Table B-1. Context of stakeholder engagement

| **Author, Year, Country** | **What is the context for s/h engagement in this article?** | **How will those engaged be impacted by the decisions they have input into?** | **What types of s/h are engaged?** |
| --- | --- | --- | --- |
| COCHRANE | | | |
| Horey, 2010[1](#_ENREF_1)  New Zealand | Cochrane paper, the purpose is to gain agreement on s/h engagement in the strategic direction for the Cochrane collaboration. | Information not found | Consumer volunteers; consumer facilitators and consumer organizations partners |
| Nilsen et al., 2006[2](#_ENREF_2)  Norway | A SR looking at s/h engagement in health care policy and health care research | Information not found | “…patients; unpaid carers; parents/guardians; users of health services; disabled people; members of the public who are the potential recipients of health promotion/public health programmes; groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services; groups asking for research because they believe they have been denied products or services from which they believe they could have benefited; and organisations that represent service user and carers.”  “…’lay’, ‘non-expert’, ‘service user’, ‘survivor’ or ‘member of the general public’.” |
| Wale et al., 2010[3](#_ENREF_3)  Australia | The Cochrane Consumer Network (CCNet) is comprised of over 500 members (volunteers) from over 55 countries . “Its core functions are to enable and support consumers in the work of the Collaboration and to enhance accessibility and relevance of reviews and evidence-based health care through consumer and community participation.” | “Consumers provide a prepublication lay-user perspective to Cochrane protocols and reviews, potentially balancing the health and medical researcher view.“ | “Members come from many different countries and have differing backgrounds in terms of roles and levels of involvement in their health systems.” |
| COMPARATIVE EFFECTIVENESS/PATIENT-CENTERED OUTCOMES RESEARCH (CER/PCOR) | | | |
| Curtis et al., 2012[4](#_ENREF_4)  United States | The Expert Interviews Project aims to identify effective methods and best practices in s/h engagement through interviews and facilitated discussions with national and international experts representing diverse stakeholder groups and various fields of expertise | Information not found | Patients; caregivers; and experts |
| Deverka et al., 2012[5](#_ENREF_5)  United States | “This paper aims to define stakeholder engagement and present a conceptual model for involving stakeholders in CER”  Article looked at results of literature review as well as The Center for Comparative Effectiveness Research in Cancer Genomics (CANCERGEN) to develop a definition for s/h and s/h engagement | Information not found | CANCERGEN: 13 s/h (2 policymakers; 1 regulator; 2 patients/consumers; 3 payers; 3 practicing clinicians; 2 from pharmaceutical and diagnostic industry. |
| Domecq Garces et al., 2012[6](#_ENREF_6)  United States | This is a systematic review of evidence about patient engagement in health care research . “We aimed to identify who are the relevant patients for engagement and how to recruit them, how can they engage, and how can their engagement result in changes in research design, conduct, analysis and dissemination.” | Information not found | “Overall, the available research suggests that patients could successfully play an active and engaged role in research, from participant, to collaborator, to partner.” “Engagement was described through all study phases (preparatory, execution and translation phases).” |
| Hoffman et al., 2010[7](#_ENREF_7)  United States | This paper discusses five general principles for successful stakeholder engagement in comparative effectiveness research. They are based on best practices and lessons learned from five comparative effectiveness research projects that involved the substantial engagement of multidisciplinary groups of experts and stakeholders. These projects are currently under way at the Center for Medical Technology Policy, in Baltimore, Maryland. | Information not found | Information not found |
| Kreis et al., 2012[8](#_ENREF_8)  Germany | Capture current practices of s/h engagement across a range of organizations and groups….that either conduct SRs or commission them.  Goal was to learn from different types of highly regarded organizations how s/h are currently involved, to obtain in-depth understanding about processes | “…increases the accountability of the research process.” | Federal agencies; payer and provider organizations; private and university-based organizations; professional societies |
| HEALTH TECHNOLOGY ASSESSMENT | | | |
| Gagnon et al., 2011[9](#_ENREF_9)  Canada | In 14 studies, pts provided consultation or data about domain of research.  Domains:   1. Selecting technologies to be assessed(2 studies) 2. Assessing selected technologies (5 studies) 3. Dissemination (1 study) | Information not found | Eligibility criteria for SR: patients, caregivers, consumers, members of public |
| Gauvin et al., 2010[10](#_ENREF_10)  Canada | Information not found | Information not found | Definition of “public” depends on time, technology, etc. Six publics (category 1: citizens, groups representing citizens, elected officials; category 2: individual affected by health condition, representatives, service users) |
| Hailey, 2005[11](#_ENREF_11)  Canada | Very high level narrative review of reviews on consumer engagement in HTA to inform Alberta HTA program . Not detailed enough to be terribly helpful. | Information not found | Consumers, defined as patients, caregivers, organizations representing patients, members of the public who may receive health care services. |
| Hailey et al., 2012[12](#_ENREF_12)  Australia | Updated Survey of INAHTA agencies (Nov 2010) on consumer involvement | Information not found | The term “consumers” was taken to include patients, carers, long-term users of services, organizations representing consumers’  interests, and members of the public, following a definition developed by the English HTA program |
| Moran et al., 2011[13](#_ENREF_13) United Kingdom | Reviewed involvement at the five stages of research management in HTA:   1. Identification 2. Prioritization 3. Commissioning 4. Monitoring 5. Publication and dissemination | Information not found | “public involvement”-potential recipients of programs. Encompasses consumers and patients |
| Nielsen et al., 2009[14](#_ENREF_14)  Denmark | Information not found | Information not found | Groups, not individuals, potentially affected by or with interest in, including policy makers, patient organizations, health care professions, and industry. |
| Oliver et al., 2004[15](#_ENREF_15)  United Kingdom | This is a review of different types of consumer involvement in topic identification and prioritization and includes a range of research designs, not only systematic review and not only health care . Therefore the context varies considerably from study to study . The purpose of the review is to inform s/h engagement for NICE HTAs. | Information not found | Consumers |
| PATIENT AND PUBLIC INVOLVEMENT | | | |
| Barber et al., 2011[16](#_ENREF_16)  United Kingdom | Delphi process to answer whether it is possible to measure the impact of public involvement on research (health and social, not SRs) | Information not found | “public” |
| Boote et al., 2006[17](#_ENREF_17)  United Kingdom | UK NHS, formal policy initiative by the Department of Health, which involves the provision of NHS guidance stating that ‘consumer involvement should exist at every stage of research where appropriate’ | No specific information on this is found  Main Study: Discussion of the value of consensus research in this policy area, and a Delphi study to reach consensus on principles and indicators of successful consumer involvement in NHS research  Scope of Research in Which Stakeholders are Engaged: Health service research, clinical trials, secondary research, behavioral research, and population-based research in a variety of health areas, including mental health, physical and learning disabilities, cancer, pregnancy, childbirth and childcare, and older adults. | Researchers, consumers (“patients, potential patients, informal (unpaid) carers, people who use health and social services, and organizations that represent the interests of people who use health and social services, and members of the public who may be the potential recipients of health promotion plans”), and consumer-researchers. |
| Boote et al., 2012[18](#_ENREF_18)  United Kingdom | Considers the range of public involvement in individual systematic reviews by reviewing the literature on public involvement in individual SRs. Includes 9 SRs that involved the public at some level during the review process. | Not reported | “patients and potential patients; people who use health and social services; informed carers; parents/guardians; disabled people; members of the public who are potential recipients of health promotion programs, public health programs and social service interventions; organizations that represent people who use services.” |
| Brett et al., 2010[19](#_ENREF_19)  United Kingdom | “Patient and public involvement has become a central tenet of health care policy in the UK and internationally in shaping health services and policy” | No specific information on this is found.  Main Study: SR of qualitative, case studies, or cross-sectional studies reporting individual or organizational views of PPI, as well as economic evaluations to provide a synthesis of the evidence base on the conceptualization, measurement, impact and outcomes of PPI on health and social care research  Scope of Research in Which Stakeholders are Engaged: The studies included in the review report on views of PPI in health research that involves different types of studies (including SR) in a wide variety of health areas. | Patients and public (“those who use health and social care services, those who are involved at different levels in research, carers/ guardians, people with a disability and other members of the public”) |
| Brett et al., 2012[20](#_ENREF_20)  United Kingdom | The focus of this systematic review was to examine the value and challenges of involving the public in health and social care research (focus on independent research and not SRs).  Includes 66 research articles that describe to impact (or value) of public involvement at some level in the research process. | Not reported | “patients and potential patients; people who use health and social services; informed carers; parents/guardians; disabled people; members of the public who are potential recipients of health promotion programs, public health programs and social service interventions; organizations that represent people who use services.” |
| Involve, 2012[21](#_ENREF_21)  United Kingdom | Provides high-level advice to individual systematic reviewers and organizations who do systematic reviews on involving the public in the systematic process. | Not reported | “patients and potential patients; people who use health and social services; informed carers; parents/guardians; disabled people; members of the public who are potential recipients of health promotion programs, public health programs and social service interventions; organizations that represent people who use services.” |
| Keown et al., 2008[22](#_ENREF_22)  Canada | Reports experience of the Institute for Work and Health SR program’s experience using s/h engagement in SR to increase utilization of SR findings | Information not found | Policy and practitioner decision makers (system level) |
| Vale et al., 2012[23](#_ENREF_23)  United Kingdom | UK NHS, formal policy initiative by the Department of Health, which involves the provision of NHS guidance stating that ‘stating that patients and the public must be involved in all stages of the research process’. | No specific information on this is found.  Main Study: Semi-structured interviews with lead members of staff at MRC CTU to formally assess both past and current levels involvement across all CTU research studies.  Scope of Research in Which Stakeholders are Engaged: RCTs, SR (including meta-analysis) and other clinical studies in a variety of health care areas, primarily cancer, HIV and other infectious diseases. | Researchers and consumers (“patients, carers or family members, health service users, patient representatives or members of groups or organizations that represent those affected by the condition being researched”). |
| Wright et al., 2010[24](#_ENREF_24)  United Kingdom | UK NHS, formal policy initiative by the Department of Health, which involves the provision of NHS guidance stating that ‘consumer involvement should exist at every stage of research where appropriate’ and requiring “all applicants [for research ethics applications] to detail their user involvement activities, regardless of methodological or disciplinary standpoint” | No specific information on this is found  Main Study: Secondary analysis of research evidence from a UK wide research prioritization exercise to develop “a framework for assessing the quality and impact of user involvement in published research and funding applications,” building off on the principles and indicators developed by Boote et al.[17](#_ENREF_17)  Scope of Research in Which Stakeholders are Engaged: Broad spectrum of NHS research activities, including psychosocial research, clinical trials, biomedical research, and surveys in a variety of health care areas, predominantly cancer and palliative care. | Researchers (“any individual engaged in undertaking research activity, whether they are users or professionals, unless stated otherwise”) and “members of the general public, patients, care-givers, potential patients and public, community and voluntary organizations.” |

Note: CCNet=Cochrane Consumer Network; CER=comparative effectiveness research; CTU=Clinical Trials Unit; CEHP=Continuing Education in the Health Professions; EUnetHTA=European Network for Health Technology Assessment; HIV=Human immunodeficiency virus; HTA=Health Technology Assessment; INHATA=International Network of Agencies for Health Technology Assessment; IOM=Institute of Medicine; MRC=Medical Research Council; N/A=not applicable; NHS=National Health Service; NICE=National Institute for Health and Care Excellence; PPI=patient and public involvement; RCT=randomized controlled trial(s); s/h=stakeholder(s); SR=systematic review(s); UK=United Kingdom; INVOLVE definition of s/h = “patients and potential patients; people who use health and social services; informed carers.