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# Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews

## **ABSTRACT**

### **Objectives**

Involvement of patients, health professionals, and the wider public ('stakeholders') is seen to be beneficial to the quality, relevance and impact of research and may enhance the usefulness and uptake of systematic reviews. However, there is a lack of evidence and resources to guide researchers in how to actively involve stakeholders in systematic reviews. In this paper we report the development of the ACTIVE framework to describe how stakeholders are involved in systematic reviews.

### **Methods**

We developed a framework using methods previously described in the development of conceptual frameworks relating to other areas of public involvement, including: literature searching, data extraction, analysis, and categorisation. A draft ACTIVE framework was developed and then refined after presentation at a conference workshop, before being applied to a series of example systematic reviews. Data extracted from 32 systematic reviews, identified in a systematic scoping review, were categorised against pre-defined constructs, including: who was involved, how stakeholder were recruited, the mode of involvement, at what stage there was involvement and the level of control or influence.

### **Results**

The final ACTIVE framework described whether patients, carers and/or families, and/or other stakeholders (including health professionals, health decision makers and funders) were involved. We defined: recruitment as either open or closed; the approach to involvement as either one-time, continuous or combined; and the method of involvement as either direct or indirect. The stage of involvement in reviews was defined using the Cochrane Ecosystem stages of a review. The level of control or influence was defined according to the roles and activities of stakeholders in the review process, and described as the ACTIVE continuum of involvement.

## **Conclusions**

The ACTIVE framework provides a structure with which to describe key components of stakeholder involvement within a systematic review, and we have used this to summarise how stakeholders have been involved in a subset of varied systematic reviews. The ACTIVE continuum of involvement provides a new model that uses tasks and roles to detail the level of stakeholder involvement. This work has contributed to the development of learning resources aimed at supporting systematic review authors and editors to involve stakeholders in their systematic reviews. This framework may support the decision-making of systematic review authors in planning how to involve stakeholders in future reviews.

## **KEYWORDS**

systematic review, evidence synthesis, stakeholder involvement, framework

## INTRODUCTION

Systematic reviews are an essential part of the research cycle, identifying and bringing together, in an explicit and transparent way, the research evidence that addresses a particular topic or health care question. They play a vital role in informing what is known about a topic, and what is not known, to support health care and policy decisions. However, there are several barriers to the implementation of evidence from systematic reviews into practice, including lack of access, familiarity and use, and lack of perceived usefulness by those who are expected to use them.<sup>1</sup>

Involving stakeholders in systematic reviews has been proposed as a way to address these barriers, and to enhance the actual and perceived usefulness of synthesised research evidence. Existing work has focused, largely, on the active involvement of patients and the wider public in research, finding this to be beneficial to the quality, relevance and impact of research,<sup>2-5</sup> and likely to reduce research waste.<sup>6</sup> Patient and public involvement (PPI) is mandatory in countries such as the United Kingdom for funded research activities, including systematic reviews.<sup>7</sup>

INVOLVE, a national advisory body funded by the National Institute for Health Research (NIHR) in England, provides guidance on research co-production and briefing notes on the principles for public involvement in research, including in systematic reviews,<sup>8,9</sup> with good practice including careful planning, clear communication, defining roles and responsibilities, provision of training and appropriate financial reimbursement.<sup>7-10</sup> Effective relationships between researchers and involved patients / members of the public are core, with behaviours such as respect, trust, confidentiality, clarity and clear communication central to successful involvement.<sup>8,11</sup>

Despite the establishment of good practice principles, there is a growing awareness of the need for more practical resources to support the involvement of patients, the wider public and other stakeholders in research.<sup>8</sup> An increasing number of guidance documents and frameworks is

available,<sup>7, 10</sup> such as the Public Involvement Impact Assessment Framework,<sup>12</sup> which is designed to help researchers assess the impact of public involvement, while GRIPP2<sup>13</sup> provides guidance for the reporting of patient and public involvement. At the same time, there remains insufficient knowledge about methods or approaches of how to (best) involve stakeholders across the different stages in the production of a systematic review.<sup>14-16</sup>

This study seeks to contribute to closing this gap by developing a framework to describe methods and approaches to stakeholder involvement used in systematic reviews, the 'ACTIVE framework'. The work was conducted as part of the ACTIVE project (Authors and Consumers Together Impacting on eVidencE), which developed an online learning resource to support systematic review authors in involving stakeholders in their systematic reviews.

## **METHODS**

### *Definition of key terms*

Internationally there is considerable inconsistency in terminology and definitions of stakeholder involvement. As noted, it is often referred to as 'patient and public involvement' (PPI). We here define a stakeholder as *any person who uses research knowledge but whose primary role is not directly in research.*<sup>17</sup> Stakeholders thus include: patients, carers and family members, or people interested in remaining healthy who are seeking information about a health condition or treatment for personal use; members of organisations that represent people who use services; people with a professional role in health and social care; and policymakers and managers.

Cochrane, a global collaboration which produces systematic reviews, uses the term 'consumer', to mean patients and the public,<sup>15</sup> and we use this term where patients or the public specifically describe themselves as Cochrane 'consumers'.

We define involvement in a systematic review as *any role or contribution of stakeholders toward the development of a review protocol, completion of any of the stages of a systematic review, or dissemination of the findings of a review*, while a systematic review as defined as *a research process in which literature relevant to a stated question was identified and brought together (synthesised) using explicit methods,<sup>18</sup> including reporting of inclusion/exclusion criteria, search methods and details of included studies.*

### ***Literature searching, data extraction and analysis***

The ACTIVE framework was developed using methods similar to those described for the development of conceptual frameworks in other areas of public involvement.<sup>19, 20</sup> We first undertook a scoping review, using an iterative team approach as described by Arksey and O'Malley,<sup>21</sup> to create a broad map of evidence relating to stakeholder involvement in systematic reviews. The scoping review, which has been fully reported elsewhere,<sup>16, 22</sup> identified 291 papers which described stakeholder involvement in systematic reviews. We developed a data extraction form, which sought to capture and summarise the key features considered important to describing *how* stakeholders were involved; the components of the extraction form were discussed and agreed between all team members prior to use. One reviewer (AP) then extracted the data, capturing information on the aim/s of the systematic review, a narrative description of the involvement of stakeholders, details of who was recruited, how they were recruited, the mode of engagement (e.g. face-to-face meeting, electronic surveys etc), and any formal research methods used (e.g. participatory action research, nominal group technique, Delphi approach). Data were tabulated into an Excel spreadsheet.

### ***Categorising data and development of the ACTIVE framework***

The author team explored and mapped the tabulated data to pre-defined constructs of interest, by means of a full-day, face-to-face meeting (AP, PC, RM, CS), using whiteboards to generate and record ideas, which informed the development of an initial proposal for the structure and content of the ACTIVE framework. The proposal was shared with the wider research team for feedback and refinement through email and teleconferences, until consensus was achieved on key constructs of interest which should be brought together within a framework. During this process, background literature relevant to each construct of interest, including existing models and systems, was explored in order to justify and agree definitions and subcategories for each construct. Five key constructs, each comprising a number of categories, were defined: (i) Who was involved?, (ii) How were stakeholders recruited?, (iii) What was the mode of involvement (approach and methods)?, (iv) At what stage in the review process did involvement occur?, and (v) What was the level of involvement (level of control or influence over the review process)?.

From the 291 papers identified in the scoping review, a sub-set of 32 systematic reviews (described in 30 papers) that were judged to provide the most comprehensive description of stakeholder involvement were identified (Online Supplement 1). Data extracted from these reviews were categorised according to each of the five constructs, to test and inform the structure of the framework. One reviewer (AP) categorised data relevant to the first four of the five constructs, consulting a second reviewer (CS or RM) where there was uncertainty. As the research team considered that categorising data from the systematic reviews according to the definitions for the fifth construct (level of control or influence over the review process) required a greater degree of interpretation of data this was carried out by two reviewers (AP, CS) independently, with any disagreements resolved through discussion, involving a third reviewer (RM) where necessary. Following data categorisation, two reviewers (AP, RM) reviewed the categorised data

and structured the five constructs within a draft ACTIVE framework, which was then shared and agreed with the full author team.

The draft ACTIVE framework was presented at a workshop held at the annual UK Cochrane symposium (see Online Supplement 2). Workshop participants comprised approximately 30 Cochrane symposium delegates who chose to attend this parallel workshop, and included a broad mix of systematic review authors, editors and consumers with an interest in this topic (some with and some without any experience of stakeholder involvement). During the workshop, participants considered the descriptions of involvement from the 32 systematic reviews and how these were categorised within the framework categorisation, working in groups to provide comments and feedback (see Online Supplement 2). Workshop feedback informed further refinement and a final ACTIVE framework was agreed by all members of the author team.

### *Stakeholder involvement*

One consumer (HG) and two consumer representatives (RM, CS) were active members of the ACTIVE project and author team, from being co-applicants on the funding application, the conduct of the evidence synthesis, the planning of the workshop and the drafting of this manuscript (see Online Supplement 3).

## **RESULTS**

Figure 1 illustrates the ACTIVE framework and Table 1 summarises stakeholder involvement reported in the 32 systematic reviews using the framework. In the following we report on the key findings which contributed to the categorisation and structure of the five constructs within the ACTIVE framework.

### ***Who was involved?***

The 32 systematic reviews reported to have involved a range of stakeholders, including people with a health care condition and/or their family/carer, health professionals or other professional stakeholders. The language used to describe stakeholders was inconsistent, and clear descriptions of who precisely was involved were often lacking.

The review by Concannon et al. developed the 7Ps framework to describe the key groups of people who may be stakeholders involved in research.<sup>23</sup> These are: patients and the public; providers; purchasers; payers; policymakers; product makers; and principal investigators. However, in seeking to apply this framework to the systematic reviews included in our study we found that information provided was generally insufficient to allow for clear-cut categorisation of stakeholders into one of the 7 groups. Indeed, it was often impossible to distinguish between different professional groups involved. Building on the evidence review, aiming to provide a framework that supports systematic review authors in involving stakeholders, rather than attempting to categorise multiple groups of stakeholders, often with limited information, the ACTIVE framework uses a simplified categorisation, distinguishing patients, carers and/or family members, and/or any other identified stakeholder (Figure 1). The majority of reviews (14/32) included in this study involved all three groups (Table 1).

### ***How were stakeholders recruited?***

We identified two broad categories of stakeholder recruitment, 'open' and 'closed' recruitment. 'Open' recruitment refers to providing opportunities for involvement through advertisement to the general population, allowing anyone to volunteer to get involved. Open recruitment may result in 'fixed' membership, where, once group members had volunteered, the membership remains the same, or in 'flexible' membership, where different people attend different events or contribute to different activities. Conversely, 'closed' (or 'targeted') recruitment strategies focus

on inviting only specific people to participate. Closed strategies include invitation of known individuals or recognised experts, recruitment from membership of an existing group, or purposive sampling to achieve representation of people with key pre-determined characteristics, experience or expertise.

### ***What was the mode of involvement?***

Ways of involving stakeholders in a systematic review varied. We identified two general categories, which we described in our framework as ‘approach’ to and ‘method’ of involvement.

*Approach to involvement* refers to the general way in which stakeholders were involved throughout the stages of a systematic review, and this is also related to the role that the stakeholders had in the review process (see also ‘stage of involvement’ below). We identified two distinct approaches to involvement, one-time (i.e. one-off) and continuous involvement.<sup>2, 24</sup> *One-time involvement* describes an approach that involves stakeholders at a specific stage of a review, for example when developing the question for the review, or writing lay-summaries of a completed review. One-time involvement can occur at just one stage or at multiple stages in the review process. *Continuous involvement* refers to the involvement of the same stakeholders throughout the entire review process. Continuous involvement approaches fell into three broad types: partnership, multiple-time closed event, and hands-on approaches (see Box A for definitions of these types), although differences between types were not clear-cut, with some areas of overlap between them. Stakeholders who had an oversight role (for example, on a project advisory group) would often also have input at one or more specific stages of the review (for example, getting involved to assist with study selection). Where this occurred, but only one group of stakeholders was involved during the review process, we still categorised this as continuous involvement. *Combined approaches* describe instances of the involvement of two (or more)

distinct groups of stakeholders, with some having continuous involvement and an oversight role, while others had input at one or more specific stages of the review.

The systematic reviews included in our study broadly described two distinct *methods of involvement*, those using direct interaction between stakeholders and the review team, through face-to-face or virtual (e.g. Skype or teleconference) meetings (direct method), and those where there was no direct (indirect) interaction between stakeholders (indirect method) (see Figure 1). In the indirect method, involvement occurred through participation in an electronic Delphi method to reach group consensus on a particular issue relating to the review. Some of systematic reviews combined involvement in an electronic Delphi method with a face-to-face consensus meeting. Where both direct and indirect methods were used in the same systematic review we categorised this as 'direct', since there was direct interaction in addition to other approaches.

#### ***At what stage in the review process did involvement occur?***

As indicated above, involvement can occur at any stage in a systematic review. To help systematically categorise the stage(s) of the systematic review process where there was involvement, we used the stages described within the 'Cochrane Ecosystem' <sup>25</sup>, which includes eleven sequential stages, from developing the question, planning the methods and protocol; develop and run the searches; collect and analyse data; to interpret findings and publish the review. Based on our review, we added a twelfth stage, which we refer to as knowledge translation and impact (Figure 1).

We noted earlier that the stage of involvement is closely linked to the approach to involvement, which we have described as one-time, continuous or combined. Categorising stages of involvement across the 32 systematic reviews, we identified a number of reviews (8/32) in which there was involvement at the initial stages (stage 1-3: framing the question and planning the

review) and at the final stages (stage 10-12: interpretation, publication and dissemination of findings), but no involvement in the middle stages (stage 4-9: conducting the review). As this was the most common pattern of involvement of stakeholders across the different stages of a review which we observed, we named this the 'top and tail' approach, and highlighted where this approach was used (see Table 1).

### ***What was the level of involvement?***

Our review found that the extent to which stakeholders were involved, and their degree of control over decisions being made in the systematic review process, could vary considerably. Terminology to describe the level of involvement or degree of control of stakeholders was inconsistent, however. Building on the review evidence and workshop feedback, and further informed by existing models that describe levels of involvement, such as INVOLVE<sup>9</sup>, which distinguishes 'involvement', 'participation' and 'engagement'; Popay<sup>26</sup> who defined five levels of involvement; and models that describe involvement, or participation, as a continuum (see Online Supplement 4 for examples of models of involvement or participation), we defined a classification that is based specifically on the tasks and roles of people involved in systematic reviews. Through an iterative process of feedback and refinement this led to the ACTIVE continuum of involvement, which ranges from 'leading', 'controlling' and 'influencing' to 'contributing' and 'receiving' (Figure 2). None of the involvement within the 32 systematic reviews was considered to be 'leading'; however this was considered to be an important category, with workshop feedback highlighting that it was deemed essential that this was a distinct category, separate from the category of 'control'. Most commonly, involvement in the 32 systematic reviews was at the level of 'influencing', with stakeholders 'controlling' decisions in only 3 of the reviews.

## **DISCUSSION**

This paper presents the ACTIVE framework, which was developed iteratively based on synthesised evidence, providing a structure to guide authors on how to involve stakeholders in the systematic review process in a transparent way, using clearly defined terminology. It proposes the ACTIVE continuum of involvement, which categorises level of involvement based on the tasks and roles of stakeholders. We have applied the ACTIVE framework on a subset of systematic reviews which describe stakeholder involvement in systematic reviews, highlighting that there is no set formula or single method of involving people in a systematic review.

In doing so, the framework goes a step further than the INVOLVE national guidance on research co-production in the UK<sup>8</sup> described earlier, which lacks detail on practical issues on how to involve stakeholders in specific types of research. The ACTIVE online learning resources<sup>27</sup> has been structured around the ACTIVE framework, with the use of icons to facilitate clear, accessible categorisation of stakeholder involvement within different systematic reviews (see icons developed for the online learning resource in Online Supplement 5). These resources will be useful for researchers planning stakeholder involvement in future systematic reviews and, as such, they have the potential to enhance reporting and consistency of terminology in future reviews. The ACTIVE framework also usefully adds to existing generic guidance on reporting of stakeholder involvement in research such as GRIPP2<sup>13</sup>, which has not been tested for use with systematic reviews and does not provide guidance on reporting of how stakeholders are specifically involved within the systematic review process. Initial feedback on the use of icons within the framework highlighted that these were considered to provide clarity to the categorisation, make the information more easily accessible, providing an understanding of involvement in different reviews 'at a glance'.

While the ACTIVE framework has not been developed as a decision-making tool, and is unlikely to be comprehensive of all decisions required, we believe that consideration of the constructs within the framework will support the planning stages of involving stakeholders in a new systematic review. This study highlights that there is no set formula or single method of involving people in a systematic review.

Factors which will influence decisions around the methods of involvement in a specific systematic review are likely to include the review topic and the stakeholders who may be affected by the results of the review; the aims of involving stakeholders, which may be highly specific (e.g. to decide on the outcomes of interest to a review) or may be more generic (e.g. to ensure the review is relevant); the available resources, including the time and funding available to carry out the review and involve key stakeholders in the process; the expertise and experience of researchers; along with the conditions ensuring meaningful involvement, such as key principles for good practice in stakeholder involvement (described earlier), the wider research environment, and stakeholder and researcher expectations, support and a sense of feeling valued.<sup>20, 28</sup> In addition, decisions may be influenced by a desire for review findings to be generalisable to a local, national or international population. Thus, there is clearly a complex interdependency between the constructs within the ACTIVE framework and external factors which will impact on decisions about stakeholder involvement in future reviews.

### ***Strengths and limitations***

To our knowledge, this is the only framework specifically describing stakeholder involvement in a systematic review. As noted it was developed using a comprehensive scoping review and with stakeholder involvement. The 32 systematic reviews used to test and refine the framework include a wide range of approaches (including qualitative and quantitative reviews) and focused

on a different health topics,<sup>22</sup> which will enhance the applicability of the framework to a range of review types and topics.

There were a number of limitations with the scoping review on which this framework development was based; these have been described in detail elsewhere.<sup>22</sup> The framework was tested and refined based on data extracted from published systematic reviews; we did not contact systematic review authors for further information or clarification relating to their involvement of stakeholders. This may have limited our understanding and interpretation of the methods of involving stakeholders and the activities in which stakeholders were involved. Furthermore, we used the Cochrane Ecosystem<sup>25</sup> to categorise the stages of a systematic review; however these stages have primarily been developed to describe the process of synthesising quantitative evidence relating to effectiveness, and key stages in the methods of other types of reviews (e.g. realist reviews) may not have been appropriately categorised.

There are also limitations to our approach to dichotomising data under the construct of “who was involved”. This was a pragmatic decision based on the information that was most commonly available in the systematic reviews included in this study. We recommend that this is reviewed, and potentially expanded, when reporting of types of stakeholders has improved.

Within this study we specifically extracted data from a subset of reviews where the methods of involvement were well described, but as the reporting of involvement in reviews is generally poor, it is unlikely that this subset will be comprehensive of all approaches to involvement within reviews. For example, our lack of examples where stakeholders were ‘leading’ does not provide evidence of absence; indeed there are examples of systematic reviews where stakeholders did play a key role, such as a recent Cochrane review, which was initiated and co-led by consumers,<sup>e.g.</sup><sup>29</sup> but the role and involvement of consumers in the review text was not reported clearly.

During the development of the ACTIVE continuum of involvement we explored the ‘tasks’ described in included systematic reviews by considering the narrative description of the involvement of stakeholders, details of what happened and any formal research methods used. It was a post-hoc decision to explore tasks in this way, and we did not use a pre-planned approach to extract and categorise details of these tasks. Future work should consider tasks as a distinct construct at the outset. The ACTIVE continuum of involvement has not been tested beyond these examples, and further testing and (possibly) refinement is required.

As noted, we presented a draft framework at a workshop in the UK and collected informal feedback (see Online Supplement 2). Furthermore, stakeholder involvement in the development of this framework has been limited to the members of the author team and the select group of conference delegates who chose to attend the workshop. The ACTIVE framework would be strengthened by more rigorous testing and peer review, with input from a wider group of international stakeholders.

Practice and policy relating to stakeholder involvement in research is rapidly evolving. In addition to the examples described earlier, other examples include the recent launch of an international network for public involvement and engagement in health and social care (#globalPPInetwork), and the requirement by the British Medical Journal of a patient and public involvement statement in all research articles.<sup>30</sup> Our work adds to this growing body of resources, providing focused, practical, information relating to *how* to involve stakeholders in systematic reviews.

## **CONCLUSION**

This paper presents the ACTIVE framework for describing the range of methods and approaches for involving stakeholders in systematic reviews. This work has contributed to the development of learning resources to support researchers to involve stakeholders in their systematic reviews. The

ACTIVE continuum of involvement defines different levels of stakeholder involvement, contributing to the transparent use and consistent reporting of involvement in the review process. The ACTIVE framework has the potential to support systematic review authors in their planning of how to involve stakeholders at the different stages of the review process, so improving stakeholder involvement overall and, in turn, enhancing the quality, relevance, and impact of systematic reviews.

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<b>Framework Constructs</b>	<b>Categories</b>	
<b>Who was involved?</b>	Patients, carers and / or their families	
	Patients, carers and / or their families + other stakeholders	
	Other stakeholders only	
<b>How were stakeholders recruited?</b>	Open	Fixed
		Flexible
	Closed	Invitation
		Existing group
Purposive sampling		
<b>What was the mode of involvement?</b>	<i>Approach?</i>	One-time
		Continuous
		Combined (i.e. both one-time and continuous)
	<i>Methods?</i>	Direct interaction
		No direct interaction
<b>At what stage in the review process did involvement occur?</b>	<p><b>What was the level of involvement (at each stage)?</b></p> <p>~~~~~</p> <p><i>Leading</i></p> <p>~~~~~</p> <p><i>Controlling</i></p> <p>~~~~~</p> <p><i>Influencing</i></p> <p>~~~~~</p> <p><i>Contributing</i></p> <p>~~~~~</p> <p><i>Receiving</i></p>	



**FIGURE 1: The ACTIVE framework of involvement in a systematic review**

People are:	Tasks:
<b>LEADING:</b> Initiating the review; lead responsibility for carrying out and completion of review.	Tasks will include authorship of a review, and may include any activities associated with review completion, including key decisions relating to the methods and execution of the review.
<b>CONTROLLING:</b> Working in partnership with researchers, with varying degrees of control or influence over the review process. Making decisions and/or controlling one or more aspects of the review process, in collaboration with or under the guidance of the review authors.	Tasks may include defining outcomes of interest, inclusion criteria, key messages arising from review findings and writing a plain language summary. In completing tasks people have control over final decisions, such as application of inclusion criteria, categorisation of interventions, or recommendations for clinical practice.
<b>INFLUENCING:</b> Stating, commenting, advising, ranking, voting, prioritising, reaching consensus. Providing data or information which should directly influence the review process, but without direct control over decisions or aspects of the review process.	Tasks may include assisting with review tasks, such as hand-searching, screening, data extraction and assessment of risk of bias, possibly in a co-reviewer role. Tasks may include peer review, such as commenting on a protocol, systematic review or plain language summary.
<b>CONTRIBUTING:</b> Providing views, thoughts, feedback, opinions or experiences. Providing data or information which may indirectly influence the review process. People may be participants in a research study (e.g. focus groups or interviews).	Tasks may include sharing views or opinions, for example within a focus group of interview. May include ranking, voting or prioritising as participants in a research study (e.g. Delphi study).
<b>RECEIVING:</b> Receiving information about the systematic review, or results of the review.	Tasks may include attending events, or reading or listening to information about the review. While the results of a review may be discussed, these discussions do not influence the review process in any way.

**FIGURE 2: ACTIVE continuum of involvement, describing the level of involvement, or control, that stakeholders have in a systematic review**

**Partnership approach:** In this approach a small group of stakeholders were on a steering committee or management group and contributed on a regular basis, attending meetings or by teleconference or email. This same group of stakeholders may also have input at one or more specific stages of the review (e.g. writing a lay summary), but the primary role of this closed group of stakeholders was one of oversight or management.

**Multiple-time closed event approach:** In this approach the same small (fixed) group of stakeholders had two or three face-to-face meetings, each at specific stages within the review process, and focussed on the completion of a particular task or role (e.g. agreeing scope of the review). In addition this same small group of stakeholders remain in touch about the progress of the review, providing some degree of oversight or management throughout the review process, which often occurs through email, phone and newsletter.

**Hands-on approach:** In this approach researchers and stakeholders worked together to plan and conduct the research. The key distinguishing features of this approach, when used within our example systematic reviews, appears to be that the stakeholders involved contribute to relatively frequent review meetings, although methods of recruitment and format of involvement can vary considerably. Unlike a partnership approach or a multiple-time closed event approach, in a participatory approach stakeholders have a role closer in equivalence to a researcher role, with responsibility for, and involvement in, all aspects of the review. Our examples often described their approach to stakeholder involvement as a “participatory” approach.

#### **BOX A: Types of continuous involvement identified in our examples**

**Table 1: Summary of involvement within the 32 systematic reviews, using the ACTIVE framework**

REVIEW	Who was involved?	How were they recruited?	What happened?		Stage and level of involvement												Top & tail?	
			Approach	Method	1	2	3	4	5	6	7	8	9	10	11	12		
Bayliss 2016	Patients*	Closed; existing group	Continuous	Direct interaction				-										
Boelens 2014	Patients* + other stakeholders	Unclear	One-time	No direct interaction														Ctb
Bond 2015	Patients* + other stakeholders	Closed; invitation	One-time	No direct interaction														R
Braye 2005	Patients* + other stakeholders	Closed; invitation	One-time	Direct interaction		-								Ctb				v
Bunn 2015	Patients* + other stakeholders	Closed; purposive sampling	One-time	Direct interaction														R
Concannon 2014	Patients* + other stakeholders	Closed; invitation	Continuous	Direct interaction	-	-								I				v
Coon 2016	Patients* + other stakeholders	variety	Combined	Direct interaction			-							Ctb		Ctb		R
Edwards 2015	Patients* + other stakeholders	Closed; invitation	One-time	Direct interaction	-													
Harris 2016	Patients* + other stakeholders	Open; fixed	Continuous	Direct interaction					-		-							
Hayden 2015	Other stakeholders only	Closed; invitation	One-time	Direct interaction	-													R
Higginson 2013	Patients* + other stakeholders	Unclear	One-time	Direct interaction										I				
Hyde 2016	Patients*	Closed; existing group	Continuous	Direct interaction		Ctb	-							Ctb				Con
Jamal 2015	Patients*	Closed; existing group	One-time	Direct interaction	-													
Liabo 2013	Patients*	Open; flexible	Continuous	Direct interaction	Ctb	Con	Con	Con	Con	Con	Ctb	Ctb						Con
Liu 2012	Patients* + other stakeholders	Open; flexible	Combined	Direct interaction	Ctb									Ctb				
Martin 2015	Patients*	Closed; purposive sampling	One-time	Direct interaction											R			
McConachie 2015	Patients* + other stakeholders	Open; flexible	One-time	Direct interaction		Ctb									R			
McCusker 2013	Patients* + other stakeholders	Open; flexible	One-time	Direct interaction														R
McGinn 2012	Other stakeholders only	Closed; invitation	One-time	No direct interaction														R
Morgan 2015	Patients*	Closed; existing group	One-time	Direct interaction														R
Oliver 2015 ("correlational" review)	Patients*	Closed; existing group	One-time	Direct interaction							Ctb							
Oliver 2015 ("views" review)	Patients*	Closed; existing group	One-time	Direct interaction										Ctb				
Oosterkamp 2016	Other stakeholders only	Closed; invitation	One-time	No direct interaction														R
Pearson 2015	Other stakeholders only	Closed; invitation	Continuous	Direct interaction	Ctb	Ctb									Ctb			v
Pollock 2014	Patients* + other stakeholders	Closed; purposive sampling	Continuous	Direct interaction		Con					-				Con		Con	v
Rees 2004	Patients* + other stakeholders	Closed; invitation	Continuous	Direct interaction				I						I			Ctb	
Saan 2015 (Review 1)	Other stakeholders only	Closed; invitation	Continuous	Unclear	-			I										
Saan 2015 (Review 2)	Other stakeholders only	Closed; invitation	One-time	No direct interaction				Ctb										
Serrano-Angular 2009	Patients*	Closed; invitation	One-time	No direct interaction	Ctb													
Smith 2008	Patients*	Open; fixed	Continuous	Direct interaction	Ctb	Ctb												Ctb
Stewart 2007	Patients*	Open; fixed	One-time	Direct interaction														R
Vale 2012	Patients*	Closed; invitation	Continuous	Direct interaction							-							

**Key:** Patients\* - patients, carers and/or their families; Con – Controlling; I – Influencing; Ctb – Contributing; R – Receiving. Blank cells in ‘Stage of involvement’ denote no stakeholder involvement.

**References:** see Online supplement 1