

A conceptual framework for patient-directed knowledge tools to support patient-centred care

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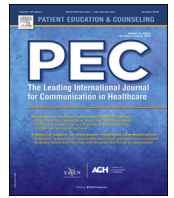
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A conceptual framework for patient-directed knowledge tools to support patient-centred care: Results from an evidence-informed consensus meeting

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ABSTRACT

Objective: Patient-directed knowledge tools are designed to engage patients in dialogue or deliberation, to support patient decision-making or self-care of chronic conditions. However, an abundance of these exists. The tools themselves and their purposes are not always clearly defined; creating challenges for developers and users (professionals, patients). The study's aim was to develop a conceptual framework of patient-directed knowledge tool types.

Methods: A face-to-face evidence-informed consensus meeting with 15 international experts. After the meeting, the framework went through two rounds of feedback before informal consensus was reached. **Results:** A conceptual framework containing five patient-directed knowledge tool types was developed. The first part of the framework describes the tools' purposes and the second focuses on the tools' core elements.

Conclusion: The framework provides clarity on which types of patient-directed tools exist, the purposes they serve, and which core elements they prototypically include. It is a working framework and will

Abbreviations: CCCC, Cochrane Consumer & Communication Group; CPG, clinical practice guideline; ePDA, encounter patient decision aid; GIN, Guideline International Network; GRADE, Grading of Recommendations Assessment, Development and Evaluation; IPDAS, International Patient Decision Aid Standards; ISDM, International Shared Decision Making conference; PDA, patient decision aid; QPL, question prompt list; SDM, shared decision making.

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require further refinement as the area develops, alongside validation with a broader group of stakeholders.

Practice implications: The framework assists developers and users to know which type a tool belongs, its purpose and core elements, helping them to develop and use the right tool for the right job.

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1. Introduction

In 1996, Sackett et al described evidence-based medicine as integrating “the best external evidence with individual clinical expertise and patients' choice”, and Charles et al tried in 1997 to define shared (treatment) decision-making [1,2]. Both heralded the more formal recognition of patient engagement. The WHO defines patient engagement as the capacity of patients, families, carers, as well as healthcare providers, to facilitate and support the active involvement of patients in their own care, in order to enhance safety, quality and people-centeredness of healthcare service delivery [3].

In the past, patient engagement might have been primarily a moral-ethical imperative [4], but this engagement is also associated with numerous beneficial outcomes such as improved knowledge, satisfaction and self-management and reduced decisional conflict [5–9]. Moreover, involving the patient is important because physicians may recommend treatments that they would not have chosen themselves [10], and physicians are mostly not adept at predicting what their patients want [11,12]. These and other reasons to engage patients in decisions about care have led to the development of a range of knowledge tools [13,14].

Overall, there exists an abundance of tool types to engage patients in decision-making and contribute to patient-centred care. Examples of knowledge tools are clinical practice guidelines (CPG), protocols, patient decision aids (PDAs) and patient education materials [15–17]. Knowledge tools distil and synthesize the highest quality knowledge and research [18]. Patient-directed knowledge tools are aimed directly at the patient (family members and carers), with the goal to engage patients in dialogue or deliberation during a clinical encounter, or to support and/or improve patient decision-making which may or may not take place during a clinical encounter [13]. The ultimate goal is to contribute to safer and higher quality healthcare. However, these types of tools are frequently ill defined [16,19,20]. Moreover, lack of clarity on development, content, and purpose has likely contributed to poor uptake [21–24].

Several streams of work have contributed to the development of this area. These include development of specific quality criteria for certain tools (such as PDAs, leading to IPDAS, the International Patient Decision Aid Standards) [25–28] as well as frameworks and taxonomies on patient involvement. The purpose of IPDAS is to enhance the quality and effectiveness of PDAs by establishing a shared evidence-informed framework [29–31]. IPDAS does not consider other patient-directed knowledge tools.

Several frameworks related to decision support tools have been developed [32]. O'Connor et al developed a decision support framework to develop a specific PDA, concentrating on determinants of decisions leading to the Ottawa Decision Support Framework [33,34]. Another example is a taxonomy of outcomes developed by the Cochrane Consumers & Communication Group (CCCG) which can be used by researchers and others to conceptually map the range of outcomes, at different levels of health care, that might be relevant when assessing different forms of communication (such as shared decision-making) [35].

Existing frameworks tend to focus on PDAs, and the CCCG taxonomy has a far broader scope than just patient-directed

knowledge tools. The aim of our study was therefore, building on existing work, to develop a conceptual framework of patient-directed knowledge tools [36]. Our objective was to create a framework that would identify existing patient-directed tool types, allow organization of these types of tools by their purpose(s) and describe their core elements. The framework is intended primarily for tool developers, and possibly also for those who commission the development of tools, healthcare professionals and policy makers. It should help developers to identify where there is a gap or need for a tool to be developed, and how such a tool may best make information, knowledge and decision support available to patients [37].

2. Methods

We used a two-day consensus meeting with international experts. We are not aware of standards for reporting a consensus-based meeting. Instead, we followed the Standards for Reporting Qualitative Research (SRQR) as closely as possible, when writing the manuscript [38].

To arrive at a conceptual framework of patient-directed knowledge tool types to engage patients and support patient decision-making within a short time frame, the initiators (TVDW, DD) and chair (JG) decided that a two-day, face-to-face meeting with experts was the most optimal design. We followed a consensus-based process based on a written meeting protocol (see annex A) [39–41]. The meeting was audio-recorded, DD took minutes. JG and TVDW made field notes. The meeting took place in February 2016, in Leiden, the Netherlands.

The participants were purposefully sampled from the Guideline International Network (GIN), International Shared Decision Making network (ISDM) and the professional networks of the initiators. The participants worked in different domains of knowledge (transfer), implementation and decision support, e.g. as tool developers, implementers or implementation researchers, decision-making researchers, or practitioners. The aim was to have representation from a range of countries, individuals with various professional backgrounds, and patients (see annex B). There were two groups of participants; those who participated face-to-face in the group meeting and those who joined remotely for the conference call with the large group, or via e-mail.

During the preparatory phase the participants received a list with relevant literature (see annex C). This list included participants' key articles – suggested by TVDW – and its aim was to achieve a common ground between the participants. They also received a list with possible knowledge tool types to be discussed (see annex D). The list was the result of a scoping review undertaken by initiator DD. The meeting protocol was also shared with the participants in this phase (see annex A) [42]. The experts were asked to add missing literature, review the proposed tools and comment on the protocol. If the experts had queries on the provided tools, DD and TVDW provided information to clarify these issues, copying all participants.

The meeting consisted of nine steps (see Table 1). In step 1, the face-to-face participant group discussed and came to agreement on the scope of the meeting, and the intended final product(s). In step 2, they discussed the list with tool types (annex D) to ensure

Table 1
Step-by-step process during two-day consensus meeting.

Step	What	Who
1	Discussed and agreed on the scope.	Participants in face-to-face meeting
2	Discussed the list with tool types to familiarize with the tools and their definitions, and if the list was complete.	Participants in face-to-face meeting
3	Including and excluding tools for the framework in subgroups; outcomes presented and discussed with whole group.	Participants face-to-face meeting
4	Identified purposes of the tools in subgroups; discussed outcomes presented and discussed with whole group.	Participants face-to-face meeting
5	Identified core elements of the included tools.	Participants face-to-face meeting
→ First draft of conceptual framework ready		
6	Presented and discussed draft framework; additional tools, purposes, and core elements suggested.	Teleconference participants
→ Second draft of conceptual framework ready		
7	Received input on draft framework via email.	Australian participants
8	Fine-tuning: reviewed & confirmed the possible tool types and purposes to ensure that these were correct and complete.	Participants face-to-face meeting
9	Fine-tuning: reviewed & confirmed the core elements to ensure that these were correct and complete.	Participants face-to-face meeting
→ Final draft of the framework as developed during the meeting		

that all participants present in the face-to-face meeting were familiar with the tools and their definitions, and, if not, described the tool, and verified that the list was complete. After agreeing on the scope and the tool list, the participants broke up into two groups to sort the tools: which ones to be included in the framework and which ones not, using the definition of the patient-directed knowledge tool (step 3). The two groups presented and discussed each other's findings, and agreed on a list of preliminary tools to be included. Based on this list, the two groups independently identified purposes of the tools, taking the discussed and agreed upon definitions from step 2 into account (step 4). The outcomes of both groups were presented and discussed. This resulted in a first draft of the framework stating the preliminary included tools and their purposes. In step 5, the participants were split up in the two same groups, and were asked – using their research and practice knowledge – to identify core elements of the included tools. Once more, the findings of both groups were presented, discussed, and categorised leading to the second draft of the framework stating tool types, purposes and core elements.

Dividing the participants into two groups facilitated involving all participants, and avoiding any individual dominating the group. When there was disagreement the participants discussed the issue until consensus was reached.

The next step involved compiling the discussions and findings during a longer break and sent via email – together with the second draft of the framework – to participants taking part via a telephone conference at the end of day 1. The first day's discussions and findings were presented by DD to the participants calling in, and the other participants in the room. The former participants were given the opportunity to ask clarifying questions, and propose/suggest additional tools, purposes, and core elements (step 6). The draft framework was adapted with the input of the remote participants. A summary of the discussions and findings, together with the latest draft framework, were sent via email to participants SH and RR in Australia who could not participate in the teleconference. They would add their knowledge and input during the night (step 7), so that it could be discussed during day 2 of the meeting.

Day 2 was dedicated to fine-tuning the draft framework. Therefore, in step 8 the chair (JG) reviewed the possible tools and purposes with the participants to ensure that these were correct and complete, and if all agreed, confirming the purpose(s) for each tool. This exercise was repeated for the core elements (step 9). These steps resulted in the final draft of the framework as developed during the meeting.

TVDW and DD finalized the draft framework based on the minutes, field notes and recorded data. This also entailed

comparing the draft framework with existing frameworks and taxonomies. The comparison was done for two reasons: first, to compare language and terminology used, and second, to establish where the frameworks differed or were alike.

The draft framework was distributed in the form of a scientific manuscript to the participants for final feedback. It took one face-to-face session between DD and JG and two rounds by email with all co-authors before consensus was reached on the draft framework.

All participants completed a declaration of interests. The initiators and chair proposed how to deal with the declared interests. This was discussed and decided upon at the start of the meeting. The plenary parts of the meeting were audio-recorded and DD took minutes during both days. Furthermore, DD and TVDW compared the minutes and field notes, and adjusted the former if needed. The adjusted minutes – checked against the recorded data – were shared afterwards with the participants for comments.

3. Results

The actual meeting was not as linear as described in the meeting protocol and methods section. It turned out to be an iterative process where discussions on tools and purposes lead to core elements and vice versa, but also prompting new or dismissed tool types to be (re-)included, such as care maps.

Meeting participants included the moderator (TVDW), secretary (DD), and 15 experts; nine participants attended in person (JG (chair), TA, GE, SF, LK, NS, DS, AS, ST), and four (MA, AG, FL, PV) additionally took part in the teleconference. Two participants (SH, RR) took part via email (see annex B). All participants took part in the iterative discussions by email afterwards to finalize the manuscript with the draft framework.

Step 1 was to select the tool types to be used when building the framework. Inclusion criteria were:

- Main target group are patients (family, care givers);
- Content driven instead of process oriented;
- Tool type globally known and used;
- Fits within the definition of the patient-directed knowledge tool.

Based on the outcomes of the subgroups and decisions on these with all participants, we excluded seven tool types (not aimed directly at the patient) from the original list of 11 and added one tool perceived to be aimed at the patient directly but not on the list provided (see Table 2). While discussing the selection with the whole group, we decided to split PDAs into an encounter patient decision aid (ePDA) and an 'independent' PDA, leading to six tools.

Table 2
overview of preliminary included and excluded tool types during face-to-face meeting and teleconference.

#	Tool type	Included, excluded and remarks
1	Decision tree	Preliminary included from list during face-to-face meeting
2	Summary of clinical practice guideline	Preliminary included from list during face-to-face meeting
3	Patient decision aid (PDA)	Preliminary included from list during face-to-face meeting, and split into:
4	- Encounter patient decision aid (ePDA)	
5	- Independent patient decision aid	
6	Patient information	Preliminary included during face-to-face meeting
7	Care map	Added during face-to-face meeting and preliminary included
8	Decision box	Added during teleconference and preliminary included
	Question prompt list	Added during teleconference and preliminary included
	Action plan	Added during face-to-face meeting, excluded
	Decision guide	Added during face-to-face meeting, excluded
	Care pathway	Excluded from list
	Quality standard	Excluded from list
	Care standard	Excluded from list
	Care module	Excluded from list
	Clinical practice guideline	Excluded from list
	Protocol	Excluded from list
	viewpoint	Excluded from list

This distinction is important because the patients will use the former while talking with a healthcare professional and the latter independently, pre- or post-encounter. Tools such as action plans and decision guides were excluded because they concentrate on 'how' (process), and less on 'what' (knowledge). Decision coaching tools were deemed out of scope as well because these are aimed at the patient's coach, rather than primarily at the patient. During the telephone conference two tool types – question prompt list and decision box – were added because they support involving the patient in the care process, leading to a total of eight tools (see Table 2 and annexes F and D).

From the preliminarily included tools, we deduced and described the possible purpose(s) of the tools. The purpose to inform patients was combined with 'to educate patients', because the emphasis was to make patients knowledgeable. Another reason to extend the purpose was that informing and educating are often used interchangeably. We made a distinction between the purpose supporting decision-making, and that of engaging in shared decision-making. Even though tools can support decision-making by patient and professional, this does not necessarily mean that the tool also promotes shared decision-making. In the end, the

listed possible purposes were aggregated into four purposes (see Table 3):

- Inform or educate;
- Provide recommendation(s);
- Support decision-making;
- Engage in shared decision-making.

When discussing possible purposes, alleviating fear(s), and decreasing decisional conflict were mentioned as well. The participants concluded they were outcomes, and were therefore not listed as a purpose. Communication was not included as a purpose as well. To engage patients, or exchange knowledge/information with a patient, as a healthcare professional, you need to communicate (verbally and non-verbally) with the patient. It is an overarching means, not a purpose in itself.

The next step was to identify core elements of the included patient-directed knowledge tool types. The participants compared the tool types, identified recurring elements within tool types and between tools. Furthermore, based on existing frameworks and taxonomies they determined which elements should be included

Table 3
Draft framework part 1: purposes of patient directed knowledge tools.

		PATIENT-DIRECTED KNOWLEDGE TOOL TYPES				
		Patient information and educational material	Decision tree	Independent / pre- & post-encounter PDA	Patient (version of) CPG	Encounter PDA
P	To inform or to educate ¹	+		+	+	+
U	To provide recommendation(s) ²		+		+	
R	To support decision-making ³		+	+	+	+
P	To engage in SDM ⁴					+
O						
S						
E						

+ knowledge tool serves purpose.

¹To inform or to educate: provide information on the disease/complaint; what its treatment/care options are; how it can affect the patient's life; what the patient can do herself/himself to cope/deal with the disease/complaint and what are the expected harms and benefits of treatment.

²To provide recommendation(s): summarize evidence & provides recommendation(s) - e.g. stemming from guidelines - regarding care option(s).

³To support decision making by the patient (and not decision making together with a healthcare professional): provide information on option(s) (including doing nothing, watchful waiting); harms and benefits, risks thereof; elicit values, preferences and contemplation so that patients can choose the treatment/care or option that suits best. Possibly indicate which % of patients in a similar situation chose which option.

⁴To engage in shared decision-making: invite, stimulate or instruct the patient to decide together with healthcare provider on treatment/care.

Abbreviations:

CPG clinical practice guideline.

PDA patient decision aid.

SDM shared decision making.

in a tool type (prototypical), even though existing examples of those tool types may not include these elements. Mentioned elements were for example, (link to) evidence, background on condition, care or treatment options/alternatives, burden (and evidence thereof), relative importance of outcomes as different patients may weigh importance of outcomes differently [43]. Also, possible effects of the tools, such as improving the knowledge of the patient, improving patient's expectations of the treatment, impact on their health and quality of life, improving patient-provider communication, and changes in decision-making behaviour) were discussed as possible purposes. Whilst discussing the elements, explicit mentioning of harms and benefits of treatment/care in the tools was stressed by the participants. Harms were especially emphasised as these are often not mentioned or mentioned less often than benefits [44–46]. At the end, the core elements were put into preliminary categories.

When discussing the framework, the purposes, and core elements of the tool types, several issues surfaced. First, at the beginning of the meeting, one participant stated that the patient-directed knowledge tools are preferably based on trustworthy clinical practice guidelines. However, there appears to be a pivotal point between PDAs and CPGs: the element 'recommendation'. A CPG centres on recommendations, meaning that the healthcare professional needs to 'translate' it together with the patient to the patient characteristics and preferences [47], whereas decision aids aim to acquaint patients with information about choices and available options, including watchful monitoring. Of late, clinical practice guidelines (recommendations) are created or re-written to include these elements as well, but it is not a common practice yet [21,48,49].

As one of the participants involved in the meeting noted: "Looking through a future lens and decision making view: [there will be] a set of guidelines that don't [provide room for contemplation], and 'innovator' guidelines that do list options."

[quote on reconciling clinical practical guidelines and shared decision-making] [50]

Furthermore, some participants argued using other sources than CPGs as a basis for patient-directed knowledge tools, such as evidence summaries or systematic reviews, and questioned how to include qualitative data in the evidence base [51].

We also discussed whether the framework should be discretionary or prototypical. Discretionary meaning that the core elements mentioned in the framework are optional; and prototypical indicating that we should aim to include the core elements listed in the framework in patient-directed knowledge tools. For example, current tools mostly disregard core elements such as harms and the need to elicit patient's values [52]. Often only one option is stated, instead of giving a complete overview of options, including watchful waiting when relevant [44]. We decided that it would be a descriptive and prototypical framework.

This decision resulted in one participant to say: "*We are wasting time on patient education material without options; we need to be bold.*" [quote on importance of a prototypical framework]

Finalizing the draft framework entailed checking and rewriting the wording used in the framework, and reorganizing the core element categories [7,53–55]. The category 'outcomes', which refers to the effect(s) of the tools, was not included in the framework. Possible effects proposed and discussed during the meeting were: improved knowledge acquisition by the patient, more realistic or informed expectations, decreased decision burden/stress or less regret. As most of these outcomes have not been confirmed by research (yet), we felt it premature to include this category in the framework [56].

The draft framework at the end of the meeting contained eight tools (see Table 2), of which two – 'care map' and decision box' – were conditionally included as we were not entirely sure if they

were patient-directed knowledge tools. The framework in the article contains 5 tool types, because when looking further into the tools 'question prompt list' and 'decision box', we decided that these tools belong to the tool type 'encounter PDAs, and they were therefore removed from the framework as separate tool types. The tool type 'care map' was left out as well, as they are also called 'care pathways' [16,19], and we excluded the latter at the beginning of the meeting. It was also suggested in the feedback rounds via email to leave out the tool 'decision tree'. Due to renewed attention to this tool type – e.g. digitalising CPGs into decision trees to enhance use by healthcare professionals and patients [57–59], and because the tool was not included conditionally, it is still part of the draft framework.

The final draft of the framework contains five patient-directed tool types, and consists of two parts: one stating the four purposes of the tools (see Table 3) and the other the core elements (see table 4 (see annex E)).

4. Discussion and conclusion

4.1. Discussion

We developed a working (or draft) framework containing five patient-directed knowledge tool types describing the purposes and (prototypical) core elements of these tools. There already exist other related frameworks; however, these tend to focus on patient decision aids. At the other end of the spectrum, the CCCG taxonomy take a far broader view, incorporating all interventions for communication without a specific focus on knowledge tools, and without delineating the core elements of the interventions [29,31,53,60].

4.2. Conclusions

As there exists an abundance of different patient-directed knowledge tools, with different names and mostly unclear definitions, our working framework can help tool developers, people who commission the development of these tools, patients and healthcare professionals to discern between the different tools, and to identify to which tool type it belongs, which purposes it serves and which core elements it should contain. Possibly, when there is more clarity on development, content and purpose of the tool, it may lead to a better understanding of the roles of, and uptake of, the tool. We feel that the field of tools development and implementation might profit from initiatives such as this one; it might provide the sought for direction.

Regarding the discussion whether to use only CPGs as basis for patient-directed knowledge tools, such as ePDAs, the group discussed the benefits of harmonizing evidence summaries across these tools, also within the context of updating content. Such CPGs and accompanying PDAs have been developed, for example within the MAGIC-project, providing proof of concept for this approach [37,49,61].

New (types of) tools will emerge. We can use these to test our working framework by assessing if the new tool fits within the current types, whether it requires adding a new tool type, additional purposes or core elements to the framework, or if it is a different type of tool not belonging within the framework.

Next steps are to review the framework thoroughly with a broader group of stakeholders, including patients and other users. Working with the framework will demonstrate if it is helpful and complete regarding tool types, purposes, and core elements. For example, it may be helpful to discuss whether or not merging the last two purposes ('support SDM' and 'engage in shared decision-making') would be a useful revision to the framework. A first cautious check of the framework took place at the International

Shared Decision Making (ISDM) Conference, Lyon, in 2017 [62], meeting general agreement and receiving no major comments with respect to content. The framework, a work in progress, could be further enhanced by identifying which effect outcomes of the tools are supported by evidence, and describing the core elements in more detail. Additionally, it is important to consider the implementation and use of these tools, for instance by exploring what skills or support patients need to be able to use them [63].

A potential weakness was the extent to which the participants are involved in this subject. We tried to counteract this by having a group consisting of participants with different expertise and from various backgrounds, and by providing descriptions of the discussed tools before the meeting. Also, the group was limited in its size. Therefore, the framework was not presented as finished but as a draft or working framework. Another risk of the group composition and size could be that it obscured tools as not being within scope. There were no patient representatives present during the face-to-face meeting; however, two participants (SH and RR) with extensive experience in health consumer participation and patient-centred care commented and added to the work of the group at the end of day 1. Having (most of) the participants together for a prolonged time in one room, contributed to enhanced participation, open discussions and the liberty to ask each other questions, making it possible to respond to non-verbal communication, and leading to a first draft of the conceptual framework.

4.3. Implications for practice

Our working framework on different types of patient-directed knowledge tools is aimed at developers, and possibly at those who commission the development of tools, healthcare professionals and policy makers, and hopefully adds to clarity on the different knowledge tools by stating the purpose(s) they serve and which core elements they should include. The ambition is that tool types are no longer developed without a clear definition and use. This framework will make it easier for developers to identify when to develop which patient-directed knowledge tool and what core elements to include, and to help patients and professionals to understand when to use which tool type.

Ethics approval and consent to participate

Not Applicable.

Consent for publication

Not Applicable.

Availability of data and material

All data processed or analysed during the current study are included in this published article.

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Authors' contributions

DD and TVDW initiated this work. With TVDW being end accountable for the project and fund raising, AS was actively involved in hosting the meeting and during the writing phase. JG was actively involved during the preparatory phase and chaired the meeting. DD wrote the first draft of the paper, supervised by TVDW. All authors contributed actively to the subsequent drafts of the paper.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2019.05.003>.

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