Table B-3. Tangible benefits of stakeholder engagement

|  |  |  |  |
| --- | --- | --- | --- |
| **Author, Year, Country** | **What were the key factors that prompted s/h engagement (i.e. mandates, research improvement, other)?** | **What did they expect/hope to achieve by engaging s/h** | **What are some of the tangible benefits?** |
| COCHRANE | | | |
| Horey, 2010[1](#_ENREF_1)  New Zealand | “- Make information about evidence based health care more accessible.  - Learn and keep up to date, either with research about a specific condition or with evidence base health care .  - Contribute to the development of evidence based health care.” | “improve the quality or accessibility of reviews and plain language summaries” | Improved readability and/or quality of reviews; improved usefulness of plain language summaries. |
| Nilsen et al., 2006[2](#_ENREF_2)  Norway | Information not found | Information not found | The potential benefits of consumer involvement in health care include: policy, research, practice and patient information that includes consumers’ ideas or addresses their concerns; improved implementation of research findings; better care; and better health. Consumer participation can be viewed as a goal in itself by encouraging participative democracy, public accountability and transparency. |
| Wale et al., 2010[3](#_ENREF_3)  Australia | “Consumers have been part of the collaboration since its beginning and are formally represented on the steering committee.” No other information is given. | Information not found | Explanation of terms; clearer language and comprehension of text |
| COMPARATIVE EFFECTIVENESS/PATIENT-CENTERED OUTCOMES RESEARCH (CER/PCOR) | | | |
| Curtis et al., 2012[4](#_ENREF_4)  United States | Information not found | Define project goals; understand patient and community needs; determine *why* to engage; determine points of engagement; create transparency; enable ease of participation & fair compensation; | Information not found |
| Deverka et al., 2012[5](#_ENREF_5)  United States | To align with the purpose of CERs in accordance with the IOM’s definition; have s/h directly inform priority areas as opposed to the traditional s/h as a passive audience | Eliminate the divide between scientist and experts and real-world decision makers | Potential to share tangible benefits |
| Domecq Garces et al., 2012[6](#_ENREF_6)  United States | Questions remain on how to engage patients or their representatives (family members, caregivers, community representatives) | Our goal was to describe the practical steps needed to better engagepatients in research. We also asked a group of patients without medical orresearch training to provide their perspective on our results | “…improve study design (by choosing outcomes more meaningful to patients or designs that are more culturally sensitive or consistent with patients’ context), execution (improving subject recruitment and retention) and translation (better implementation, dissemination and uptake).”  “Patient engagement appears to enhance the quality of research  (e.g., improving enrollment rates in studies, making studies more consistent with patients’ values, goals, and preferences).” |
| Hoffman et al., 2010[7](#_ENREF_7)  United States | Evidence and knowledge gaps | This paper’s main purpose is to describe and assess our experiences with engaging stakeholders in comparative effectiveness research, to provide useful insights for others doing similar work. We also hope that the paper will encourage more-systematic documentation and sharing of information about these activities. | From the interviews, our personal experience,  and a review of documents from the Center for Medical Technology Policy, we identified five general principles that contribute to the successful engagement of stakeholders in comparative effectiveness research. The principles are as follows: ensure a balanced representation of all stakeholder groups; get stakeholders to “buy in” to the process and make sure that they clearly understand their roles; provide neutral, expert facilitation of the stakeholder discussions; establish connections among the stakeholders; and keep the stakeholders engaged throughout the research process. |
| Kreis et al., 2012[8](#_ENREF_8)  Germany | IOM recommendations | Information not found | Potential beneficial effect on the relevance and usefulness of the reviews; led to re-shaping the review questions; increased readability and/or quality of reviews, usefulness of summaries in a consumer-friendly language.  Positive effects for consumers: acquiring knowledge and skills with the evidence-based approach, benefits from taking part in discussions with clinicians about the condition that affects them.  Positive effects for researchers: feeling that their research actually makes a difference  Positive effects for organizations: lending credibility and trust to the programme, establishment of a culture of knowledge exchange between researcher and consumers. |
| HEALTH TECHNOLOGY ASSESSMENTS | | | |
| Gagnon et al., 2011[9](#_ENREF_9)  Canada | Information not found | Information not found | Information not found |
| Gauvin et al., 2010[10](#_ENREF_10)  Canada | Information not found | Information not found | Information not found |
| Hailey, 2005[11](#_ENREF_11)  Canada | This is a review, so cites a range of views, mostly UK . Primary themes are: political imperative, morally correct, benefits the research by bringing in perspectives and information that might otherwise not be considered. | Ensure research is relevant to people, improve the legitimacy of the decision-making process. | Cites points for consideration from INHATA, including improving HTA products, increased visibility and uptake of products. |
| Hailey et al., 2012[12](#_ENREF_12)  Australia | Not stated | Transparency; reflects values of all users | Potential to broaden the perspective of assessments; broaden advice provided to decision makers |
| Moran et al., 2011[13](#_ENREF_13)  United Kingdom | Public involvement first piloted in 1997. Ethical obligation – public as part-owners of NHS | Information not found | Information not found |
| Nielsen et al., 2009[14](#_ENREF_14)  Denmark | Information not found | Information not found | Information not found |
| Oliver et al., 2004[15](#_ENREF_15)  United Kingdom | Pragmatism, in the face of consumer demand or  non-cooperation, political principle and the  pursuit of ‘better’ research. | Consumer involvement would improve the way in which research is prioritized, commissioned, undertaken and disseminated . Also result in ‘better’ research that has a higher methodological or ethical quality; produces findings which are more relevant to practical decisions made by consumers and those caring forthem; is presented in more accessible and widely disseminated reports; or more appropriately influences policy and practice. | Benefits firmly taken for granted – lack of benefit assumed due to lack of expertise or leadership in the process. |
| PATIENT AND PUBLIC INVOLVEMENT | | | |
| Barber et al., 2011[16](#_ENREF_16)  United Kingdom | N/A | Public involvement seen as an intrinsic value, but also able to improve the quality of the final product and make it more relevant to end users and increase implementation of findings. | Information not found |
| 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 additional information on this is found | ‘Add synergy to the traditional disease focus of health research, and can facilitate the generation of more relevant research questions and outcomes measures that are grounded in the social realized of those being researched’  ‘Improve both the quality and relevance of health research’ | (i.e., benefits of consensus):  - To further assist researchers on issues of best practice relating to consumer involvement.  - To provide consumers with criteria by which to assess their ‘successful’ involvement in research.  - To provide funding bodies with guidance on consumer involvement that can be incorporated into applications for funding .  - To provide policy analysts with a tool to monitor the extent of ‘successful’ consumer involvement in research. |
| Boote et al., 2012[18](#_ENREF_18)  United Kingdom | Not reported | Not reported | Refining scope of the review by helping SRs select outcomes, populations, or interventions to study (3 cases); set inclusion criteria or framework for analysis (1 case);  Suggesting and locating relevant literature (3 cases)  Appraising the literature (1 cases);  Interpreting review findings or putting review findings into perspective (5 cases);  Writing up the review by either directly authoring or providing input (3 cases) |
| Brett et al., 2010[19](#_ENREF_19)  United Kingdom | To democratize health and social care research  - To ensure it has maximum health and social benefit | See answer to question 7, no additional information is found. | (Areas with Most Evidence of Impact)  Impact on Research and Research Process:  - PPI helps build important links with the community and can help with accessing participants, improving response rates, recruitment from seldom heard groups, development of greater empathy with research subjects and better informed consent based on a more informed participant.  - PPI can help in the assessment and development of research instruments, improve the timing of interventions and ensure the instruments are more acceptable to the community.  - Users can also collect deeper and more insightful data based on their rapport with the participant. Impact on data analysis with users providing a wider perspective, different insights and identifying knowledge gaps for future research.  - PPI can also impact on dissemination and implementation due to the dedication of users, and in some cases through the development of a cohort of advocates who disseminate key findings.  Impact on Users:  - The beneficial impacts were divided into three main areas: personal benefits, impact on level of knowledge and impact on their level of skill, both positive and negative. |
| Brett et al., 2012[20](#_ENREF_20)  United Kingdom | Not reported | Not reported | Initial stages of research: helped identify relevant topics for research agenda, assisted in prioritizing topics, and provided pragmatic feedback on protocol  Undertaking research: assisted in development of appropriate research instruments, helped recruit subjects, and helped researchers gain better insight on subject’s perspectives  Analysis and write-up: helped ensure that emerging themes and trends were interpreted from users perspective, helped identify research gaps, and helped to ensure that final research reports were readable and accessible  Dissemination: helped to ensure that research was disseminated to wider audience and was user friendly. |
| Involve, 2012[21](#_ENREF_21)  United Kingdom | Not reported | Not reported | Not reported  At the individual level: public involvement helps to ensure that questions and outcomes are relevant; deal with specific issues and questions as they arise.  Across a group of SRs: public involvement helps to develop involvement across a coherent program of SRs, draw on experience and expertise of people who best understand the condition covered; ensure reviews address relevant questions and outcomes; ensure involvement throughout review process; provide opportunities for people to develop more strategic roles in review process.  At the unit level: public involvement helps to ensure a consistent or strategic approach across a unit or department; develop public involvement in a broad range of review activities; coordinate the approach to involvement across reviews; lead to public involvement at the earliest stages of reviews; support researchers and public by ensuing they are not isolated; and facilitate quick response to specific issues. |
| Keown et al., 2008[22](#_ENREF_22)  Canada | Not clear, possibly to increase utilization of reviews. | Information not found | Information not found |
| 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 additional information on this is found | “it was the right thing to do”.  - to learn more about the disease or population essential or necessary in  - to ensure recruitment and  - to ensure the appropriateness of research materials or giving guidance on issues  - to meet the recommendations set by funding bodies to involve consumers, without it being a requirement  - “Respondents did not know what reasons had lead to involvement in their studies.” | - Improvements in study design and recruitment  - Improvements in study promotion and dissemination  - Improvements in study documentation, including protocol development, writing patient information, study papers  - Improvements in decision making about the study or its findings  - Increased confidence in the study, leading to better targeting and responding to consumer needs and to better understanding of the conditions or treatments being studied and the relevant research context |
| Wright et al., 2010[24](#_ENREF_24)  United Kingdom | A political imperative for the engagement of service users in research  - the growth in patient and carer advocacy, advocating ethical and moral right for patients and carers to be informed about and engaged in research activity.  - the dissemination of evidence of the benefits of service user engagement by the academic community | No specific information on this is found | (i.e., benefits of assessment tool)  - To enable readers to assess the quality and impact of user involvement in published studies  - To help researchers ensure effective strategies for user engagement are employed in research  - To enable funding bodies to establish principles of effective user involvement in their own practice and to assess the quality of user involvement in applications |

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.