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## Recording and Accounting for Stakeholder Involvement in Systematic Reviews

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### ABSTRACT

#### Objectives

The use of stakeholders in systematic reviews is increasingly valued, but their influence on the systematicity of the review is often unclear. The aim of this study was to describe some of the processes of involvement of stakeholders and to demonstrate a Tool for Recording and Accounting for Stakeholder Involvement (TRASI).

#### Methods

We demonstrate the TRASI in two worked examples. In one project, the reviewers collaborated with the end-user and an expert during the literature search. In the other project, experts were consulted to generate keywords before searching the literature.

#### Results

In the first project, disagreements about keywords to identify studies for the research topic were solved by informal discussion. In the second project, difficulties arose in reaching agreement between experts and reviewers about the core construct and the meaningful keywords associated with it.

#### Discussion

The TRASI aids researchers to systematically and transparently account for the decisions taken. The TRASI supports information specialists and librarians to shape the search strategy to match the objectives of the review.

## Conclusions

We propose the TRASI as a first step in resolving the challenges of detecting and reconstructing stakeholder influences. Potential new applications of the TRASI are discussed.

## BACKGROUND

Systematic reviews originated in the evidence-based policy and practice movement in medicine, which emphasised that prior research evidence needed to be summarised and synthesised in a systematic and transparent way to avoid mistakes. They were a reaction to conventional reviews in which researchers arbitrarily used a selection of the body of evidence, worked from their own perspective and did not perform a quality assessment of primary studies. All these factors could bias the outcomes.<sup>[1]</sup> Systematic reviews nowadays use recognised methods for all steps to be taken, to be reproducible, from generating the review question, searching and retrieving studies, appraising quality, extracting findings, synthesising findings, to reporting the outcomes.<sup>[2]</sup> In line with quantitative studies, qualitative evidence is increasingly synthesised to create new configurations of existing qualitative outcomes (also referred to as qualitative evidence synthesis).<sup>[3]</sup> We will use the term systematic reviews to refer to both quantitative reviews and qualitative evidence syntheses.

Decision support reviews are a specific type of reviews that explicitly aim to provide information that is needed by stakeholders. Stakeholders have some self-interest in the review, either because they are going to use the findings of the review or because decisions made by others in light of the findings might have an impact on them,<sup>[4]</sup> for example policymakers, practitioners, service users and the wider public. Because a decision-support review focusses on a particular decision in a particular context, the utility depends on its being used by decision makers, especially due to the lack of generalisability.<sup>[5]</sup> There remains a gap between research findings and their application in practice.<sup>[6]</sup> The different languages that are used to discuss a specific scientific domain by researchers and the stakeholders are well known and referred to as user warrant and literary warrant, respectively.<sup>[7]</sup> Low utilisation of research findings can be a result of the absence of interaction between researchers and decision makers, and it is argued that stakeholders can play a valuable role by adding oversight, knowledge, and expertise.<sup>[6, 8, 9]</sup>

The involvement of stakeholders with researchers can be described using the framework of Rees and Oliver.<sup>[4]</sup> Researchers can draw on stakeholder opinions by inviting organised stakeholders, inviting individual stakeholder's involvement, responding to stakeholders' initiatives and considering the stakeholder as a minor partner. There are four approaches to describe stakeholder involvement in systematic reviews: Stakeholders taking control, stakeholders collaborating with researchers, stakeholders being consulted and stakeholders having a minimal interaction with the researchers. The type of partnership between researchers and stakeholders can be described using a combination of the characteristics mentioned above. For example, individual stakeholders can be invited by researchers on the basis of consultation. While the involvement of stakeholders is supposed to be beneficial for the relevance of an individual project, it can also compromise the essential characteristic of being systematic in reviewing. First, stakeholders may act to serve their own information

needs and relevance for their professional practice, where they will probably act as end-users. Although this has an inherent logic for them and their perspective, their interests do not have to be scientifically correct or the most interesting for the wider public. Second, the influence of stakeholders stemming from their interests during the review process is not very transparent and difficult to grasp, because it mainly takes place during conversations which are complex to reconstruct.<sup>[10]</sup> In its turn, this makes it complex to account for their influence in a transparent and replicable way. To involve stakeholders and also maintain the aim of being systematic and transparent in the review process, we examined stakeholder involvement and generated a tool to account for the role of stakeholders. We focus on the first stage of the review process, this being searching and retrieving studies for inclusion in the review. Stakeholders are considered crucial partners at this stage of the review.<sup>[4]</sup> It is emphasised that early and consistent involvement of relevant decision-makers improves the utilisation of the review.<sup>[6]</sup> In this phase, the relevancy of keywords and the ultimate objectives and course of the review are determined. As mentioned above, stakeholders and reviewers can use different types of keywords.

For information specialists, it is important to acknowledge this difference because it will enable them to better understand the issues that are important for stakeholders, the key concepts they use, their relative importance, and the options for search strategy and information management.

But the process of search and retrieval should be transparent and reproducible for others and lead to the best possible coverage of papers. Omitting useful publications could possibly bias the answer given to the review question.<sup>[11]</sup> Previous research showed furthermore that it is in this particular stage of the review process that difficulties with systematicity and transparency exist, most notably in a qualitative evidence synthesis.<sup>[12, 13]</sup> On one hand, the identification of brainstorming terms and keywords is employed to find the appropriate literature on the topic of the review. On the other hand, identifying brainstorming terms and keywords can also be part of delineating and defining a construct. The Tool for Recording and Accounting for Stakeholder Involvement (TRASI) is geared towards explicitly accounting for generating keywords in a partnership between researchers and stakeholders. The TRASI is in line with recognised procedures that are employed during the first stage of searching and retrieving, in particular the tools available for developing review questions and generating search keys. Frequently used are the PICO (Population-Intervention-Comparison-Outcome)<sup>[15]</sup> and the SPICE (Setting-Perspective-Intervention-Comparison-Evaluation)<sup>[14]</sup> tools. Recently, the SPIDER (Sample-Phenomenon of Interest-Design-Evaluation-Research Type) tool has been developed specifically for use in qualitative and mixed-methods research, and its use has recently been evaluated.<sup>[15]</sup> While stakeholders can be involved in the application of the tools mentioned above, there is yet no procedure available for systematically describing their role in this.

The importance of the search and retrieval stage when performing a systematic review, both electronically through databases searches and by manual checks of relevant journals, has been extensively discussed in the literature. Additionally, problems with indexing qualitative material in databases are well known,<sup>[15]</sup> leading to difficult detection of qualitative studies and to overlooking potentially relevant studies.<sup>[16]</sup> Qualitative research as a keyword was recognised as a Medical Subject Heading (MeSH) term in PubMed in 2003, which makes qualitative research much

easier to identify in PubMed. MeSH terms are keywords added by PubMed to abstracts. In this study, we focus on generating and accounting for keywords on the substantive topic of the specific review rather than on studies using a specific methodology, that is qualitative. Stakeholders involved in the search stage can suggest key publications, databases or keywords that are relevant for a specific field of expertise. Our tool enables tracking their suggestions and their influence on the project.

In recognition of the current methodological limitations surrounding the search process for systematic reviews, the objective of this study was to examine stakeholder involvement and demonstrate the application of the TRASI for accounting for the role of stakeholders in conducting the search and the selection stage of a review. We employ the tool in two cases of systematic reviews (quantitative and qualitative) that are presented below as worked examples.

### **TWO WORKED EXAMPLES**

The first example is a research project about the needs of victims of crime, such as assault, robbery and intimate partner violence. Researchers of Utrecht University (Department of Methodology and Statistics) carried out the study in collaboration with Victim Support Netherlands (VSN). VSN offers free practical, emotional and legal support to victims of crime and other calamities. This support is provided mainly by volunteers. VSN wished to have a broad evidence base to further legitimise their current services and to guide future policy decisions. Therefore, a qualitative evidence synthesis was performed on the needs of victims of crime with regard to helpful and unhelpful reactions of their social network including volunteer services.

The stakeholders involved in this project were a senior staff member of VSN and a professor in victimology from the international Victimology institute Tilburg (Intervict) at Tilburg University. This way of working together with stakeholders can be characterised as ‘collaboration with invited organised stakeholders’, which means that stakeholders are involved as member of a stakeholder organisation (i.e. VSN or Intervict) and participate in decision making during the review.<sup>[4]</sup> The involvement of the stakeholders in this case aimed at retrieving the appropriate literature for the purpose of the end user and discovering user warrant terms.

The second example is a research project focusing on self-management and self-management support, aimed at young people with chronic medical conditions. A research team of the Expertise Center Innovations in Care connected to Rotterdam University performed the study. This research center works in close collaboration with the Erasmus Medical Center (EMC) in Rotterdam. To provide the EMC with guidelines for evidence-based practice, a state-of-the-art review<sup>[17]</sup> on self-management intervention studies were carried out, aimed at systematically assessing the concepts, determinants and outcome measures used to evaluate self-management support. However, as it is unclear what self-management exactly comprises, the research team decided it was necessary to develop a sound demarcation of the construct of self-management first.

Therefore, they initiated a Delphi study to consult academic experts about this topic. Stakeholders in this project were 39 invited academic experts. They shared an established research expertise in self-management of patients with various chronic conditions. To gather their opinion about keywords pertaining to the self-

management construct, they participated in an anonymous Delphi study conducted online. This type of stakeholder involvement can be characterised as ‘inviting individual stakeholders on the basis of consultation’.[4] The stakeholders can add knowledge and expertise to the review. In contrast to the involvement of the stakeholders in the VSN project described above, the involvement here aimed at accurately defining the characteristics of the topic.

Below, we describe the involvement of the stakeholders and the use of the TRASI in both projects.

### **Application of the TRASI in the victim support example**

Victim Support Netherlands (VSN), as commissioner of the research project, was interested in the views of victims on the effectiveness of their current services. Their support services are based on two principles. One is the ‘from citizen to citizen’ principle, which means that if an individual becomes victimised by another being, the harm done can be (partially) restored by the performance of another individual offering help.[18] This is the reason that VSN offers services using volunteers, who are extensively trained, both before and during the period they work for VSN. The second principle is that individuals are resilient and that most victims will recover by themselves. That is why VSN offers the least intensive help for the need of an individual victim and employs ‘watchful waiting’, which means actively monitoring a victim without direct interference. People can step up the pathway according to changing needs. The support is considered low threshold, as VSN is a well-known office, their support is free of charge, and it is offered by volunteers.

There is no robust evidence base that underlies the services that VSN offers.

Therefore, a partnership between the commissioner and researchers was established, and they discussed the scope of the review. The discussion centred on the interventions VSN offers. First, volunteers performed their services, and this resulted in a discussion about the operational definition of a volunteer. VSN defines a volunteer as a non-professional, without formal training and without sharing a paid employment relation with VSN. The research team agreed that the definition in the review had to match the operational definition that VSN uses as this would guarantee the relevance of the outcomes for the end-user. Second, VSN facilitates peer groups for victims to meet and help each other. By discussion, the team reached consensus on expanding the scope of the review to the help offered by the social network and self-help groups. The researchers and commissioner jointly formulated the final review question as: What are supportive responses offered by the social network, self-help groups and non-professional volunteers for victims of crime and incidents? Following the review question, the researchers had to come up with keywords for searching relevant studies. The SPIDER tool was used to generate the groups of keywords that functioned as the backbone of the search process. The S(ample) of the SPIDER acronym was translated as ‘Victims’. Also, the P(henomenon of interest) was translated as ‘Trauma’. The stakeholder connected to VSN objected to this term and wished to change this in ‘Incident or Crime’. These terms would better fit the target group that they wish to serve. I(ntervention) was used as such, and D(esign) and E(valuation) were not defined. R(earch type) was established as qualitative research because the researchers were interested in victims’ views and qualitative research often focuses on studying these views.[19, 20] In cooperation with the stakeholder, I(ntervention) was considered insufficient for searching relevant studies and expanded with two other groups that would reflect the type of intervention of



interest: volunteers and social network. The groups of keywords constitute the rows of the TRASI (see Table 1).

**[TABLE 1]**

After generating the word groups, the next step was to systematically collect search keys. The keys within a word group consist of synonyms and related terms. As a start, the researchers came up with a list of types of incidents and crimes, such as violence, abuse, rape, trauma and murder (see the third column of the TRASI). These were mainly literary warrant terms. In a brainstorm session, this list was discussed with the stakeholder connected to VSN. This stakeholder indicated that several keys could be removed, for example ‘tsunami’ and ‘natural disaster’ in the group Incident/Crime. In her opinion, these words were not relevant in the specific context of VSN in the Netherlands. The stakeholder also suggested several terms which could be added to some of the word groups, for example ‘human trafficking’ in the word group Incident/Crime and ‘basic support’ in the word group Intervention. In doing so, she added user warrant terms to the set of brainstorming terms. In marking all changes in the word groups, the decisions made by the research team while searching primary studies were transparently recorded. This resulted in a list of word groups validated by the end-user (fourth column TRASI).

Subsequently, we performed broad pilot searches to generate more keywords.

Abstracts that seemed to pertain to our phenomenon of interest after a first pilot search within the database CINAHL were retrieved. When such a study provided new keywords, we added them to the corresponding word groups after discussing them with the stakeholder. The keys added after this first search are described in the fifth column of the TRASI. None of the keys resulting from the pilot search was deleted by the stakeholder. To transparently record stakeholder influences, it is essential to keep track of the keys that are added or removed in each stage.

Then, based on the established word groups, the following databases were searched: CINAHL, PsycInfo, Scopus and PubMed. Note that the term ‘victim’ can be described by a formal definition stating what a victim is, but that in the current review, a list of types of crimes and incidents was used to describe what constitutes a victim. So the term is defined by a list of examples of victims of different incidents and crimes that are included, such as ‘intimate partner violence’, ‘theft’, ‘homicide’ or ‘rape’. Conceptually, it made sense to distinguish between terms that refer to specific groups of individuals that are victimised, such as ‘survivors’, ‘aged’, ‘women’ and ‘children’. Both word groups can be combined within the TRASI, like ‘aged’ who have met ‘abuse’ or ‘women’ who have met ‘intimate partner violence’. As a final check, the second stakeholder – who is an expert in victimology but not an end-user of the review outcomes – validated the final word groups. This action illustrates the field of tension between scientific aims and the interests of the end-user we mentioned in the introductory section. While our end-user was not directly interested in victims of major disasters that are unlikely to happen in the Netherlands (i.e. tsunami), the expert stakeholder in victimology mentioned the scientific importance of including these groups. He underlined that scientifically, it could not be justified to exclusively focus on the groups of victims that are supported by VSN. After negotiating this point, the research team reached consensus by including victims of disasters, but only if they were victimised in western countries. Also, emergency aid, such as food, shelter and medicine, was excluded, because this type

of aid was considered inherently different from the services VSN offers. These decisions are marked in the last column of the TRASI. None of the keys were deleted by the second stakeholder. Working this way, the review will focus on groups of victims and types of support that are closely related to the support services of VSN, while at the same time maintaining the scientific interests mentioned by the expert stakeholder and making the outcomes interesting for a wider public.

### **Application of the TRASI in the self-management support example**

As the Rotterdam University is linked to the Erasmus Medical Center (EMC) in Rotterdam, their interests are influenced by this partnership. Care for patients with a chronic disease is increasingly guided by the principle of self-management. However, health care professionals encounter problems supporting patients with self-management and experience a lack of effective interventions.<sup>[21]</sup> These professionals would like to have more evidence available about effectiveness and acceptability of interventions based on self-management support. Therefore, a review of existing self-management support interventions was initiated. The review question formulated was as follows: What are the concepts, determinants and outcome measures used to evaluate existing self-management support interventions? This question will be answered with a state-of-the-art review, which addresses the literature in a certain area.<sup>[17]</sup>

Before starting the search for these studies, the self-management construct turned out to be problematic, because it is multifaceted, and different definitions originating in different theoretical models are used. A clear decision was necessary as to which key terms needed to be included, choosing from the numerous keys potentially related to self-management that could be generated. To decide upon this issue, expert agreement was sought on adequate keywords for self-management of patients with chronic conditions. This is substantially different from the VSN project, in which a descriptive concept was used (i.e. victim). The problem of using a complex construct with numerous definitions in a qualitative synthesis has been identified before.<sup>[22]</sup> The SPICE tool was used to generate different groups. (S)etting was translated as 'outpatient clinics of academic medical centres', for (P)opulation 'chronically ill patients aged 7–25 years' was used, (I)ntervention was translated into 'programs and interventions for self-management support', (C)omparison was defined as 'care as usual', and (E)valuation was considered 'the effectiveness of the specific intervention for self-management support'. Chronic illness is not a straightforward term; it contains many different types of illnesses and a range of physical and mental symptoms. This warranted discussion about what kind of chronic diseases needed to be addressed in the review, similar to what we demonstrated in the first example of victim support. In this case, we do not focus on the demarcation of chronic illness as it would be a repetition of the steps we showed in the first worked example. Here, we focus on the description of the construct of self-management and the involvement of the academic experts to shed light on this construct.

The method chosen to consult experts is the Delphi method.<sup>[23]</sup> The Delphi process is a method to measure group consensus. A typical Delphi study consists of three rounds in which invited experts can give their opinion on a certain topic. After the first and the second rounds, they can also give their feedback on the results of the previous round provided to them. In the case of Rotterdam University, an online Delphi study was conducted between September and November 2012. To gather a broad range of opinions, 39 experts from the Netherlands (34 researchers and five

policy advisors) were invited by e-mail. They were contacted through the contact list of a recent expert meeting on self-management in the Netherlands and through the professional network of members of the research group. The question posed to them was as follows: ‘What entry terms should researchers use when searching for self-management interventions?’ Of the 39 invited experts, 20 actually agreed on participating in the first round of the Delphi (17 researchers and 3 policy advisors). This number dropped to 17 participants in the second round and 16 in the final, third round.

During the first round of the Delphi, the experts were requested to rate eleven keywords related to self-management selected by the research team as to be included or to be excluded for a search for interventions dealing with self-management support. These keywords are presented in the second column of the TRASI for the self-management project (Table 2). These keywords are literary warrant terms, but also contain possible user warrant terms as the team contacted the end-users of the review when brainstorming about these terms.

### **[table 2]**

Consensus was reached when 70% or more of the participants agreed about inclusion or exclusion of a specific term. In case of an acceptable consensus rate (>70%), the term was added to the self-management word group. After the first round, it became clear that the experts reached consensus about four keywords, namely self-monitoring, self-care, empowerment and self-control. Furthermore, the experts were asked whether there were additional terms that, in their opinion, comprised self-management of patients with a chronic condition. Them being experts, they contributed several literary warrant terms and possible user warrant terms as well. The keywords for which they reached consensus and newly added words are presented in the third column of the TRASI.

During the two subsequent Delphi rounds, the experts were asked to give their opinion about the terms from the previous round again. Also, they were asked to judge non-consensus terms from the previous round(s) and terms proposed by other participants. After the second round, still no consensus about the remaining seven starting terms had been reached. However, consensus was reached about three additional terms that had been proposed by experts in the first round, namely self-regulation, self-efficacy and shared decision-making. Moreover, consensus was reached regarding the exclusion of the following terms proposed by the Delphi participants: confidence, self-development, learning skills and telemedicine. These terms can be found in the fourth column of the TRASI.

After the third and final round, the experts reached consensus about the inclusion of two more of the original terms proposed by the research team, namely coping and independence. Furthermore, consensus was reached about the exclusion of several terms which had been newly proposed by other Delphi participants: self-diagnosis, together-management, e-health, communication skills, self-reflection and knowledge. Also, the proposed term personal health maintenance was included. All these changes are found in the fifth column of the TRASI. It has to be noted that during the third round, only 16 experts participated, which means that the level of consensus of 70% means that 11 experts reached agreement.

Based on the resulting word groups, the following databases were searched: Embase, Medline, PsycINFO, Web-of-Science, CINAHL and Cochrane CENTRAL. During the search process, it became clear that the keys collected in the word groups on the



basis of consensus were not sufficient to shed light on the research question. This question addressed the evaluation of existing self-management support interventions, and in the outcomes of the search, the research team missed important self-management support interventions, such as patient education about coping strategies and health. They concluded that the results did not cover the self-management interventions needed for the purposes of their research project, because, contrary to their expectations, they did not find anything about existing psychosocial interventions about self-management.

To resolve this, the researchers needed to add more keys to the word groups. Therefore, the following keys were added to the TRASI by the research team to the self-management word group: coping behaviour, patient education and health education. Working this way, it became clear that the consultation of the stakeholders in the search and retrieval process did not result in all of the expected gains for the study. The outcomes of the consultation of the stakeholders in the Delphi rounds resulted in keys with a scope too narrow for the search with the theoretical perspective that the researchers had in mind. After collecting additional keys, the researchers performed a new search, using the same databases as mentioned above.

## DISCUSSION

The goal of the current study was to describe processes of stakeholder engagement and to demonstrate a tool for systematically accounting for the role of stakeholders in searching and retrieving studies in a systematic review. Involving stakeholders in a systematic and transparent way is complex for two reasons. First, stakeholders act in their own interest, which does not necessarily align with scientific interests. Second, the stakeholders' influence on the project is difficult to reconstruct, because it takes place mainly during informal contact. The TRASI proved to be an effective aid in addressing both of these issues by logging stakeholder participation in a systematic and transparent way. Working with the tool, stakeholder's influences on key word selection can be traced back to the stage of the research project in which they occurred and every decision in the search and retrieval process can be easily documented. In this way, the tool proposed in the current study is a first step in resolving the problem of non-transparent and unsystematic stakeholder influences. We have described two different worked examples of accounting for stakeholder influences on the search and retrieval process of decision-oriented systematic reviews: A qualitative evidence synthesis (the VSN project) and a state-of-the-art review (the self-management support project). In the VSN example, the involvement of the stakeholders could be characterised as collaboration with invited organised stakeholders who influenced the entire search process. In the self-management support project, however, individual stakeholders were invited for consultation purposes solely and were consulted a priori, and not during following stages. However, in both projects, the TRASI was successfully used to systematically record the stakeholders' influences.

For decision-making reviews, the role of stakeholders is increasingly acknowledged to increase the match between the knowledge needed for making decisions and the outcomes of the review.<sup>[4]</sup> The worked examples show substantial differences on the process level. They showed different objectives and approaches of involving stakeholders in the review projects. The process of decision-making became visible

as well. In the partnership of reviewers and stakeholders in the VSN project, the objective of the review was clearly to support the commissioner who had to decide on policy issues. The consultation of an external expert on the topic preserved the balance between the specific focus on services and interest of the commissioner and a somewhat broader relevance of the review. In the TRASI it can be seen that discussions about the review question and the scope of the review changed the opinion on key terms that were considered relevant to find the appropriate literature. In the self-management support case, the reviewers first tried to clarify the concept of self-management by consulting experts on the field. In the TRASI, it can be seen that many key terms were added but that it was hard to achieve consensus on the concept and that the ultimate objective to examine effective interventions was lost. The TRASI can be used to account for the reviewers' decision to bring in key terms that they deemed necessary for not missing important results.

It is suggested that in larger review projects, budget needs to be reserved for information specialists to help reviewers with an efficient and useful search strategy including key terms and bibliographic databases.<sup>[10, 17]</sup> To provide optimal support, they need to understand that the information that the review is ought to produce can be the result of a partnership of reviewers and stakeholders. Generally, the literary warrant terms are formulated by the reviewers, and the user warranted terms will be brought in by the stakeholders as was the case in our victim support example. However, this was quite different in the self-management support case. Here, the reviewers started out with literary warrant terms already, and the consulted experts added even more of them. In the eyes of the reviewers, this endangered the usefulness of the outcomes of the review for the end-user and they added user warranted terms to the search process. By keeping track of the keywords which were added by specific stakeholders, such as the commissioner or experts, the logic and perspective of the different parties involved in the research project become clear. This also enables the discovery of the rationale of the review and the remaining requirements in terms of an effective search strategy.

There are limitations to the current study. Only two projects using the TRASI are described, one in the field of psychology and one in the field of chronic care. Due to this fact, we were only able to demonstrate the use of the tool utilising three different types of stakeholders, that is commissioners, decision-makers and experts. This makes it difficult to generalise our findings to other disciplines and to situations where other types of stakeholders are involved. More research using the TRASI with other types of stakeholders participating is therefore warranted. In the current study, we report on projects with a decision oriented character. Stakeholders are incorporated into support future decision making. Examples of other important stakeholders that need to be involved in a systematic and transparent way are stakeholders having hands-on experience with the subject of the systematic review and users of care or support services. We are aiming to address this issue in an upcoming research project. However, the experiences from these two highly different projects suggest that using the TRASI contributes to a more systematic and transparent way of accounting for the influence of stakeholders in a decision-oriented review.

## CONCLUSION

In conclusion, the current study is a first step in improving current methods to systematically account for the involvement of stakeholders in the search and selection process of systematic reviews. While the worked examples highly differed in the way stakeholders were involved, both of them were able to use the TRASI to systematically record the influences of their stakeholders. More research is necessary to confirm our experiences and to compare them with search and retrieval processes in decision-oriented reviews that do not use the tool.

Future research using the TRASI is necessary. Most notably, review teams and information professionals could work together to identify promising further applications of the tool. An example of such an application could be in a review or synthesis conducted following the Rapid Evidence Assessment (REA) guidelines.<sup>[24]</sup> In this case, for a rapid finishing of the review, concessions are made with regard to the breadth and depth of the review. The TRASI can be used to systematically document these decisions about what can be included and what needs to be excluded.

## REFERENCES

- 1 Dixon-Woods, M., Bonas, S., Booth, A., Jones, D. R., Miller, T., Sutton, A. J., Shaw, R. L., Smith, J. A. & Young, B. How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research* 2006, 6, 27–44. doi:10.1177/1468794106058867.
- 2 Harden, A. & Thomas, J. Methodological issues in combining diverse study types in systematic reviews. *International Journal of Social Research Methodology* 2005, 8, 257–271. doi:10.1080/13645570500155078.
- 3 Paterson, B. L. It looks great but how do I know it fits? An introduction to meta-synthesis research. In: Hannes, K. & Lockwood, C. (eds). *Synthesizing Qualitative Research*, 2012. West-Sussex: Wiley-Blackwell, 2012: 1–20.
- 4 Rees, R. & Oliver, S. Stakeholder perspectives and participation in reviews. In: Gough, D., Oliver, S. & Thomas, J. (eds). *An Introduction to Systematic Reviews*, 2012. London: Sage, 2012: 17–34.
- 5 Pope, C., Mays, N. & Popay, J. *Synthesizing Qualitative and Quantitative Health Evidence: A Guide to Methods*. New York: McGraw-Hill, 2007.
- 6 Ginsburg, L. R., Lewis, S., Zackheim, L. & Casebeer, A. Revisiting interaction in knowledge translation. *Implementation Science* 2007, 2, 34. doi:10.1186/1748-5908-2-34.
- 7 Turner, A. M., Liddy, E. D., Bradley, J. & Wheatley, J. A. Modeling public health interventions for improved access to the gray literature. *Journal of the Medical Library Association* 2005, 93, 487–494.
- 8 Pawson, R. *Evidence-Based Policy: A Realist Perspective*. London: Sage, 2006.
- 9 McDonald, P. W. & Viehbeck, S. From evidence-based practice making to practice-based evidence making: creating communities of (research) and practice. *Circle of Research and Practice* 2007, 8, 140–144. doi:10.1177/1524839906298494.
- 10 Swinkels, A., Briddon, J. & Hall, J. Two physiotherapists, one librarian and a systematic literature review: collaboration in action. *Health Information and Libraries Journal* 2006, 23, 248–256.
- 11 Papaioannou, D., Sutton, A., Carroll, C., Booth, A. & Wong, R. Literature searching for social science systematic reviews: consideration of a range of search techniques. *Health Information and Libraries Journal* 2009, 27, 114–122.
- 16 Shaw, R. L., Booth, A., Sutton, A. J., Miller, T., Smith, J. A., Young, B., Jones, D. R. & Dixon-Woods, M. Finding qualitative research: and evaluation of search strategies.

- BMC Medical Research Methodology 2004, 4, 5–9.
- 17 Booth, A., Papaioannou, D. & Sutton, A. *Systematic Approaches to a Successful Literature Review*. London: Sage, 2012.
- 18 van Dijk, J. J. M. Ideological trends within victim movements: an international perspective. In: Maguire, M. & Pointing, J. (eds). *Victims of Crime: A new Deal?*. Milton Keynes: Open University Press, 1988: 115–126.
- 19 Pope, C. & Mays, N. Reaching the parts that other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995, 311, 42–45.
- 20 Britten, N. Qualitative research on health communication: what can it contribute? *Patient Education and Counseling* 2011, 82, 384–388. doi:10.1016/j.pec.2010.12.021.
- 21 Newman, S., Steed, L. & Mulligan, K. *Chronic Physical Illness: Self-Management and Behavioural Interventions*. New York: Open University Press, 2009.
- 22 Connell, J., Brazier, J., O’Cathain, A., Lloyd-Jones, M. & Paisley, S. Quality of life of people with mental health problems: a synthesis of qualitative research. *Health and Quality of Life Outcomes* 2012, 10, 138. doi:10.1186/1477-7525-10-138.
- 23 Jones, J. & Hunter, D. Consensus methods for medical and health services research. *BMJ* 1995, 311, 376–380.
- 24 Blank, L., Coster, J., O’Cathain, A., Knowles, E., Tosh, J., Turner, J. & Nicholl, J. The appropriateness of, and compliance with, telephone triage decisions: a systematic review and narrative synthesis. *Journal of Advanced Nursing* 2012, 68, 2610–2621. doi:10.1111/j.1365-2648.2012.06052.
- 12 Dixon-Woods, M., Booth, A. & Sutton, A. J. Synthesizing qualitative research: a review of published reports. *Qualitative Research* 2007, 7, 375–422. doi:10.1177/1468794107078517.
- 13 Hannes, K. & Maicatis, K. A move to more systematic and transparent approaches in qualitative evidence synthesis: update on a review of published papers. *Qualitative Research* 2012, 12, 402–442. doi:10.1177/1468794111432992.
- 14 Booth, A. Clear and present questions: formulating questions for evidence based practice. *Library Hi Tech* 2006, 25, 355–368. doi:10.1108/07378830610692127.
- 15 Cooke, A., Smith, D. & Booth, A. Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research* 2012, 22, 1435–1443. doi:10.1177/1049732312452938.

TABLES

Table 1 Tool for Recording and Accounting for Stakeholder Involvement (TRAS) for the victim support project

| Components of SPIDER                   | Word groups              | Starting key terms   | First brainstorm session with commissioner/ end-user   | Yield of broad pilot search in one database (CINAHL)  | Discussion in project team consulting expert stakeholder   |
|--|--------------------------|--|--|---|--|
| Sample)<br>P(henomenon)<br>of interest | Victim<br>Incident/crime | Victims, women, survivors, needs, aged, elderly<br>Crime, incident, violence, trauma, psychological<br>trauma, murder, traumatic stress, traumatic<br>event, secondary trauma, physical abuse,<br>abuse, assault, sexual assault, sexual violence,<br>rape, intimate partner violence, domestic<br>violence, tsunami, disaster, natural disaster | Added: children, students, vulnerable<br>Added: victimisation, violent crime,<br>homicide, accident, manslaughter,<br>psychological abuse, theft, burglary,<br>robbery, kidnapping, stalking, human<br>trafficking<br>Removed: tsunami, disaster, natural disaster | Added: eyewitness<br>Added: dating violence,<br>honor crimes, sex<br>trafficking, child<br>trafficking                                    | Brought back /rc<br>disaster, natural<br>disaster, tsunami |
| (Intervention)                         | Intervention             | Intervention, intervening, victim support, mental<br>health support, program, brief intervention,<br>trauma counseling, group work, self-help, self-<br>care, self-help telephone program, therapy   | Added: basic support, sessions, service,<br>screening, compensation, restoration,<br>repair, healing<br>Added: hands-on expert, amateur  | Added: help-seeking, rape<br>crisis program, sexual<br>assault hotline, mental<br>health first aid guidelines<br>Added: volunteer's skill |  |
|  | Volunteer                | Volunteers, voluntary worker, volunteer<br>counselors, trained volunteer, informal<br>teaching, training, crisis counsellor, trauma<br>counsellor  |  |   |  |
|  | Social network           | Spouse, peers, informal, self-help groups, circles<br>of support   | Added: family  | Added: informal third<br>parties  |  |



**Table 2** Tool for Recording and Accounting for Stakeholder Involvement (TRAS) for the self-management support project

| Description of the construct | keywords initially selected by research team  | Key terms in first Delphi round with experts and policymakers   | Key terms in second Delphi round with experts and policymakers  | Key terms in third Delphi round with experts and policymakers   | keywords added by researchers after Delphi consultation   |
|------------------------------|---|---|---|---|---|
| Self-management              | Self-care<br>coping<br>self-control<br>self-monitoring<br>autonomy<br>goal setting<br>adherence<br>problem solving<br>self-determination<br>independence<br>empowerment | Consensus inclusion of the initial keys:<br>self-care<br>self-control<br>self-monitoring<br>empowerment   | Consensus inclusion newly added terms:<br>self-regulation<br>self-efficacy<br>shared decision-making        | Consensus inclusion newly added terms:<br>personal health maintenance   | Patient education<br>health education<br>coping behaviour |
|                              |   | Newly proposed terms:<br>active patient involvement<br>participation<br>chronic care management<br>disease management<br>motivation<br>compliance<br>education<br>competencies<br>social support<br>lifestyle changes<br>self-medication<br>shared management<br>patient compliance | Consensus exclusion newly added terms:<br>confidence<br>self-development<br>learning skills<br>telemedicine | Consensus exclusion newly added terms:<br>self-diagnosis<br>together-management<br>E-health<br>communication skills<br>self-reflection<br>knowledge |   |