

Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts

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Implications for rehabilitation research

- Using several strategies to engage various stakeholders throughout the research process is thought to increase the quality of the research and the rehabilitation process by developing proposals and programs responding better to their needs
- Engagement strategies need to be better reported and evaluated in the literature
- Engagement facilitate uptake of research findings by increasing stakeholders' awareness of the evidence, the resources available and their own ability to act upon a situation
- Factors influencing opportunities for stakeholder engagement need to be better understood

For Peer Review

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3 TITLE
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8 *Engaging stakeholders in rehabilitation research: a scoping review of strategies used in*
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10 *partnerships and evaluation of impacts*
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ABSTRACT

Purpose: To describe how stakeholder engagement has been [undertaken and evaluated](#) in rehabilitation research.

Method: A scoping review of the scientific literature using five search strategies. [Quantitative](#) and qualitative analyses [using](#) extracted data. Interpretation of results was iteratively discussed within the team, which included a parent stakeholder.

Results: Searches identified 101 [candidate](#) papers; 28 were read in full to assess eligibility and 19 were [included in the review](#). People with disabilities and their families were more frequently involved compared to other stakeholders. Stakeholders were often involved in planning and evaluating service [delivery](#). A key issue was identifying stakeholders; strategies used to support their involvement included creating committees, organizing meetings, clarifying roles and offering training. Communication, power sharing and resources influenced how stakeholders could be engaged in the research. Perceived outcomes of stakeholder engagement included the creation of partnerships, facilitating the research process and the application of the results, and empowering stakeholders. Stakeholder engagement outcomes were rarely formally evaluated.

Conclusions:

[There is a great interest in rehabilitation to engage stakeholders in the research process. However, further evidence is needed to identify effective strategies for meaningful stakeholder engagement that leads to more useful research that positively impacts practice.](#)

BACKGROUND

The knowledge-to-practice-gap in health care and rehabilitation is well documented [1, 2].

Traditional knowledge generation and dissemination processes may be one of the crucial reasons for the existence of such a gap [3]. With advances in the science of knowledge translation (KT), the dissemination process is being gradually transformed to include stakeholders (i.e. potential knowledge users such as patients) in the research process. Several reasons for involving stakeholders in the research process have been suggested including: pragmatic (e.g., to facilitate recruitment), theoretical (e.g. to justify the use of a given framework), and mandatory (e.g. requested by funding agency) [4, 5]. Nevertheless, the most important reason may be that collaborating with stakeholders leads to the identification of more relevant research questions, which results in the creation of knowledge that is more readily transferable, relevant and usable to solving real-world problems [4, 5]. The assumption is that stakeholder engagement could increase the relevance of research, thereby promoting its use in practice and helping to close the knowledge-to-practice-gap.

In rehabilitation research, authors have called for greater involvement of stakeholders in research [2, 5, 6]. However, no summary of the literature is available to [bring together how stakeholder engagement in research has been conceptualized, undertaken and evaluated in rehabilitation research](#). Summarizing this information would be helpful for designing effective KT partnerships and research proposals. Knowing how best to involve stakeholders could accelerate the uptake and implementation of knowledge to improve [interventions, evidence-based practice and policies influencing the research and care for individuals with disabilities](#).

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6 The purpose of this paper is to report the findings of a scoping review conducted to identify
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8 which stakeholders are involved in rehabilitation research and to describe: (i) effective strategies
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10 to engage stakeholders meaningfully in the research process, (ii) the factors that influence
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12 engagement, and (iii) the impacts of such engagement. In addition we discuss the implications for
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14 researchers and for the field of rehabilitation science.
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17 18 19 20 METHODS

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24 A scoping review is a review of the literature used to map the key concepts underpinning a
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26 research area and the main sources and types of evidence available [7]. To ensure a diversity of
27
28 perspectives about stakeholders' engagement, efforts were made to include co-authors with
29
30 different background (e.g., senior researchers, students, a parent, physical and occupational
31
32 therapy postdoctoral fellows.). A six-step iterative process [7, 8] was used to guide the scoping
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34 review. We outline the specific steps in the following sections.
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41 **Step 1: Identifying the research question(s)**

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43 The questions guiding the scoping review were: "How has stakeholder engagement been
44
45 conceptualized in rehabilitation research: who are the stakeholders, what strategies are used, what
46
47 factors influenced engagement and what are the impacts of engagement?"
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53 **Step 2: Identifying relevant scientific articles**

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55 Four team members (CC, KST, TN, EG) searched the scientific literature. With guidance from a
56
57 librarian, an initial search of the electronic databases Medline, Embase, CINAHL and PsycINFO
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3 using a combination of keywords yielded too many articles not related to stakeholder engagement
4
5 in the research process (many related to engagement in the rehabilitation process). The search
6
7 strategy was modified to narrow the scope of the database search to focus on engagement and
8
9 participation *in research*, and used a combination of the following keywords: engagement,
10
11 participatory research, participation, rehabilitation, translational research, knowledge translation,
12
13 dissemination and knowledge management ([see Supplementary File 1 for a list of keywords used](#)).

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17 Key terms were adapted to each database. This search led to more targeted results but only a few
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19 articles met our criteria. The team then decided to add, sequentially, four more targeted search
20
21 strategies: 1) a search within the same databases, searching specifically for “integrated
22
23 knowledge translation” (iKT) and “rehabilitation”; 2) a search in the INVOLVE database
24
25 (www.invo.org.uk/) ([a comprehensive database specifically focusing on patient, caregiver, and](#)
26
27 [public involvement in health research](#)), screening all abstracts and titles for “rehabilitation” or
28
29 “disability”; 3) a snowball strategy, wherein team members identified relevant articles (team
30
31 members represent a variety of professional and research backgrounds, countries and stakeholder
32
33 roles, including physical and occupational therapist, midwife, graduate students and a parent of a
34
35 child with disabilities); and 4) backwards citation chasing, (i.e. we reviewed the reference lists of
36
37 the articles included in the previous steps for eligibility using our inclusion criteria).

38 39 40 41 42 43 44 45 **Step 3: Article selection**

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47
48 Potentially eligible articles were read [in full](#) by two team members; in case of disagreement
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50 regarding inclusion, a third team member was consulted until consensus was reached. For final
51
52 inclusion, the pragmatic decision of including papers published in English between January 2003
53
54 and August 2013 was taken since preliminary scanning of the literature allowed us to estimate the
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56 interest for stakeholder engagement increased considerably [starting](#) about ten years ago. Papers
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3 also needed to describe strategies used to engage stakeholders in a specific rehabilitation research
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5 project. We defined stakeholders as people whose primary job is not directly in research and
6
7 included the following groups of individuals: children or adults with disabilities (i.e. chronic
8
9 health conditions, long-term intellectual or physical disabilities), their families and caregivers,
10
11 individuals representing community groups, policy-makers, and clinicians (e.g., physical
12
13 therapists, occupational therapists). To be considered a rehabilitation research project, a study had
14
15 to involve individuals with disabilities or relate to rehabilitation interventions. With regard to
16
17 engagement, we built on the Canadian Institutes of Health Research (CIHR) definition of
18
19 integrated KT where each “stage in the research process is an opportunity for significant
20
21 collaboration with knowledge users, including the development or refinement of the research
22
23 questions, selection of the methodology, data collection and tools development, selection of
24
25 outcome measures, interpretation of the findings, crafting of the message and dissemination of
26
27 the results” [9]. We were looking for papers in which stakeholders were reported to have been
28
29 included throughout the research process and where at least one concrete example of engagement
30
31 (e.g. meetings) was described. We included both qualitative and quantitative research studies, and
32
33 opinion/reflection papers as long as they were describing strategies used in a specific study. We
34
35 excluded opinion papers presenting general statements on the virtue of stakeholder engagement,
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37 as well as book chapters and abstracts for which no full papers were available.
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48 **Step 4: Data charting**

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50 | A data charting form was developed and piloted with five articles. The form included the
51
52 following categories of information: type of stakeholders engaged, study objectives, methods,
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54 rationale for including stakeholders, specific stakeholder engagement strategies, factors
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56 influencing engagement, and impacts associated with engagement. We also documented whether
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3 the factors influencing stakeholder engagement and the impacts reported in the papers were
4
5 evaluated. Evaluation was defined as the use of some instrument (e.g. survey, questionnaire,
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7
8 interview) to collect information to document factors influencing engagement and impacts related
9
10 to engagement. No evaluation was considered to have occurred when authors described the
11
12 process or discussed possible benefits and pitfalls without empirical data. To ensure validity and
13
14 consistency of data extraction, four team members independently extracted and recorded data for
15
16 a subset of articles retained (n=5) and then met to discuss the charted data. Minor modifications
17
18 concerning principally the headings (i.e. formulation of the questions guiding the data extraction)
19
20 and the organization of the charting form were made. The final version of the charting form was
21
22 agreed upon following this exercise. One team member (TN or EG) then extracted data from all
23
24 remaining articles, and a second team member (KST or CC) verified the data charted.
25
26
27 Disagreements were rare (2 % of the data extracted) and consensus was achieved on the data
28
29 extracted through discussions and revisions of the original articles.
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36 **Steps 5 & 6: Collating, summarizing, reporting, and Consultation**

37
38 All team members discussed the data extracted. A numerical analysis (i.e. counting the
39
40 stakeholders identified to describe who they were) and a thematic analysis were performed.
41
42 Themes for the thematic analysis related to the aims of the paper (i.e. strategies, factors and
43
44 impacts) while the subthemes were the concepts nested within each theme. First, four team
45
46 members met to identify the key concepts emerging from the data charting form. A co-author
47
48 (KST) extracted all the citations, across references and related the concepts to the subthemes. An
49
50 iterative process was used to collate the citations, review the data charting form and re-review the
51
52 original articles when needed to better describe the concepts. In addition, identifying, describing,
53
54 merging and subdividing the themes was done in collaboration with two other co-authors (CC
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3 and AT). These three co-authors then discussed the emerging results with the parent stakeholder
4
5 (JS) to explore the meaning of each theme, provide new perspectives to the interpretations and
6
7 highlight the most relevant topics for both researchers and stakeholders. All team members
8
9 reviewed the final results to ensure clarity and consistency.
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13 14 15 RESULTS

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20 The first search strategy identified 74 papers, while the supplementary strategies identified a
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22 further 27 papers, for a total of 101 papers. Of those, we retained 28 articles based on title and
23
24 abstracts screening; these articles were read in full to assess eligibility and 19 articles were
25
26 included (Figure 1). Table 1 outlines the details of the articles included. Individuals with
27
28 disabilities (n=13) and their families (n=6) were the stakeholders most frequently involved
29
30 compared to other stakeholders. Other stakeholders included clinicians (n=9), individuals
31
32 representing community groups (n= 6), decision-makers at program and policy levels (n=2) and
33
34 program managers (n= 1). Studies described strategies to involve stakeholders in specific
35
36 research steps: identifying research questions (n=10), collecting/generating data (n= 14),
37
38 analyzing data (n= 10), interpreting results (n= 11), disseminating results (n=11), formulating and
39
40 implementing action plans (n=9). Only one article clearly reported having engaged stakeholders
41
42 on the writing of the article. No studies evaluated the strategies used. Few studies used data
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44 collection to evaluate factors influencing engagement (n=3) or outcomes of engagement (n=6).
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53 [Insert Figure 1 and Table 1 about here]
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3 Stakeholders were engaged to help identify service users' needs [10-12], to understand the
4 experiences of service users [13-19], to develop and assess the impact of consumer-led programs
5 [13, 20], to support the development of strategies and interventions [14, 21], and to identify
6 outcomes that are meaningful for individuals with disabilities [16]. Some articles focused on
7 describing stakeholder engagement in the research process [11, 19, 22-25]. Specifically, articles
8 reflected upon the support needs for engaging individuals who are not researchers [15] and on
9 teamwork between researchers and non-researchers [12].
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21 Approaches presented as useful to support engagement include participatory-action research
22 (PAR) [12, 21, 26], iKT [27], inclusive research [15], community-academic partnerships [28], the
23 Praxis Framework [10], critical/reflexive approaches [18], narrative approaches [20], the Concern
24 report method [10], the PESTEL model [11] and the Radical reflexive approach [18].
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34 **Thematic analysis**

35 **Strategies for stakeholder engagement**

36 *Identifying stakeholders*

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38 Two types of strategies were used to recruit stakeholders for volunteer or paid roles: targeted or
39 open. In targeted strategies, researchers selected the organizations or the individuals to be
40 included. Direct invitations were made to partner organizations to nominate members on working
41 committees [12, 20, 27] or to individuals having previous relationships with the researchers [12].
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50 In open strategies, researchers asked partner organizations to disseminate the invitation to their
51 members (e.g., by mail with a return stamped envelope) or used the media [15, 19, 23, 24]. For
52 some paid positions, researchers drafted a job description delineating stakeholders' roles, with
53 opportunities to renegotiate roles later in the process. No details were provided on the
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3 interview/selection process. However, many authors suggested paying attention to the following
4
5 criteria: 1) stakeholders' characteristics (i.e. do they share key features of the group they
6
7 represent), 2) stakeholders' willingness to speak for the group they represent (as opposed to
8
9 personal interests), 3) ability to communicate well, 4) achieving diversity in the group [20, 23, 24,
10
11 27]. Identifying and engaging the right stakeholders was perceived as a challenge [26]; however
12
13 partnering with organizations, providing salary and having a clear job description were factors
14
15 perceived as facilitators for stakeholders' identification and engagement.
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20 21 22 *Roles and committees*

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24 The creation of one or various committees with different roles (e.g., working, steering or advisory
25
26 committees, expert panel) was a strategy commonly used [11-13, 16, 19, 26, 28]. Stakeholders
27
28 included persons with disabilities, caregivers, clinicians, researchers and support/community
29
30 groups. They were reported to be active and engaged throughout the process. Roles of committee
31
32 members included: reviewing the proposal and the results [26], being champions of the research
33
34 program, liaising with research sites and adapting the research accordingly [27]. In some
35
36 instances, stakeholders were involved in the whole research process, from setting the research
37
38 agenda and research questions to data collection and analysis, and dissemination [12, 14, 19]. In
39
40 two papers, stakeholders were considered as co-researchers [19, 23]. Some committees
41
42 participated in activities such as writing job descriptions, doing interviews and hiring personal,
43
44 managing funds and organizing social events [13].
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53 Committee activities included face-to-face and teleconference meetings and group discussions
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55 [11, 26]. Frequency and duration of meetings varied across studies but it was perceived to be
56
57 important to be able to keep stakeholders motivated and engaged. Buettgen et al. [12] reported
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3 having used face-to-face meetings when decisions needed to be taken, and phone meetings
4
5 between face-to-face meetings to keep participants informed and engaged. In general, group
6
7 discussions were held around themes such as service delivery issues, stakeholders' roles and
8
9 explanation of the research process in general (e.g., explaining the PAR steps to a co-researcher
10
11 with a disability) [15, 18, 19]. Numbers of participants in those activities varied; some were open
12
13 to all stakeholders interested while others were done with a smaller, selected group of participants.
14
15 Written documents (e.g., presenting data to analyze or materials for dissemination) and flipcharts
16
17 were reported as facilitating participation and were seen as useful to document the stakeholder
18
19 engagement process [12, 15]. Other important considerations for engaging stakeholders included
20
21 scheduling meeting times and locations convenient for stakeholders (e.g., having meetings
22
23 outside of the service-provider organization), engaging stakeholders in planning agendas, sharing
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25 the lead for activities among stakeholders, and outlining a plan for sustainability of group
26
27 activities from the outset [12, 14, 19, 26].
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36 *Supporting stakeholders*

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38 It was perceived that stakeholders needed to be supported in order to understand research and to
39
40 fulfill their role. Formal training and courses were used to build skills around different research
41
42 components (e.g., research design, collecting data, facilitating meetings) [11, 12, 15, 19, 25] or to
43
44 increase knowledge on different topics (e.g., client-centred services) [20]. The training
45
46 occasionally integrated the use of videos to elicit discussions (e.g., about respectful relationships
47
48 in the research context) [20]. Participants were sometimes paid to attend these training sessions
49
50 [11]. Informal training was also reported to occur, mostly during committee meetings [18, 19] or
51
52 during data collection and analysis [15, 17]. Using a specific framework to interpret data,
53
54 debriefing field notes and hiring a research assistant as mentor were strategies used to increase
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3 research skills of the stakeholders. Key strategies found to integrate stakeholders in research are
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5 summarized in the Supplementary File 2.
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10 **Factors influencing engagement**

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12 *Implementation of the strategies* described above was perceived to *facilitate* engagement of
13
14 stakeholders. In addition, three overarching themes emerged related to factors that positively or
15
16 negatively influenced stakeholder engagement: communication/culture, power sharing, and
17
18 resources.
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22 *Communication/culture*

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27 Researchers and stakeholders were reported as having different perspectives about stakeholders'
28
29 roles and expectations. Clarifying and agreeing on realistic expectations at the beginning of the
30
31 process was recommended to find a balance between obtaining valid research results and meeting
32
33 personal stakeholders' goal (e.g., having personal information about one's health condition) [13,
34
35 14, 18, 19, 23, 24]. This upfront negotiation could avoid conflicts, demotivation, dissolution of
36
37 partnerships, or frustration in situations where stakeholders could perceive a lack of concrete
38
39 actions. On the other hand, ongoing communication [13, 18], engaging stakeholders in
40
41 community based activities [27], creating spaces for voicing their concerns [24], and creating risk
42
43 management strategies (i.e., what to do if problems arise in the group) [13] were perceived to
44
45 contribute to motivation and engagement, and to foster satisfying partnerships.
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53 Scientific language and research materials (e.g. protocols, pamphlets and questionnaires) needed
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55 to be adapted to avoid jargon, ensuring everyone understood and felt comfortable and confident
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57 to engage in meaningful dialogue [11, 12, 15, 16, 23, 28]. Since written materials might have low
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3 meaning for stakeholders with low literacy skills, the use of flip charts and photos might be more
4
5 appropriate to build on participants' strengths and improve communication [12]. During group
6
7 discussions, having stakeholders leading conversations could also reduce the cultural barriers,
8
9 creating a safe environment for the engagement of other participants [19, 27]. However, caution
10
11 was advised, given that different stakeholder groups (e.g., service users and service providers)
12
13 can have different expectations. Tensions can arise when one group failed to acknowledge
14
15 another group's needs and priorities [20]. Facilitators of good group dynamics included planning
16
17 (in grant proposals) enough time and opportunities to consult and understand the different group
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19 needs, to further include their feedback and adapt the materials [24].
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27 *Power sharing*

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29 Power sharing was essential for establishing a common ground, negotiating the study agenda,
30
31 resolving conflicts, and supporting meaningful engagement, teamwork and collaboration [10, 12,
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33 20]. The number of stakeholders involved was also a factor to consider for power sharing [13].
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35 Often, few stakeholders represented an entire group and were a minority compared to the number
36
37 of researchers. Stakeholders, and especially those from vulnerable populations, need to feel
38
39 entitled to contribute at the same level of the researchers [17]. Researchers' willingness to share
40
41 control over the research process and their previous experiences with participatory processes
42
43 were reported as facilitator for stakeholders' engagement [15].
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50 Shifting ownership of the research process from researchers to stakeholders takes time [12].

51
52 Inviting stakeholders gradually to take more decisions (e.g., setting meeting agendas or taking
53
54 specific decisions about the research process) was perceived as facilitating power sharing [21, 24].

55
56 On the other hand, pre-determined roles and expectations of how stakeholders should participate
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3 was perceived as a barrier, since it removed the possibility for the stakeholders to determine how
4 they would like to be engaged [12, 14, 15, 19, 23]. Likewise, engaging stakeholders only at the
5 end of the research project limited power sharing because participants were expected to
6 contribute in a predefined way [16]. Nevertheless, some studies reported having engaged
7 stakeholders exclusively in analysis of the data while providing them with the opportunity to
8 make decisions around dissemination and service design [13, 15, 19]. It was suggested that
9 dissemination should ensure stakeholders' opinions are represented [18].
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22 *Time, funding and resources*

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24 Engaging stakeholders meaningfully required substantial time and financial commitments [11-13,
25 15, 22, 23, 28]. Allocating proper financial resources was important to support stakeholders'
26 participation. Costs to consider included traveling expenses, training, support, administration,
27 promotional activities, KT, and accommodating stakeholders' special needs (e.g., adapting
28 materials) [11, 13, 15, 21, 26, 27]. Funding agency deadlines were often perceived as a barrier for
29 creating opportunities for engagement [11, 15, 18, 22]. Strategies to overcome time restrictions
30 included hiring staff with time allocated to support stakeholder engagement, and maintaining
31 flexible timelines in the project [13, 14, 28]. Finally, planning for sustainability of stakeholder
32 engagement was key as funds supporting engagement are often not available after data collection
33 and stakeholders have limited opportunities to participate in dissemination activities [12, 15].
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51 Impacts related to stakeholder engagement

52 53 54 55 *Creating partnerships and building value*

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3 A frequently mentioned **impact** was the creation of partnerships where each participant learned to
4 value different perspectives [19, 20, 23]. Researchers can learn about the political system
5
6 dynamics [27], the potential applications of research findings [23], and the lived experiences of
7
8 stakeholders [19, 20, 24]. Service users and providers can gain insights on challenges related to
9
10 service delivery, and immediate applications of research results [11, 19]. Partnerships can also
11
12 evolve **into** long-term collaborations where other projects can be generated [12, 27]. Families
13
14 could also benefit from networking with others through engagement in research [20], and learn
15
16 about ways of dealing with their members having a disability [22]. Some authors reported that
17
18 partnerships could promote a model whereby theory, practice and research are interwoven to
19
20 generate knowledge that will have important benefits for patient care [10, 13]. This model could
21
22 lead to significant improvements in the life of persons with disabilities (e.g., increasing
23
24 accessibility by adding signs and ramps on campus) [11].
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34 *Making knowledge more easily applicable and facilitating the research process*

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36 Stakeholders' engagement fostered identification of relevant questions, credibility of the
37
38 knowledge produced and application of results adapted to contexts [13, 14, 16, 21, 26, 27]. For
39
40 example, services developed with stakeholders were more widely accepted and responsive to
41
42 stakeholders' needs [10, 14, 20, 21, 23, 27]. Specifically, engaging policy-makers helped secure
43
44 funds for new services [27] while engaging individuals from patient support groups facilitated
45
46 intervention delivery [26]. Engagement also helped adapting the study processes and materials,
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48 and facilitated the research process from recruitment to retention and dissemination of results [16,
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50 20-22, 26-28]. Benefits were, however, questioned when stakeholders were consulted only at the
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52 end of the project [16].
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Empowerment

As a result of engagement, stakeholders increased their confidence and skills, their awareness about specific needs and resources, their ability to advocate, to access information and social support [12, 14, 16, 19]. Interactions between stakeholders also contributed to feelings of belonging to a group [12, 20]. Specifically, PAR contributed to empowerment as stakeholders became more aware of their strengths and personal resources [12, 23]. Authors did mention that stakeholders needed to have real control over how they did their work to ensure engagement would not lead to disempowerment [15, 18].

Evaluating impacts

Only six studies collected data to document the impacts of stakeholder engagement [10, 14, 15, 18, 19, 21] and none used standardized measures for evaluation. Evaluations consisted of post-hoc analysis of focus groups about stakeholders' engagement [15], debriefing and interviewing stakeholders about their satisfaction with the involvement process [19] and interviews and questionnaires about perceived outcomes around stakeholders' engagement [14]. Qualitative analysis of records around knowledge coproduction in a radical reflective approach was also used as an assessment method [18]. Within PAR, a non-specific reflective approach was used to outline the outcomes of involving stakeholders in relation to the changes in research directions, service delivery and satisfaction with training offered [10, 21].

DISCUSSION

This scoping review illustrates a diversity of practices associated with stakeholder engagement in rehabilitation research and outlines many potential benefits and challenges in engaging different

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2
3 individuals in the entire research process. It also highlights the lack of evidence formally
4
5 describing and evaluating the engagement in the different stages of research. We identified
6
7 several factors facilitating and hindering engagement of stakeholders in rehabilitation research.
8
9 Moreover, this scoping review revealed the complexity of searching for evidence in a body of
10
11 literature that is still in its infancy and with a large variation in terms and definitions used to
12
13 describe stakeholder engagement. Our findings and recommendations to move the field forward
14
15 are presented around key questions about stakeholder engagement in rehabilitation research.
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20 21 22 *Who's involved and who should be involved?*

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24 Individuals with disabilities and their caregivers were more frequently engaged in rehabilitation
25
26 research compared to other stakeholder groups. This is not surprising given the emphasis on
27
28 patient and family-centered care in rehabilitation [29]. Moreover, many of the articles retrieved
29
30 were about service delivery where it is common to engage direct service users, but other
31
32 stakeholders are less often represented [30]. We would argue that many other stakeholders groups
33
34 could also contribute through their unique perspectives, skills and resources. The implication is
35
36 that researchers should identify their goals up front and then identify all the stakeholder groups
37
38 that could be interested or need to be involved to increase project feasibility, outcomes and
39
40 sustainability. These stakeholders could include decision-makers, health care professionals,
41
42 administrative personnel, community group representatives as well as researchers in other fields
43
44 out of the rehabilitation specialties (e.g., politics).
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51 52 53 *How are stakeholders engaged and when should they be engaged?*

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55 Practices around stakeholder engagement identified in this review varied. Many studies reported
56
57 having engaged stakeholders throughout the research process, but in only a few articles were we
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1
2
3 able to identify specific strategies in each research step (i.e., from identifying research questions
4
5 to disseminating findings and implementing plans). This could be explained by authors not
6
7 reporting all the strategies they used, or because stakeholders were *informed* throughout the
8
9 process without real opportunities to *influence* and *engage in* the process. Using approaches to
10
11 support stakeholder engagement, such as PAR [26] could help planning for engagement strategies
12
13 through the research process. Other approaches, such as scholarships of practice (a collaborative
14
15 model whereby theory, research and practice are interwoven [31]), could also support
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17 engagement.
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24
25 In many studies, stakeholders joined the project once it had already started and were thus not
26
27 engaged in *generating research questions*. Collaboration in identifying the research questions is
28
29 crucial as it impacts the whole process, and influences the ownership over the project [4, 5].
30
31

32 Opportunities for researchers and stakeholders to interact might need to be in place first to allow
33
34 stakeholders to participate *meaningfully* in this step (as opposed to only providing letters of
35
36 support). Examples of research projects that involve stakeholders in developing consensus on
37
38 research priorities exist (e.g., [33]); however, they have been funded as a single project. Research
39
40 funding opportunities might need to be restructured to support involvement in research more
41
42 broadly, supporting continuous stakeholder involvement in and across projects as opposed to
43
44 funding engagement in single projects [32].
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50 *Data collection and analysis* require specialized skills, which stakeholders might not have; this
51
52 may explain why stakeholders were not always involved in this step. Nevertheless, it is important
53
54 to identify their desired level of involvement and support it. Involving stakeholders in
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3 interpretation might be more feasible and could facilitate tailoring knowledge to context, an
4
5 important step toward generating knowledge that will be useful for practice [17, 34].
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10 Many groups have recommended including stakeholders in *dissemination* and KT [9, 35, 36].

11 Few articles retrieved reported concrete strategies used in the dissemination and action plan steps.

12
13 Moreover, the majority of papers were written by researchers who shared their perceptions about
14
15 the processes and outcomes of stakeholder engagement, without inputs by stakeholders or data
16
17 about stakeholder engagement. Stakeholders might not have the interest or skills to write
18
19 scientific papers. Nevertheless, opportunities should be offered to stakeholders to participate in
20
21 disseminating results. Besides scientific articles, other research outputs might better match
22
23 stakeholders' skills, comfort level and interests, such as clinical and policy briefs, lay summaries,
24
25 newsletters and dissemination on social media.
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34 *What are the facilitators and barriers to engagement?*

35
36 Several barriers and facilitators for stakeholder engagement were identified in the different
37
38 studies. Factors facilitating integration of stakeholders (e.g. having regular meetings, assigning
39
40 clear roles, sharing power, and having the time and financial resources) are similar to the ones
41
42 described in the KT literature. It is also likely that strategies documented as being effective for
43
44 KT, such as using active and multi-modal approaches, using plain language and fostering
45
46 continuous interactions between researchers and non researchers [2, 3, 37, 38] would also support
47
48 stakeholders' engagement through the process. Likewise, barriers to KT such as limited resources
49
50 could also be barriers for stakeholder engagement. Both funding agencies and researchers need to
51
52 be aware of the time and resources needed to support engagement. Organizations use different
53
54 strategies to promote stakeholder involvement, including developing resources (e.g., guidelines
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3 for stakeholder engagement), coercion (e.g., “obligating” researchers to have letters of support
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5 from knowledge users) or targeted grants (e.g., planning grants that allow time to involve
6
7 stakeholders).
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12 *What is the evidence, and what evidence is needed?*
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15 We originally intended to include only papers in which strategies for engagement had been
16
17 trialed and evaluated in rehabilitation research, but we broadened our criteria since no such study
18
19 was found. Of the articles retained, few used empirical data collection to identify factors
20
21 influencing engagement or outcomes of engagement. Among these, no standardized measures
22
23 were used, and the questionnaires, focus group guides and debriefing techniques used were not
24
25 clearly described. This is consistent with the fact that research documenting stakeholder
26
27 engagement in the research process is emerging slowly; the mechanisms to ascertain and measure
28
29 engagement are largely unstructured [39, 40].
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37 An evidence-based approach to promote stakeholder engagement is necessary, where the
38
39 outcomes are measured and benchmarked to establish the most effective strategies. This would
40
41 follow the development of KT science in other areas where randomized control trials and
42
43 observational studies are used to measure the effectiveness of KT interventions [41-44].
44
45 Strategies and tools to assess the impacts of stakeholder engagement (e.g., (piaf.org.uk/),
46
47 evidence library and database of projects involving stakeholders (e.g., www.involve.org.uk/), and
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49 models that could support stakeholder engagement (e.g., the Knowledge-to-Action [34]) are
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51 available. However, none of these resources were tested in the articles retrieved. Rehabilitation
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53 research needs to move beyond the conceptualization of stakeholder engagement to the use and
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55 evaluation of these strategies and models.
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6 *Why is it so difficult to find current evidence?*
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8 Our search strategies were limited by the variety of terms referring to stakeholder engagement
9 and we may have missed relevant articles. Engagement might have many synonyms (e.g.,
10 involvement or participation), and can refer to participation as research participants or
11 participation in the rehabilitation process, in community life or in the research process. The word
12 ‘stakeholders’ may have many synonyms (e.g. partners) and can also be named by “who they
13 are” (e.g., patients, decision-makers). Challenges around having multiple names to label the same
14 concepts, or using the same name to describe different processes, have already been identified for
15 the term “knowledge translation” [45]. All these nuances in language affect the ability to really
16 understand the processes used and the ability to retrieve relevant information.
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31 The parent stakeholder in our team (JS) also pointed out that current evidence about stakeholder
32 engagement might not be in scientific articles but on the Internet and social media, where much
33 discussion is going on. These conversations were, however, not captured by this scoping review,
34 since we only searched evidence in scientific articles to describe how stakeholder engagement
35 was conceptualized in the literature. However, social media could be a mechanism to retrieve,
36 review and evaluate information including a broader and more democratic representation of
37 stakeholder engagement. Social media discussions are not usually critically appraised, but they
38 are increasingly being used by stakeholders to retrieve and disseminate information [46, 47] and
39 are gaining a growing appreciation in rehabilitation research and practice [48]. They could also
40 offer new venues to foster stakeholder engagement and contribute to diminishing cultural barriers,
41 fostering understanding of stakeholders’ priorities and policy trends, creating effective evaluation
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3 methods, improving the efficacy of research collaborations and reaching individuals outside
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5 traditional circles of evidence-based information.
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10 The parent stakeholder on our team also highlighted that it is currently difficult for stakeholders
11 to be aware of the evidence and the current research opportunities. Researchers might need to
12 actively solicit and build relationships with stakeholders. National databases using the Internet
13 and social media to connect stakeholders and researchers with similar interests could be helpful
14 in building those relationships, presenting clearly the research processes and the expectations
15 around stakeholder involvement. Stakeholders may feel voiceless and limited by shortcomings
16 within the system; being involved in research that leads to intervention and system improvements
17 can be empowering, especially for those who may feel an overwhelming sense of
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disempowerment.

STUDY LIMITATIONS AND FUTURE DIRECTIONS

As stated above, search strategies were limited by the great variety of terms used for each of the terms searched (e.g., knowledge translation, stakeholders), and the heterogeneity of the field of rehabilitation itself (different populations and settings). As a result, relevant articles may have not been included in our review. Whilst a parent of a child with a disability was part of the team, given our predominant personal experiences in childhood rehabilitation, there are other stakeholders across various rehabilitation contexts that were not consulted and whose perspectives would have been useful to engage. It would be optimal to involve representatives of other stakeholder groups, such as policymakers, decision-makers, clinicians and individuals with various disabilities and ages.

Homogenizing terms used in rehabilitation research, and defining them consistently will be essential for further developing the field, and contributing to more comprehensive literature reviews. The development of solid and long-term relationships with a variety of stakeholders will also improve their participation in research and consequent impacts.

CONCLUSION

This scoping review revealed that: a) a limited group of stakeholders are being involved in rehabilitation research; b) engagement practices vary; c) the research process is still mainly controlled by the researchers and stakeholders are rarely meaningfully involved in all the research steps; d) barriers and facilitators for engaging stakeholders in research are similar to the ones in KT (e.g., financial and time constraints, culture and language); and e) there have been few evaluations of stakeholder engagement processes and [impacts](#). There is a need to document and evaluate the diversity of approaches and strategies used to integrate stakeholders. This will allow us to better understand how to develop fruitful partnerships between researchers and stakeholders and to quantify the [impacts](#). *Identifying what works best under which circumstances is crucial*, since it is unlikely that one approach fits all contexts, research goals and stakeholder needs.

Identifying effective strategies to enable meaningful stakeholder engagement is likely to lead to research that actually changes practice and improves care.

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Figure 1. Illustration of the search process to identify articles pertaining to stakeholders' engagement in rehabilitation research

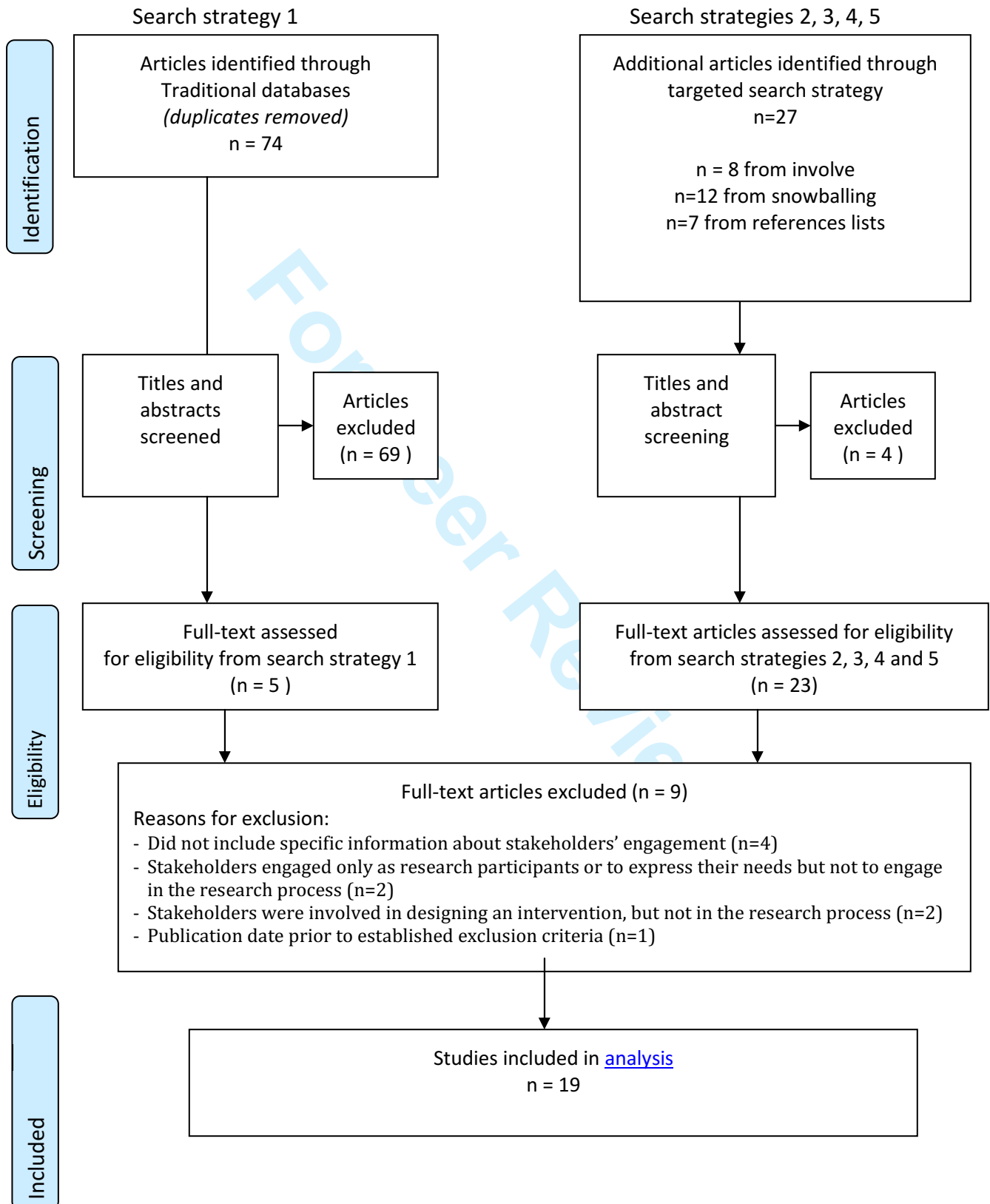


Table 1: Characteristics of studies retained

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# (Ref#)	First Author	Year	Country	Title	Type of Stakeholders engaged						Research steps in which stakeholders were engaged						Factors influencing engagement		Outcomes of engagement		Stakeholders are co-authors/have reviewed the article
					PWD ¹	Family	Clinicians	Com. ²	D Makers. ³	Managers	Id. Quest. ⁴	Data Col. ⁵	Analysis	Interpret. ⁶	Dissem. ⁷	Action plan	Described (X=Yes)	Assessed	Described (X=Yes)	Evaluated	
1 (16)	Amtmann	2011	USA	The PROMIS Initiative: Involvement of Rehabilitation Stakeholders in Development and Examples of Applications in Rehabilitation Research	X		X				X								X		
2 (15)	Bigby	2010	Australia	Reflections on doing inclusive research in the "Making Life Good in the Community" study	X							X				X	X	X	X	X	
3 (12)	Buettgen	2012	Canada	We did it together: a participatory action research study on poverty and disability	X						X	X	X	X	X						X
4 (17)	Cotterell	2007	UK	Exploring the value of service user involvement in data analysis: 'Our interpretation is about what lies below the surface'	X						X	X	X	X							
5 (26)	Ehde	2013	USA	Developing, Testing, and Sustaining Rehabilitation Interventions Via Participatory Action Research	X						X				X	X	X		X		
6 (18)	Gillard	2012	UK	Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study	X	X	X			X	X	X	X	X			X	X	X	X	
7	Hutton	2008	UK	Involving parents as service	X	X	X					X					X		X		

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16 (19)	Walmsley	2009	Ireland	Parents as co-researchers: a participatory action research initiative involving parents of people with intellectual disabilities in Ireland		X							X	X	X	X		X		X	X	
17 (25)	Walmsley	2004	UK	Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research	X	X							X	X	X	X	X	X				
18 (24)	Williams	2005	UK	More researching together: the role of nondisabled researchers in working with People First members	X								X	X	X	X	X	X	X	X		
19 (11)	Wood	2003	UK	Disability, Participation and Welfare to Work in Staffordshire	X												X	X		X		

Legend.

- 1. PWD = Persons with Disabilities
- 2. Com = individuals representing community groups
- 3. D. Makers = Decision Makers
- 4. Id. Quest. = Identification of Research Questions
- 5. Data Col. = Data Collection/generation
- 6. Interpret. = Interpretation

Dissemin. = Dissemination of results

Ref # = Reference number of the article in the reference list at the end of the paper

Supplemental file 1.

Keywords used initially that led to many articles which were not related to stakeholder engagement in the research process.

There were four main types of terms that we needed to identify: those relating to knowledge translation, those relating to service providers, those pertaining knowledge users and those relating to decision making and collaboration. Like terms were combined using OR and all four concepts were combined using AND.

The keywords were adapted according to each database (ie MEDLINE, EMBASE, CINAHL, PsycINFO); however, the search strategy for EMBASE is listed below:

Terms relating to knowledge translation

1. translational strateg*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

or

2. exp Translational Medical Research/

or

3. translational research.mp.

or

4. exp "Diffusion of Innovation"/

or

5. implementation science.mp.

or

6. exp Information Dissemination/

or

7. information dissemination.mp.

or

8. exp "Diffusion of Innovation"/

or

9. diffusion of innovation.mp.

AND

Terms relating to service providers

10. occupational therap*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

or

11. physio*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

or

12. physical therap*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

or

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2
3 13. speech language patholog*.mp. [mp=title, abstract, subject headings, heading word, drug
4 trade name, original title, device manufacturer, drug manufacturer, device trade name,
5 keyword]

6
7 or

8 14. pediatric*.mp. [mp=title, abstract, subject headings, heading word, drug trade name,
9 original title, device manufacturer, drug manufacturer, device trade name, keyword]

10
11 or

12 15. audiolog*.mp. [mp=title, abstract, subject headings, heading word, drug trade name,
13 original title, device manufacturer, drug manufacturer, device trade name, keyword]

14
15 or

16 16. Rehabilitation/

17
18 or

19 17. exp Physical Therapy Modalities/

20
21 or

22 18. exp Physical Therapy Specialty/

23
24 or

25 19. rehabilitation.mp.

26
27 or

28 20. rehabilitation*.mp. [mp=title, abstract, subject headings, heading word, drug trade name,
29 original title, device manufacturer, drug manufacturer, device trade name, keyword]

30
31 AND

32 Terms relating to knowledge users

33 21. exp Family/

34
35 or

36 22. child*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original
37 title, device manufacturer, drug manufacturer, device trade name, keyword]

38
39 or

40 23. exp Administrative Personnel/

41
42 or

43 24. exp Adolescent/

44
45 or

46 25. youth.mp.

47
48 or

49 26. occupational therapist.mp.

50
51 or

52 27. exp Physical Therapists/

53
54 or

55 28. physiotherapist.mp.

56
57 or

58 29. speech language pathologist.mp.

59
60 or

30. pediatrician.mp.

1
2
3 or
4 31. audiologist.mp.
5
6 or
7 32. exp Patients/
8
9 or
10 33. patient.mp.
11
12 or
13 34. client.mp.
14
15 or
16 35. stakeholder.mp.

17 AND

18
19 Terms relating to decision making and collaboration

20 36. exp Decision Making/
21
22 or
23 37. exp Cooperative Behavior/
24
25 or
26 38. exp Communication/
27

28 AND

29
30
31 39. limit to (english language and yr="2003 -Current")
32
33

34
35 The initial search did not effectively address the research question, particularly with respect to
36 engaging stakeholders. Therefore, researchers decided to conduct a new search strategy by
37 choosing keywords from target papers that effectively addressed the research question.
38 Engagement, participatory research and participation were combined using OR. Rehabilitation,
39 rehabilitation medicine and rehabilitation nursing were also combined using OR. Translational
40 research, translational medical research, knowledge translation, information dissemination and
41 knowledge management were combined using OR. The three concepts were combined using
42 AND, and the list of articles was limited to English language and those published from 2003
43 onwards. The revised search strategy for EMBASE is below:
44
45

46
47
48 1. engagement.mp.
49
50 or
51 2. exp participatory research/
52
53 or
54 3. participation.mp.

55 AND
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1
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3 4. exp rehabilitation/
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5 or

6 5. exp rehabilitation medicine/
7

8 or

9 6. exp rehabilitation nursing/
10

11 or

12 7. rehabilitation.mp.
13

14 AND
15

16 8. exp translational research/
17

18 or

19 9. translational medical research.mp.
20

21 or

22 12. knowledge translation.mp.
23

24 or

25 13. exp information dissemination/
26

27 or

28 14. exp knowledge management/
29

30 AND
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32 16. limit to (english language and yr="2003 -Current")
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Supplemental file 2: Strategies, theoretical approaches and methods, and objectives for engaging stakeholders

Key strategies used for engagement
Cognitive interviews (Amtman et al., 2011)
Focus/structured groups (Buettgen et al., 2012; Gillard et al., 2012; Walmsley et al., 2009)
Workshops (Dawn et al., 2013)
Regular teleconferences and/or in-person meetings (Buettgen et al., 2012; Dawn et al., 2013; Gillard et al., 2012; Walmsley et al., 2009; Williams et al., 2005; Suarez-Balcazar et al., 2005a)
Sporadic meeting in specific steps of the research process at the stakeholder's locations (e.g school, community center) (Hutton et al., 2008)
Brainstorming sessions about outcomes and possible applications (Suarez-Balcazar et al., 2005b)
Service users developed and conducted semi structured interviews (Gillard et al., 2012; Sax et al., 2007)
Stakeholders helped to design project's web page-members and provided feedback (Suarez-Balcazar et al., 2005b)
Stakeholders paid as co-researchers (Bigby et al., 2010; Dawn et al., 2013; Williams et al., 2005; Wood et al., 2003)
Stakeholders participating in steering/advisory committee (Buettgen et al., 2012; Dawn et al., 2013; McGrath et al., 2009; Langston et al., 2005; Ottman et al., 2008; Suarez-Balcazar et al., 2005a; Taylor et al., 2004; Walmsley et al., 2009)
Training stakeholders to engage in research: formal and informal training (Williams et al., 2005; Wood et al., 2003)
Use of different media and materials to ascertain engagement and understanding: lay summaries, flipchart, videos, drafts of project at different stages (Bigby et al., 2010; Dawn et al., 2013; Sax et al., 2007; Walmsley et al., 2009; Williams et al., 2005)