in enhancing the dialogue between researchers and service users, and challenges experienced by researchers in carrying out their qualitative research. http://dx.doi.org/10.1111/hex.12127

287.   Wallen, M., N. Gerrand. Patient and public involvement (PPI) in research is perceived to benefit stroke survivors and the research process. Barriers and facilitators exist which can be addressed to enable PPI in stroke research. Australian Occupational Therapy Journal, 2016. 63(3): p. 218-219.
The article presents abstract of the article "Exploring patient and public involvement (PPI) in stroke research: A qualitative study" by M. Harrison and R. Palmer is presented, and offers an opinion on it. Topics discussed include exploration of experiences of stroke survivors in PPI, positive impact of PPI like development of supportive relationships and intellectual stimulation, and a lack in involvement of stroke survivors due to their non-consideration as an oppressed group.
http://dx.doi.org/10.1111/1440-1630.12304

288.   Varsi, C., E. Børøsund, J. Mirkovic. User participation for successful development of eHealth

self-management interventions. BMC Nursing, 2017. 16: p. 9-9.

Background eHealth interventions have the potential to support patients in self-managing their illness, improve quality of life and enhance self-efficacy. Despite interest from patients and their health care providers, eHealth interventions are seldom used as intended and have high attrition rates. To avoid this, it is important to ensure that the interventions are designed in line with the users' requirements and contexts. Therefore, at Center for Shared Decision Making and Collaborative Care Research, Oslo University Hospital, we use Service Design methods to involve end-users and other stakeholders in the whole process of design and development of eHealth interventions. This presentation will show how we integrate the Service Design methods into our work, by showing some examples. Materials and Methods Service Design (Stickdorn & Schneider 2011) is used as an approach to support the entire design and development process, aiming to elicit user wants and needs, and identifying how to best fit the eHealth intervention into the daily routines of patients and health care providers. Together with researchers and software developers, patients and health care providers are involved at each stage of intervention development. In the initial phase we use methods such as interviews and focus groups with stakeholders to identify their needs and requirements and observations to identify contextual conditions. The results are summarized into for example intervention Journey maps ("road maps") or Personas (fictive patient characters). Based on gained insights, the next phases include series of workshops, where we together define opportunities, get inspiration, co-create ideas and develop intervention prototypes. Prototypes are then iteratively tested, validated and adapted through series of formative evaluations, using methods such as usability testing, think-aloud protocol, before the interventions are ready for final efficacy trials. Results We will present some examples of how Service Design methods can be used to involve different stakeholders into design and development of eHealth intervention. The close collaboration between researchers, software developers, patients and health care providers creates a genuine platform to develop solutions which are inspired by genuine behaviors, contexts and needs. Conclusions Even if the involvement of patients and health care providers is time-consuming and there is need for careful facilitation, the Service Design approach is useful for creating eHealth and other healthcare interventions that are in line with the users' needs and requirements. In this way, we are able to create interventions that people want to use, and thus contribute to creating better health for people. [ABSTRACT FROM AUTHOR]

289. Vereist, T., *Design for all: Experience-based strategies for user involvement in IST research projects*, in *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)*. 2004. p. 104-109.

Ever since 1998, ISdAC International Association has been actively promoting a Design for All approach with regard to IST applications, as well as supporting several initiatives in this regard. It is ISdAC's belief that Design for All starts with active user involvement in the earliest stage of the product development process. Therefore, part of our activities focused on gathering information on disabled people's experiences with existing products, as well as on creating an inventory of the difficulties encountered when becoming active online. We have been able to put together a group of disabled experts online, who can act as a user test bed for several research projects in

this regard. Recently we have been involved in three IST research projects. This paper will present in detail the user requirements capture strategies and experiences, mainly in the scope of the IPCA project. Furthermore I will formulate some conclusions and recommendations in the field of an IST DfA approach based on our experiences. © Springer-Verlag 2004.
Article

290. Veseth, M., P.E. Binder, M. Borg, L. Davidson. Collaborating to stay open and aware: Service user involvement in mental health research as an aid in reflexivity. Nordic Psychology, 2017: p. 1-8.
Research collaboration with people with first-hand knowledge of mental distress and recovery processes has been argued to hold potential of making studies more relevant and more rigorous. There is, however, less awareness of how service user involvement can increase reflexivity in research, which is another important component to evaluating the quality of studies. In this conceptual analysis, we explore our experiences of doing collaborative research and discuss these in relation to the concept of reflexivity. We argue that both in planning investigations, collecting the material as well as in data analytic phases, partnering up with service users can be a valuable way to stay open and aware in the process of conducting qualitative studies on issues in mental health. We identify reflexivity as a possible benefit of service user involvement in research and as crucial for actualizing the full potential of such research collaborations. © 2017 The Editors of Nordic Psychology
http://dx.doi.org/10.1080/19012276.2017.1282324

291. Whiteford, M. Square pegs, round holes: Rough sleeping and service User involvement? Practice, 2011. 23(1): p. 45-58.
In contemporary social work practice and education service, user involvement has become an iridescent concept. Yet, in the case of homeless people, the specific challenges and potentially powerful effects of such participatory approaches have been significantly neglected. As a result, the distinctive 'voices' and experiences of homeless people in general and rough sleepers in particular are all too frequently overlooked or ignored. This paper, drawing on a study of a small voluntary day-centre for people experiencing homelessness in a 'rural county', sets out to raise fundamental questions about the link between homelessness, the practice of citizenship and the mobilisation of the vocabulary of 'user involvement'. Using an engaged ethnographic research approach, this article suggests that there are deep-rooted flaws in the service user involvement project and its emancipatory claims. © 2011 British Association of Social Workers.
http://dx.doi.org/10.1080/09503153.2010.532547

292. Williamson, T., L. Kenney, A.T. Barker, G. Cooper, T. Good, J. Healey, . . . C. Smith. Enhancing public involvement in assistive technology design research. Disability and rehabilitation. Assistive technology, 2015. 10(3): p. 258-265.
PURPOSE: To appraise the application of accepted good practice guidance on public involvement in assistive technology research and to identify its impact on the research team, the public, device and trial design.
METHODS: Critical reflection and within-project evaluation were undertaken in a case study of the development of a functional electrical stimulation device. Individual and group interviews were undertaken with lay members of a 10 strong study user advisory group and also research team members.
RESULTS: Public involvement was seen positively by research team members, who reported a positive impact on device and study designs. The public identified positive impact on confidence, skills, self-esteem, enjoyment, contribution to improving the care of others and opportunities for further

involvement in research. A negative impact concerned the challenge of engaging the public in dissemination after the study end.

CONCLUSIONS: The public were able to impact significantly on the design of an assistive technology device which was made more fit for purpose. Research team attitudes to public involvement were more positive after having witnessed its potential first hand. Within-project evaluation underpins this case study which presents a much needed detailed account of public involvement in assistive technology design research to add to the existing weak evidence base.

IMPLICATIONS FOR REHABILITATION: The evidence base for impact of public involvement in rehabilitation technology design is in need of development. Public involvement in co-design of rehabilitation devices can lead to technologies that are fit for purpose. Rehabilitation researchers need to consider the merits of active public involvement in research.
http://dx.doi.org/10.3109/17483107.2014.908247

293.   Wing, J., T. Andrew, D. Petkov, Ieee. The Changing Nature of User Involvement in Information System Development Projects. 2017 Conference on Information Communication Technology and Society (Ictas), 2017.
This paper presents an investigation into the changing nature of user involvement in Information System Development (ISD) projects. This analysis shows the representative papers that have been published on user involvement in ISD projects and identifies areas requiring further investigation and research. Considering different project contexts the need for a new approach where an ISD project is steeped within social complexity is proposed. The specific phase of requirements elicitation and the need to consider more than the technical requirements for an ISD project are clearly presented. The systems approach is proposed for considering the "whole" rather than the separate social and technical systems as well as considering the business processes that are associated with the ISD project. It is proposed that creating a shared understanding between users and developers at the very beginning stages of an ISD project will influence a projects success.

294.   Witteman, H.O., S.C. Dansokho, H. Colquhoun, A. Coulter, M. Dugas, A. Fagerlin, . . . W. Witteman. User-centered design and the development of patient decision aids: Protocol for a systematic review. Systematic Reviews, 2015. 4(1).
Background: Providing patient-centered care requires that patients partner in their personal health-care decisions to the full extent desired. Patient decision aids facilitate processes of shared decision-making between patients and their clinicians by presenting relevant scientific information in balanced, understandable ways, helping clarify patients' goals, and guiding decision-making processes. Although international standards stipulate that patients and clinicians should be involved in decision aid development, little is known about how such involvement currently occurs, let alone best practices. This systematic review consisting of three interlinked subreviews seeks to describe current practices of user involvement in the development of patient decision aids, compare these to practices of user-centered design, and identify promising strategies. Methods/design: A research team that includes patient and clinician representatives, decision aid developers, and systematic review method experts will guide this review according to the Cochrane Handbook and PRISMA reporting guidelines. A medical librarian will hand search key references and use a peer-reviewed search strategy to search MEDLINE, EMBASE, PubMed, Web of Science, the Cochrane Library, the ACM library, IEEE Xplore, and Google Scholar. We will identify articles across all languages and years describing the development or evaluation of a patient decision aid, or the application of user-centered design or human-centered design to tools intended for patient use. Two independent reviewers will assess article eligibility and extract

data into a matrix using a structured pilot-tested form based on a conceptual framework of user-centered design. We will synthesize evidence to describe how research teams have included users in their development process and compare these practices to user-centered design methods. If data permit, we will develop a measure of the user-centeredness of development processes and identify practices that are likely to be optimal. Discussion: This systematic review will provide evidence of current practices to inform approaches for involving patients and other stakeholders in the development of patient decision aids. We anticipate that the results will help move towards the establishment of best practices for the development of patient-centered tools and, in turn, help improve the experiences of people who face difficult health decisions. Systematic review registration: PROSPERO CRD42014013241. http://dx.doi.org/10.1186/2046-4053-4-11

295. Wright, D., C. Foster, Z. Amir, J. Elliott, R. Wilson. <mark>Critical appraisal guidelines for assessing the quality and impact of user involvement in research</mark>. Health expectations : an international journal of public participation in health care and health policy, 2010. 13(4): p. 359-368.
The involvement of service users in the design and conduct of health research has developed significantly in the UK in recent years. Involving service users is now seen as a core component of good research practice for all forms of health research. Given the important role that users have in health research, it is necessary to develop guidelines for their effective involvement. Whilst guidelines are currently being formulated, there remain no criteria with which to assess user involvement in published studies and funding applications. This study offers guidelines for appraising the quality and impact of user involvement in published papers and grant applications. Appraisal guidelines for user involvement have been developed on the basis of available literature and experiences from studies involving cancer patients and carers in the design and conduct of research. Nine appraisal criteria have been developed. Criteria include issues such as 'Is the rationale for involving users clearly demonstrated?', 'Is the level of user involvement appropriate?', 'Is the recruitment strategy appropriate?', and 'Is the nature of training appropriate?' Generating and applying guidelines is vital if the impact of user involvement agenda in health research is to be understood. © 2010 University of Southampton. Health Expectations © 2010 Blackwell Publishing Ltd.

296. Wright, N., E. Rowley, A. Chopra, K. Gregoriou, J. Waring. **From admission to discharge in mental health services: a qualitative analysis of service user involvement**. Health Expectations, 2016. 19(2): p. 367-376.
BackgroundUser involvement and recovery are now widely used terms within the mental health policy, research and practice discourse. However, there is a question mark about the impact these ideas have in everyday practice. Of interest is the degree of involvement in key transitions of care. In particular, admission to and discharge from acute inpatient mental health wards. ObjectiveTo explore the nature of service user involvement in the admission and discharge process into and out of acute inpatient mental health care. DesignA qualitative study using focus groups. Setting and ParticipantsOne acute, inpatient mental health ward was the focus of the study. Seven uniprofessional focus group interviews were conducted with ward staff, community staff and service users (total number of participants=52). Conventional, thematic qualitative techniques were used to analyse the data. ResultsThe data analysed and presented in this article relate to the loss of the service user voice at the key transition points into and out of acute inpatient care. Due to the lack of resources (inpatient beds and community care follow-up), the role service users could play was diminished. In their narratives, clinical staff associated the person with the process and used language which dehumanized the individual. ConclusionService users experience

numerous care transitions into and out of hospital. As there is the potential for these encounters to have a lasting negative effect, the importance of ensuring service users have a voice in what is happening to them is crucial.
http://dx.doi.org/10.1111/hex.12361

297.   Xu, J.J., G.M. Li. **The Impact of User Involvement in Virtual Brand Communities on Customer-Brand Relationship**. 2014 China Marketing International Conference - China's Contributions to Marketing: Theory and Practice, 2014: p. 53-65.
This research survey of the registered users of the forum "MEIZU", which is an emerging domestic electronics brand. Based on the theoretical model of participation in virtual brand communities, brand relationship and brand experience, this research applied multivariate regression to analyses the impact of customer participation to brand relationship via brand experience. Research findings are: the participation in virtual brand communities has positive effects on brand experience; the dimensions of brand experience affects brand relationship differently; the dimensions of brand experience affects has different mediate effects; affection experience and act experience have positive mediate effects significantly, while sense experience, think experience and relate experience do not have significant mediate effects.

298.   Yates, L.A., M. Orrell, A. Spector, V. Orgeta. **Service users' involvement in the development of individual Cognitive Stimulation Therapy (iCST) for dementia: A qualitative study**. BMC Geriatrics, 2015. 15(1).
Background: Individual Cognitive Stimulation Therapy (iCST) is a one to one, carer led psychosocial intervention for people with dementia, adapted from group Cognitive Stimulation Therapy (CST). It is increasingly recognised that involving service users in research is key to developing interventions and treatments that successfully address their needs. This study describes the contribution of people with dementia and carers during the development phase of the intervention and materials. Methods: Twenty-eight people with dementia and carers were consulted in a series of six focus groups and 10 interviews. The purpose of this study was to gain insight into perceptions of mental stimulation from the point of view of carers and people with dementia, to ensure the materials are easy to use, clear, and appropriately tailored to the needs of people with dementia and their carers, and to assess the feasibility of the intervention. Results: The importance of mental stimulation was emphasized by carers and people with dementia. People with dementia saw activities as a way of 'keeping up to date ' and spending time in a meaningful way. Carers reported benefits such as improved quality of life, mood and memory. The concept of iCST was well received, and both carers and people with dementia responded positively to the first drafts of materials. Feasibility issues, such as finding time to do sessions, were identified. Conclusion: The feedback from the focus groups and interviews will be used to further develop and refine the iCST programme materials in preparation for a field testing phase prior to a large scale randomized controlled trial (RCT). Trial registration: ISRCTN65945963. Date of registration: 05/05/2010. © 2015 Yates et al.; licensee BioMed Central.
http://dx.doi.org/10.1186/s12877-015-0004-5

299.   Ynnesdal Haugen, L.S., A. Envy, M. Borg, T.J. Ekeland, N. Anderssen. **Discourses of service user involvement in meeting places in Norwegian community mental health care: a discourse analysis of staff accounts**. Disability and Society, 2016. 31(2): p. 192-209.
Abstract: In previous research, meeting places have been favourably addressed by service users, but they have also been contested as exclusionary. In this participatory explorative study, we sought to perform a contextual analysis of meeting places in Norway based on a discourse

analysis of three focus group discussions with 15 staff members. We asked the following question: how do meeting-place employees discuss their concrete and abstract encounters with service users and their experiences? We focused on service user involvement, which was largely analysed as neoliberal consultation and responsibilisation. Service users were positioned as resisting responsibility trickling down and defending staffed meeting places. Social democratic discourse was identified in the gaps of neoliberal discourse, which is noteworthy given that Norway is a social democracy. This relates to global concerns about displacements of democracy. We suggest that meeting places appear to hold the potential for staff and service users to collaborate more democratically. © 2016 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.
http://dx.doi.org/10.1080/09687599.2016.1139489

300.   Zaviršek, D., P. Videmšek. **Service users involvement in research and teaching: Is there a place for it in Eastern European social work**. Ljetopis Socijalnog Rada, 2009. 16(2): p. 207-222.
The article presents three major prerequisites for users' participation in research and teaching: a) the »narrative turn« in social sciences and particularly in social work, b) the impact of disability movements and other social movements in local contexts for the development of users' participation, c) the need for the development of an anti-paternalistic, strengths and resilience-oriented perspective of the professionals towards service users. In Eastern European countries which rather lack all of these three elements, users' participation and involvement in research and teaching still require a lot of cultural and professional changes. The article presents two case studies of users' involvement in research and teaching in Slovenia. In 2007 a group of mental health services users were trained to become researchers in group homes for people with mental health problems in Ljubljana. They have proven, like most of the western studies on this matter, the need for participatory research in social work in order to gain a deeper understanding of the everyday experiences of service users. Since 1999 more service users, especially those experiencing mental health problems and with diff erent impairments, were invited to give lectures and seminars to the social work students at the University of Ljubljana. The article analyses their experiences including the one of the »glass ceiling« in the dominant culture of the power-knowledge discourse.

301.   Åberg, A.C., K. Halvorsen, I. From, Å.B. Bruhn, L. Oestreicher, A. Melander-Wikman. **A study protocol for applying user participation and co-learning—lessons learned from the ebalance project**. International Journal of Environmental Research and Public Health, 2017. 14(5).
The eBalance project is based on the idea that serious exergames—i.e., computer gaming systems with an interface that requires physical exertion to play—that are well adapted to users, can become a substantial part of a solution to recognized problems of insufficient engagement in fall-prevention exercise and the high levels of fall-related injuries among older people. This project is carried out as a collaboration between eight older people who have an interest in balance training and met the inclusion criteria of independence in personal activities of daily living, access to and basic knowledge of a computer, four staff working with the rehabilitation of older adults, and an interdisciplinary group of six research coordinators covering the areas of geriatric care and rehabilitation, as well as information technology and computer science. This paper describes the study protocol of the project's initial phase which aims to develop a working partnership with potential users of fall-prevention exergames, including its conceptual underpinnings. The qualitative methodology was inspired by an ethnographical approach implying combining methods that allowed the design to evolve through the study based on the participants' reflections. A participatory and appreciative action and reflection (PAAR) approach,

accompanied by inquiries inspired by the Normalization Process Theory (NPT) was used in interactive workshops, including exergame testing, and between workshop activities. Data were collected through audio recordings, photos, and different types of written documentation. The findings provide a description of the methodology thus developed and applied. They display a methodology that can be useful for the design and development of care service and innovations for older persons where user participation is in focus. © 2017 by the authors. Licensee MDPI, Basel, Switzerland.
http://dx.doi.org/10.3390/ijerph14050512