Summary

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Summary

The body of knowledge in health care is vast and accumulating daily. To help healthcare professionals and patients handle and use this wealth of knowledge (something also dubbed 'information overload') when deciding about the patient's care, so-called knowledge tools are developed. The aims of this thesis were firstly, tool types are no longer developed without a clear definition and use. Secondly, there exists a common terminology when referring to tool types. Thirdly, to make better use of the different knowledge sources available, and finally provide healthcare professionals and patients, and possibly other users such as policy advisors and insurers, with a set of pragmatic tools that cover their needs in knowledge translation and decision support. This resulted in the following research questions:

- What tool types to translate knowledge and support (shared) decision-making are available to healthcare professionals (and patients) in the Netherlands? (Chapter 2)
- How are these tool types defined and does consensus exist on the definitions across the healthcare domains in the Netherlands? (Chapters 2 and 3)
- Which criteria do these tool types need to meet and which purposes do they serve so that healthcare professionals and patients consider them trustworthy and useful? (Chapter 4)
- Do we consider all knowledge sources when developing tools, and what does that mean for tool development? (Chapter 5)
- What are healthcare professionals' needs using tools for knowledge translation and shared decision-making? (Chapter 6)

Available tool types

There exist different kinds of tool types that support knowledge translation and/or (shared) decision making. A scoping review among national organisations that develop and implement tools yielded 67 different tool types in the Netherlands. Of these tool types, many were ill-defined; meaning that there was no definition of the tool type (readily) available or the definition was (partially) incomplete: it contained no description of the tool type, its goal, and/nor who their intended target users were. In the pursuit of curtailing the information overload, we might have created an overload of tools and by ill defining them partially nullified the strived for use of knowledge and achieving optimal patient care.

Defining tool types

Therefore, a consensus procedure to limit the amount of tool types and to agree on the definition of the tool types was carried out at a national level in the Netherlands. Stakeholders from various domains in health care (curative care, long term care and public health) and with different expertise participated; patients, tool developers, healthcare professionals, policy advisors. In the end, consensus was reached on a core set of nine tool types and there was agreement on the definitions of five of these tools. These were: 'summary', 'flowchart', 'clinical practice guideline', 'protocol' and 'patient decision aid'. Despite the participation of the stakeholders and some organisations already adopting the core set, the reached consensus was just a first step. It remains a challenge to adhere to the core set. A more concerted effort by the parties involved is needed. But also, because new tool types or seemingly new tool types

(pseudo innovation) keep emerging. Possibly illustrating that something new is more alluring and exciting than tinkering with and adhering to existing tool types. However, for change and implementation to take effect, a certain constancy of purpose and consistency is needed.

Purposes and criteria of tool types

Believing the issue of too many tool types available to healthcare professionals and patients, was not confined to the Netherlands, international experts were approached to participate in a two-day evidence-informed consensus meeting. The aim of this invitational meeting was to develop a conceptual framework categorizing the different tool types aimed directly at patients. The participants considered a framework including all tool types infeasible during a two-day meeting. The developed framework clarifies the purposes of the patient-directed tool types and indicates the core elements these tool types prototypically consist of. In this way, the 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. As the framework was developed by a small group of experts, it is called a conceptual or working framework and it needs to be further tested and probed to check if it is usable and to make it more robust.

Knowledge sources and tool types

Besides having a closer look at the various tool types that convey knowledge, knowledge itself was looked at as well, as part of the work done by the G-I-N Working Group Appraising and Including Different (AID) Knowledge. Different knowledge sources exist but some seem to be favoured more than others. Evidence-based guidelines are supposed to search for, and explicitly consider, evidence from sources other than conventional clinical trials and their quantitative data. These different types of knowledge can be used and are needed in situations when for example evidence from RCTs is unavailable, impossible to obtain, contradictory or inappropriate. These sources can also be used in conjunction with RCTs to provide context, to assess relevance and to understand bias(es). Additionally, more complex forms of knowledge like experiential and contextual knowledge can help guideline developers to take an approach consistent with the intentions of early evidence-based medicine: the best evidence is not restricted to evidence from RCTs and meta-analyses. However, in the context of medicine and guideline production, integrating different types of knowledge continues to be underexplored and undertheorized.

Paediatricians' reflections on tool types

The worlds 'evidence-based medicine', 'shared decision-making' and 'tools' can come up with a lot of ideas, theories and concepts of how to move knowledge into use in daily practice but how do healthcare professionals feel about these endeavours. In interviews, 15 paediatricians reflected on several strategies to enhance shared decision-making (SDM) in paediatric palliative care. The first one being the clinical practice guideline Palliative care for children that contains recommendations on shared decision-making. The other strategies were a modified guideline recommendation on pain relief to reflect available options and patient preferences, and patient decision aids. Not all paediatricians felt that guidelines could enhance SDM as they regarded

it a skill or attitude. Others, however, thought that guidelines in general could enhance shared decision-making in daily practice. In the case of the guideline Palliative care for children, however, they commented that the recommendations needed to focus more on how to practice SDM. When presented with a one option recommendation on pain relief and a multiple options recommendation on pain relief, most paediatricians preferred the latter, as it would open the discussion with the patient and/or its parents. Furthermore, most interviewed paediatricians felt that patient decisions aids were beneficial to patients, e.g. to ensure that all topics relevant to the patient are covered. For guidelines to enhance SDM, guideline developers could consider formulating more 'open' recommendations, especially in case of preference sensitive choices. Moreover, SDM should not be limited to non-treatment recommendations, should describe (treatment) trade-offs and (treatment) alternatives and provide more detailed guidance. Another consideration is to provide tools amalgamated with specific guideline recommendations to enhance shared decision-making, such as patient decision aids.

A case of consilience

Taking a step back and looking at the research findings some overarching issues could be discerned. If we want to help healthcare professionals and patients with making sense of all the knowledge and knowledge sources available to them, we should not inundate them with tools. And we need to be more vigilant about their definitions and implementation. More discipline by and collaboration between stakeholders is necessary for sustainability of the core set that was agreed on a national level.

Furthermore, we need to combine and connect the EBM and SDM approaches to integrate research evidence and patient preferences better. That means developing tools that provide healthcare professionals and patients with answers to evidence-based questions and help them elicit and integrate patient preferences. Next to patient decision aids, clinical practice guidelines should be more preference-sensitive so that viable choices are not taken away from patients.

To achieve optimal patient care, provide more effective healthcare services and strengthen the healthcare system, the use of all knowledge sources is necessary. Not using all sources is a waste of research as well. This means making tool developers (and other stakeholders) more aware of the availability of different knowledge sources, the possible flaws within the predominantly used knowledge base and that it is pertinent to continue working on methods how to appraise and include different knowledge sources.

To achieve all this an interdisciplinary and interprofessional approach is needed. The many domains, disciplines, expertise, parties and professionals involved in knowledge translation, (shared) decision-making and tool development should abandon their silos, combine their knowledge, compare methods. In addition, the different domains in health care such as cure, social care, occupational health, public health and long term care, could collaborate more frequently and learn from each other. And they might even look outside health care for other knowledge sources and how these other domains appraise and include the array of knowledge sources available. Getting knowledge used in daily practice is a case of consilience. The policy domain is a part of this as well and could contribute (more) by acknowledging that patients

need to be better positioned, by having governmental agencies fund a more diverse palette of studies such as research on patient preferences and implementation, and by following up on governmental reports that looked into the psychology of deciding, choice and behaviour and how this affects the decision-making in healthcare practice.

Strengths and limitations

No thesis can go without a critical reflection on the used research methods. This thesis consists of predominant qualitative research as the research was exploratory in nature. First, it tried to achieve an improved understanding of perspectives, experiences, opinions, attitudes concerning translation of knowledge. Second, it looked into the use of knowledge tool types. Third, the comprehension of the needs of healthcare professionals was examined when using these tool types. And last, it tried to reach consensus on (developing) criteria and purposes of these tool types. Strengths and limitations of qualitative research relate to credibility, transferability and dependability. To increase credibility several approaches were used, such as involving participants as much as possible by sharing results and outcomes and by member checking and independent coding by three authors. Transferability is regarded as limited, mainly because the research was largely executed with tool types used in the Netherlands and a Dutch clinical practice guideline. However, methods and outcomes can be used in international settings and other guidelines as well. Qualitative research is characterised by fluid structures, which change because of incoming and available data. Therefore, to improve dependability, for each study the approach and/or method chosen and the changes therein, if any, were exhaustively described. Furthermore, the SRQR or COREQ checklists were applied for all the studies in this thesis, except chapter five.

Conclusion

It has become clear that healthcare professionals and patients are inundated with (loosely defined) tools. A first step to limit the number of tool types and agree on their definitions has been achieved in the Netherlands. The next step is more robust adherence to maintain a certain level of consistency of the available tool types. Pseudo innovation of tool types needs to be avoided.

Furthermore, the current knowledge tools do not always use all the knowledge sources that are available. Awareness of this is growing and efforts are underway to include and appraise these other knowledge sources. Different approaches in health care, such as SDM and EBM, exist to achieve optimal patient care. These approaches should combine their efforts more. Strategies to achieve this have been proposed and tentative steps have been taken. One strategy suggests integrating tools used in EBM and SDM or to use these tools more in concordance. Further recommendations for practice, policy and further research are described in detail at the end of the general discussion.

Samenvatting

De hoeveelheid kennis in de medische wetenschap en (gezondheids)zorg is enorm en dijt dagelijks verder uit. Geen arts of patiënt overziet deze schat aan kennis (ook wel 'information-overload' genoemd, zeg maar 'overdosis' aan informatie), laat staan dat ze in staat zijn er volledig gebruik van te maken in de dagelijkse praktijk. Daarvoor zijn hulpmiddelen nodig, en vooral op die momenten dat men beslissingen moet nemen. Deze kennishulpmiddelen heten in het Engels 'tools' en in het Nederlands 'instrumenten'. De doelstellingen van dit proefschrift vormen een drieluik. In de eerste plaats: eraan bijdragen dat men niet langer instrumenten ontwikkelt en inzet, zonder eenduidige definitie en handleiding voor gebruik. Ten tweede: bijdragen aan deze noodzakelijke gemeenschappelijke terminologie voor dit instrumentarium. Ten derde: beter gebruikmaken van de beschikbare kennisbronnen. Hoe? Door zorgprofessionals en patiënten, en mogelijk ook andere gebruikers, zoals beleidsadviseurs en verzekeraars, te voorzien van een kernset van pragmatische instrumenten, aansluitend bij hun behoefte aan kennisontsluiting en beslissingsondersteuning. Die doelstellingen resulteerden in de volgende onderzoeksvragen:

- Welke typen instrumenten om kennis te ontsluiten en (gezamenlijke) besluitvorming te ondersteunen, zijn beschikbaar voor zorgprofessionals (en patiënten) in Nederland? (Hoofdstuk 2)
- Hoe luiden de definities van de verschillende instrumenten en in hoeverre bestaat hierover consensus binnen de diverse zorgdomeinen in Nederland? (Hoofdstukken 2 en 3)
- Aan welke criteria moeten deze instrumenten voldoen en voor welke doeleinden dienen ze, opdat zorgverleners en patiënten ze betrouwbaar en bruikbaar achten? (Hoofdstuk 4)
- Nemen we alle kennisbronnen bij het ontwikkelen van instrumenten in overweging en, afhankelijk van het antwoord, wat betekent dat voor de ontwikkeling van deze instrumenten? (Hoofdstuk 5)
- Welke behoeften hebben zorgprofessionals wat betreft instrumenten voor kennisvertaling en samen beslissen? (Hoofdstuk 6)

Beschikbare typen instrumenten (instrumentarium)

Er bestaan uiteenlopende instrumenten die kennisontsluiting en/of (gezamenlijke) besluitvorming ondersteunen. Een scoping review bij Nederlandse organisaties deze instrumenten ontwikkelen en implementeren, resulteerde in 67 verschillende typen. Veel hiervan waren slecht gedefinieerd: de definitie bleek niet (eenvoudig) vindbaar of de definitie was - deels – onvolledig. Wat vaak ontbrak was een beschrijving van het instrument, het doel ervan en/of een heldere omschrijving van de beoogde doelgebruikers. Jongleren met definities valt af te raden. Als antwoord op de 'information-overload' ontstond mogelijk een overdaad aan instrumenten. Bovendien gebeurde dat slordig wat niet zonder gevolgen blijft; een slechte of onvoldoende heldere definitie doet het streven naar kennisgebruik mogelijk deels teniet, waardoor de uiteindelijke uitkomst – optimale patiëntenzorg – achter de horizon verdwijnt.

Typen instrumenten gedefinieerd

Een helder definitie is dus een basisvoorwaarde voor instrumenten. Via een

consensusprocedure in Nederland is getracht om op landelijk niveau eensgezindheid te bereiken over de inperking van het instrumentarium en de definities van de type instrumenten. Belanghebbenden uit verschillende zorgdomeinen (curatieve zorg, langdurige zorg en volksgezondheid) en met verschillende expertise gingen ermee aan de slag: patiënten, toolontwikkelaars, zorgverleners, beleidsadviseurs. Het resultaat bestond uit een kernset van negen typen instrumenten. Over de definities van vijf instrumenten bestond overeenstemming. Dit waren: 'richtlijn', 'samenvatting', 'stroomdiagram', 'protocol' en 'patiëntenkeuzehulp'. Een mooie eerste stap. De daadwerkelijke uitdaging ligt echter daarin de belanghebbenden en sommige organisaties te overtuigen – of te verleiden – tot het zich committeren aan en beperken tot de instrumenten uit de kernset. Een meer gezamenlijke inspanning van de betrokken partijen is dan een vereiste, een inspanning die verder reikt dat de eigen perceptie van een instrument. Een andere verschijnsel onderstreept de noodzaak van die inspanning: het opduiken van alsmaar nieuwe instrumenten of schijnbaar nieuwe instrumenten (noem dat gerust pseudo-innovatie). Mogelijk illustreert dat fenomeen dat iets nieuws aantrekkelijker en spannender is dan sleutelen aan en vasthouden aan het bestaande instrumentarium. Het is een algemeen menselijk fenomeen, waarop bijvoorbeeld marketing berust. Met andere woorden: ook ontwikkelaars van instrumenten hebben menselijke trekjes... Een beter scenario: het vereist een zekere standvastigheid en consistentie – en misschien zelfs koppigheid – om instrumenten en de implementatie daarvan aan (zeggings)kracht te doen winnen.

Instrumentarium: doeleinden en criteria

Nederland is geen eiland, Nederlandse problemen zijn daarmee niet uniek (vooruit, enkele uitzonderingen daargelaten). Om het internationale perspectief zuiverder in beeld te krijgen, namen internationale experts deel aan een tweedaagse, empirisch onderbouwde consensusvergadering. Het doel: de ontwikkeling van een conceptueel kader inclusief een onderverdeling van de verschillende typen kennisinstrumenten, specifiek gericht op patiënten. Het bleek niet haalbaar een allesomvattend raamwerk te ontwikkelen met ruimte voor het hele instrumentarium.

Het ontwikkelde raamwerk verheldert de doelen van de patiëntgerichte instrumenten en maakt duidelijk welke kernelementen onderdeel uitmaken van deze typen instrumenten. Op deze manier kan het raamwerk behulpzaam zijn voor instrumentontwikkelaars, opdrachtverleners voor de ontwikkeling van deze instrumenten, patiënten en zorgverleners. Aangezien het raamwerk is ontwikkeld door een kleine groep experts, noemen wij dit een conceptueel of werkkader; meer onderzoek en tests zijn nodig om het werkkader te evalueren op bruikbaarheid en het kader robuuster te maken.

Kennisbronnen en instrumenten

Instrumenten dragen bij aan de kennisoverdracht naar de gebruiker. In die drietrapsraket van kennis via instrument naar gebruiker verdienen dus tevens de kennisbronnen nadere aandacht. Laten we inzoomen op dat punt. Er bestaan verschillende kennisbronnen, maar sommige lijken meer de voorkeur te genieten dan andere; al kan populariteit nimmer de doorslaggevende factor zijn. De ontwikkeling van evidence-based richtlijnen gaat uit van de volgende vooronderstelling: men houdt ook rekening met andere bronnen dan conventionele klinische studies en hun kwantitatieve gegevens. Deze aanvullende soorten kennis zijn namelijk

nodig in situaties waarin bijvoorbeeld bewijsmateriaal van RCT's niet beschikbaar, onmogelijk te verkrijgen, tegenstrijdig of weinig passend is. Deze bronnen kan men ook combineren met RCT's om de context te schetsen, relevantie te beoordelen en mogelijke vertekening(en) te begrijpen. Bovendien helpen meer complexe vormen van kennis, zoals ervarings- en contextuele kennis, richtlijnontwikkelaars te ondersteunen in een aanpak overeenkomstig de klassieke intenties van evidence-based medicine (EBM): het beste bewijs beperkt zich niet tot bewijs van RCT's en meta-analyses. Helaas is deze integratie van verschillende soorten kennis binnen de context van farmacotherapie en richtlijnontwikkeling nog steeds onderbelicht en onderbestudeerd is.

Instrumentarium: attituden en overwegingen van kinderartsen

In theorie valt een ideale wereld te bedenken. Analoog hieraan is theorievorming over kennisoverdracht, samen beslissen en noodzakelijke hulpmiddelen beslist van waarde. Maar hoe denken gebruikers hierover? In interviews reflecteerden 15 kinderartsen op verschillende verbeterstrategieën om samen beslissen (shared decision-making in het Engels, ofwel SDM) in pediatrische palliatieve zorg. Dit gebeurde aan de hand van drie strategieën: de richtlijn Palliatieve zorg voor kinderen met daarin aanbevelingen over samen beslissen, de herziene aanbeveling over pijnverlichting en keuzehulpen voor de patiënt. Niet alle kinderartsen waren van mening dat richtlijnen samen beslissen zouden kunnen verbeteren omdat zij het samen beslissen veeleer als een uitgangshouding of als een vaardigheid beschouwen. Anderen waren echter van mening dat richtlijnen in het algemeen kunnen bijdragen aan samen beslissen in de dagelijkse praktijk. In het geval van de richtlijn Palliatieve zorg voor kinderen merkten ze echter op dat de aanbevelingen meer gericht zouden moeten zijn op de uitvoering van samen beslissen.

Overeenkomsten zijn de schaduwen van de verschillen. Ondanks dat idiomatisch geschipper leverden de interviews concreet resultaat op. Gesteld voor de keuze: een aanbeveling met één optie voor pijnverlichting of een aanbeveling met meerdere opties voor pijnverlichting, gaven de meeste kinderartsen de voorkeur aan de laatste variant. Als reden geven zij aan dat het weergeven van meer opties de discussie opent met de patiënt en/of ouders. Daarnaast waren de meeste kinderartsen van mening dat keuzehulpen nuttig en behulpzaam zijn voor patiënten, bijvoorbeeld om ervoor te zorgen dat alle, voor de patiënt relevante onderwerpen, aan bod komen.

Willen richtlijnen een grotere bijdrage leveren aan samen beslissen, zouden richtlijnontwikkelaars dus kunnen overwegen om aanbevelingen mee 'open' te formuleren. Zeker waar het voorkeursgevoelige keuzes betreft. Het lijkt een open deur dat samen beslissen in richtlijnen alle zorgaspecten betreft, maar de nadruk ligt nog vaak op procesmatige aspecten en communicatie, terwijl juist dilemma's over behandeling de kern vormen. Er is nadrukkelijk behoefte aan een nadere beschrijving van overwegingen en alternatieven plus het bieden van uitgewerkte specifieke begeleiding. Een andere overweging is het expliciet opnemen van handvatten in richtlijnen ter verbetering van samen beslissen; denk hierbij aan geïntegreerde keuzehulpen voor patiënten.

A case of consilience

Laten we een blik werpen in de achteruitkijkspiegel van dit onderzoek om de onderzoeksresultaten te bezien. Enkele overkoepelende kwesties tekenen zich af. Als we zorgverleners en patiënten willen helpen met het begrijpen en gebruiken van alle kennisbronnen, mogen we hen niet overspoelen met instrumenten. En we moeten minder achteloos zijn inzake hun definities en implementatie. Zorgvuldigheid loont. Omzichtigheid evenzeer. Meer discipline door en samenwerking tussen stakeholders is nodig voor de bestendiging van de overeengekomen kernset op nationaal niveau.

Bovendien moeten we de EBM- en SDM-benaderingen combineren om onderzoeksbewijs en patiëntvoorkeuren beter te integreren. Dat betekent instrumenten ontwikkelen die zorgprofessionals en patiënten van evidence-based antwoorden voorzien en hen helpen bij het expliciteren en integreren van patiëntvoorkeuren. Naast de keuzehulpen voor patiënten, zouden richtlijnen meer voorkeurgevoelig moeten zijn, opdat patiënten geen relevante keuzes onthouden blijven.

Om optimale patiëntenzorg te realiseren, effectievere zorg te verlenen en het zorgstelsel te versterken, is benutting van alle kennisbronnen noodzakelijk. Niet alle bronnen gebruiken, is namelijk per definitie ook verspilling van onderzoek. Het rendeert om instrumentontwikkelaars (en andere belanghebbenden) bewuster te maken van de beschikbaarheid van verschillende kennisbronnen, te wijzen op mogelijke gebreken binnen de eigen, gebruikelijke kennisbronnen en het belang om te blijven werken aan methoden voor het beoordelen en opnemen van verschillende kennisbronnen te blijven benadrukken.

Dit alles vereist een interdisciplinaire en interprofessionele aanpak. De vele domeinen, disciplines, expertise, partijen en professionals die zich bezighouden met kennisvertaling, medische besluitvorming, samen beslissen en instrumentontwikkeling moeten hun stellingen verlaten, hun kennis combineren, methoden vergelijken. Hokjesgeest, verdediging van eigen belangen en kokerzicht verenigen niet, ze werken splijtend. Daarnaast zouden de verschillende domeinen in de zorg vaker kunnen samenwerken en van elkaar leren. En ze kunnen zelfs buiten de gezondheidszorg zoeken naar andere kennisbronnen, en hoe deze domeinen deze beoordelen en uiteindelijk gebruiken. Kennisontsluiting en kennis opdoen in de dagelijkse praktijk is ‘a case of consilience’: een kwestie van voortdurend heen en weer denken in een streven naar een reflectief evenwicht (dat voortdurend in ‘beweging’ is). In die zin pleit dit proefschrift voor invalshoeken die verder reiken dan het eigen domein, en is het tevens een pleidooi voor grensoverschrijdend denken en doen.

Het (overheids)beleidsdomein maakt hier eveneens deel vanuit en heeft een rol in de kennisontwikkeling en -ontsluiting. Het beleidsdomein kan (meer) bijdragen door de erkenning dat patiënten een sterke positionering toekomt, door overheidsinstanties een meer divers palet aan studies te laten financieren, zoals onderzoek naar patiëntvoorkeuren en implementatie, en door follow-up te geven aan overheidsrapporten via onderzoek naar de psychologie van besluitvorming, keuze en gedrag en hoe dit de besluitvorming in de gezondheidszorg beïnvloedt.

Sterke punten en beperkingen

Geen proefschrift kan zonder kritische reflectie op de gebruikte onderzoeksmethoden. Dit proefschrift bestaat uit overwegend kwalitatief onderzoek, aangezien het onderzoek verkennend van aard was in het streven naar een dieper inzicht in perspectieven, ervaringen, meningen, attitudes met betrekking tot vertaling van kennis en het gebruik van hulpmiddelen hiervoor. Dit alles met inbegrip van de behoeften van zorgprofessionals bij het gebruik ervan deze instrumenten enerzijds, en anderzijds een poging tot consensus te komen over criteria en doelen van dit instrumentarium. De kracht en de beperkingen van kwalitatief onderzoek hebben betrekking op geloofwaardigheid, overdraagbaarheid en betrouwbaarheid. Om de geloofwaardigheid te vergroten, zijn verschillende benaderingen gebruikt, zoals het zoveel mogelijk betrekken van de deelnemers door resultaten met hen te delen en te laten controleren, plus een onafhankelijke codering van de interviews door drie auteurs. De overdraagbaarheid mag beperkt heten, omdat het onderzoek grotendeels is uitgevoerd met in Nederland gehanteerde instrumenten, een Nederlandse richtlijn, binnen een Nederlandse context. Methoden en resultaten zijn echter ook internationaal bruikbaar en voor andere richtlijnen. Kwalitatief onderzoek kenmerkt zich door fluïde structuren die voortdurend veranderen door de nimmer aflatende stroom van inkomende en beschikbare data. Ter verhoging van de betrouwbaarheid, is besloten een uitputtende beschrijving te geven van de gekozen aanpak en/of methode. Verder pasten wij de SRQR- of COREQ-checklists toe voor alle studies in dit proefschrift, behalve in hoofdstuk vijf.

Conclusie

Het is duidelijk dat zorgprofessionals en patiënten overspoeld worden met (losjes gedefinieerde) instrumenten. In Nederland is een eerste stap gezet om het aantal instrumenten te beperken en tot overeenstemming te komen over de definities. De volgende stap is krachtiger naleving om het consistentieniveau van het beschikbare instrumentarium te behouden; pseudo-innovatie van instrumenten verdient afkeuring.

Daarnaast benutten kennisinstrumenten niet altijd alle beschikbare kennisbronnen. Dit besef groeit en er wordt gewerkt aan het opnemen en beoordelen van andere kennisbronnen. Er bestaan verschillende benaderingen in de gezondheidszorg, zoals SDM en EBM, om optimale patiëntenzorg te realiseren. Deze benaderingen zouden hun inspanningen meer moeten bundelen. Er zijn strategieën voorgesteld om dit te bereiken en eerste stappen zijn gezet. Een strategie behelst de integratie van de instrumenten binnen EBM en SDM dan wel deze instrumenten beter op elkaar af te stemmen. Verdere aanbevelingen voor praktijk, beleid en verder onderzoek staan in detail uitgewerkt aan het einde van de algemene discussie.


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the acceptability and feasibility of the draft criteria by gathering experiences with the draft guidance from knowledge tool developers; WP4/ the Dutch Federation of Patients' Organisations (AK) organised the consensus procedure aiming to support the guidance by national stakeholders.

Work package 1

We searched for formal criteria and methodologies in the scientific literature, in policy reports, and on websites by developers of guidelines and patient decision aids. The search strings that we used to explore PubMed are described in Table 1, as are the websites to search for the grey literature. This inventory supplied the basis for the first draft of the guidance. One of the researchers of WP1 made a first selection of the search based on title and abstract, and excluded references clearly not fulfilling the inclusion criteria. All full-text versions that resulted from this first selection were downloaded and assessed along the pre-set in- and exclusion criteria. In case of doubt a second researcher was consulted to reach consensus on in- or exclusion.

Inclusion criteria for literature on patient versions of guidelines:

- The paper describes the development process of a patient version or lay summary of a clinical practice guideline.
- Explicit description of the methods used (be it short or extensive) for development.
- English or Dutch language.

Exclusion criteria:

- Papers describing only the process of patient participation in development of a clinical practice guideline.

Inclusion criteria for literature on patient decision aids:

- The title reports the term 'development' or 'design'.
- The abstract reports the development of a patient decision aid as the aim of the paper.
- Description of development process of disease specific or generic decision aids.
- Explicit description of the methods used (be it short or extensive) for development.
- English or Dutch language.

Exclusion criteria:

- Papers describing development of tools that stretch further than patient decision aids (e.g. social support, self-management).
- Papers describing development of tools on other decisions than medical decisions.

Table 1: *Search strings used to explore Pubmed, and websites used to search for grey literature*

Search strings
Patient information based on guidelines - (((method*[Title/Abstract] OR approach*[Title/Abstract] OR framework[Title/Abstract] OR develop*[Title/Abstract] OR creat*[Title/Abstract])) AND ("patient version*"[Title/Abstract] OR "information for the public"[Title/Abstract] OR "public information"[Title/Abstract] OR "patient booklet*"[Title/Abstract] OR booklet*[Title/Abstract])) AND ("clinical practice guideline*" OR "Practice Guidelines as Topic"[Mesh] OR "quality standard*") - ("Practice Guidelines as Topic"[Mesh] OR "Practice Guideline" [Publication Type] OR guideline*) AND "patient version" AND develop* - Patient decision aids - "Decision Support Techniques"[Majr:NoExp] AND (method*[tiab] OR approach*[tiab] OR framework[tiab] OR develop*[tiab] OR creat*[tiab]) AND ("Patient Satisfaction"[Mesh] OR "Patient Participation"[Mesh] OR "Patient-Centered Care"[Mesh]))
Websites
- Dutch Knowledge Institute of Medical Specialists - Netherlands Comprehensive Cancer Organisation - Guidelines International Network, Patient and Public Involvement working group - UK National Institute for Health and Care Excellence (NICE) - German Ärztliches Zentrum für Qualität in der Medizin (ÄZQ) - Finnish Duodecim - Australian National Health and Medical Research Council (NHMRC) - USA Oncoline Kaiser - USA Agency for Healthcare Research and Quality (AHRQ) - Canadian Task Force on Preventive Health Care (CTFPHC) - IPDAS working Group www.ipdas.ohri.ca - Patient Decision Aids Research Group https://decisionaid.ohri.ca - The Preference Laboratory http://optiongrid.org/option-grids/about-the-grids - Mayo Clinic for shared decision making http://shareddecisions.mayoclinic.org - DECIDE research Group www.decide-collaboration.eu - Joanna Briggs Institute University of Adelaide http://joannabriggs.org

Work package 2

The project was coordinated via monthly meetings with all WP leaders, complemented by numerous one-to-one contacts. We used definitions of the patient-directed knowledge tools that were recently formulated in another Dutch national consensus procedure; see Box[24-25]. The findings from the literature review were used to draft the first set of the minimal quality criteria for development, content and governance of patient-directed knowledge tools. The findings of the feasibility checks (WP3) and consensus meetings (WP4) were used to write the second and third draft of the guidance.

Box 1: *The Dutch definitions of the patient-directed knowledge tools.*[24-25]

> Patient information based on a guideline (= patient version of a guideline): Explanation of a specific condition or (health) care issue based on a guideline; made available to patients and their next of kin; provides information on available care choices and the care that they can expect from the care process.

Summary of guideline: Concise overview of the guideline, providing main conclusions and recommendations in clear and simple language; can be applied in practice independently from the guideline; intended for both care providers and patients.

Patient decision aid (PDA): Auxiliary information and answers to frequently asked questions for patients when choosing, with their care providers, from different options – including the option to forgo care – in a specific area such as diagnostics, treatment, screening, counselling or aftercare; discusses the possible outcomes and effects of each option – desirable or otherwise – and their likelihood of occurring; helps patients to weigh up their options based on their own values, standards and personal circumstances.

Work package 3

The first and second draft guidance was presented for a critical assessment of its feasibility to the project leaders of nine working groups tasked with the development of patient versions of guidelines or patient decision aids along clinical practice guidelines. These working groups were at that time in various phases of their development projects. Five projects focused on developing patient information based on guidelines, e.g. for patients with inflammatory bowel disease. Four projects focused on developing patient decision aids for specific recommendations, e.g. in the care for orthopaedic patients. For the third draft of the guidance we did not only seek for critical assessment by the project leader, but we also asked the project leader to actually apply (part of) the guidance steps in their working groups and to report about their experiences. Four of these nine ongoing projects were further analysed by means of outreach visits and participatory observations of working group meetings. Finally, the last draft and the experiences were fed back to each project leader in individual semi-structured qualitative interviews. The interviews were audiotaped, transcribed and analysed with thematic content analysis[26].

Work package 4

The draft versions of the guidance were discussed in three invitational meetings. We purposefully sampled the participants for the first two meetings to guarantee continuity in the process by inviting a core group for both meetings. While we planned the input from academic experts in the first meeting, the profile of participants gradually shifted to stakeholders representing end-users only in the last meeting.

First, a two-hour expert meeting was held in March 2016 aimed at collecting the experts' suggestions, for which 43 stakeholders representing patients, care providers, researchers, web and tool designers and healthcare insurers were invited. Second, a two-hour meeting was held in June 2016, for which 29 stakeholders representing patients, care providers, knowledge institutions, healthcare insurers and the government were invited to question their support to the draft version of the guidance. Third and finally, a 90-minute consensus meeting was held in September 2016, for which only the formal representatives of patients, healthcare providers and healthcare insurers were invited in order to gain formal support.

Results

How did we arrive at the guidance?

WP1 Inventory of existing methods and criteria in scientific and grey literature

We found 51 hits in PubMed, of which four studies were included that describe criteria for developing patient versions of guidelines. The grey literature revealed many websites publishing patient versions of guidelines, but information on how these knowledge tools were developed was scarce. Detailed descriptions were found, however, in the Guidelines International Network 'GIN Public toolkit on patient and public involvement in guidelines'. For developing patient decision aids, we found 385 hits in PubMed, of which 24 studies were included; 10 more relevant publications were added by the experts in the project group. In addition, the websites revealed rich data on what exactly patient decision aids are and how they should be developed.

The criteria for the content of patient decision aids were mostly based on empirical data[26], while such data were more or less absent for the content of patient versions of guidelines. IPDAS criteria (ipdas.ohri.ca) enjoy broad support where criteria for the content of decision aids are concerned, due to their substantiation by means of systematic consensus methodology.

WP3 Feasibility assessment in ongoing development projects

While reactions to the ordering of the development steps in the draft guidance were unanimously positive, the project leaders were extremely divided as to the degree of detail when it came to the instructions *within* the steps of the guidance, such as how best to map the patient perspective in the scoping and needs assessment phase. Whereas some project leaders expressed a clear desire for procedural standards (*it should be clear at all times who does what and when*), others felt that it would be sufficient for the instructions in each step to provide only general direction. Concerning the other issues raised, we report those most frequently mentioned:

- Deviating from the linear ordering of the guidance should be possible. For example, the guideline working group may be no longer active, while the patient-directed tool is urgently needed.
- Language and jargon used in the guidance was often found to be too academic.
- The amount and complexity of the work to map the patients' perspective in the scoping and needs assessment phase, e.g. by organising a focus group or a questionnaire survey, was often underestimated. Due to limitations in resources and the high workload, work should not be done twice, in the guideline working group and in the patient tool development group. Moreover, the required minimum number of two patients in the team - as was prescribed in the earlier drafts - was a concern, as well as the mandatory inclusion of a representative of the guideline working group.
- Formal authorisation of the tool was not regarded necessary by all stakeholders, with the argument that the guideline was already approved.
- All project leaders plead for a central portal to host the patient directed knowledge tools, supported by a national party taking care of the governance of the tools.

WP4 The consensus meetings

For the first meeting, 28 out of 43 invited experts were present. When asked to mark the most important sections of the guidance, experts prioritised the following issues: chose the right type of knowledge tool for the aim it pursues; use the guideline (recommendation) itself as the most important source of information for the knowledge tool; determine who will become the owner of the knowledge tool; make the knowledge tool easily accessible and free to use; organize authorization by the healthcare professional organization(s) as well as the patients' organization(s).

For the second meeting 21 out of 29 invited were present. All stakeholders were well represented. In general, they expressed a positive attitude towards the guidance although two critical remarks were made. Firstly, multiple stakeholders emphasized to widen the scope of the guidance so that patient-directed knowledge tools can also be developed on topics that are not covered by clinical practice guidelines; especially patient organizations claimed that the information needs of patients should determine the content of patient-directed knowledge tools, as opposed to only following the existing guideline recommendations. Secondly, the nursing organisation criticized the language of the guidance being too scientific and loaded with too much medical jargon.

The third meeting was attended by formal representatives of all parties except for the Dutch Association of Insurers, which formally declined while giving blind consent to the guidance as a token of trust in the representatives of the patients and providers. Therefore, the final meeting was attended by four participants, representing the Dutch Federation of Patients' Organisations (HP), the Dutch College of General Practitioners (TD), the Dutch Association of Medical Specialists (IM), and the Dutch Nurses' Association (SK). They expressed their positive intentions with regard to supporting the guidance, but only after the following issues were clarified: the minimum criteria should clearly be listed separate from the additional suggestions; developers of patient-directed knowledge tools should be encouraged to use the guidance according to the comply or explain principle; authorization of patient-related knowledge tools should be done on a process level and not on the level of authorizing the content of the tools, as content was already authorized in the final phase of the guideline development process.

In retrospect, it can be observed that the quest for clear and outspoken procedural standards that was verbalised by some project leaders in WP3 was strongly echoed in the first meeting but that it faded away in the second meeting, while only crude instructions for each step were regarded sufficient in the third and final meeting.

The guidance

WP1 provided rich data for formulating eight distinct development steps in the guidance (Table 2). The final guidance consists of three components: a) recommendations for which type of knowledge tool (such as a lay summary or decision aid) best fits the objectives of the development group; b) minimum criteria for the eight development steps, content and governance of each tool (Box 2); c) supplemental, detailed and concrete suggestions for each step in a second layer of information (14 pages in total, not presented, available on request). Developers deviating from these minimum criteria would have to provide a rationale for why a criterion does not apply ('comply or explain'). The steps need not always be followed in linear fashion, as the guidance establishes the criteria for an effective development process rather

than laying out a strictly prescribed series of ordered steps. In the event that the development of the knowledge tool (patient information on a guideline or a patient decision aid based on a specific guideline recommendation) is part of a guideline project, the development team will ideally be commissioned by the guideline working group itself.

Table 2: *The similarities and differences between the eight development steps for a) patient information on a guideline and b) a patient decision aid (PDA) connected to specific guideline recommendation(s)*

Typical of patient information on a guideline(s)	**DEVELOPMENT STEPS**	**Typical of PDA connected to specific recommendation(s)**
	1 TEAM Chose members and define tasks	
	2 SCOPE	
Provides an overview of the entire guideline (module)	Establish provisional scope Create inventory of existing versions	Concerns one or several specific recommendations.
	3 NEEDS	
Not a one-to-one application of guideline. Information needs may also differ from those mentioned in the guideline.	Identify information needs	Establish attributes for consideration in decision-making. Needs of care providers as well.
	4 CONTENT	
Purposeful selection of guideline recommendations.	Content and form	International criteria are in place; IPDAS (Int. Pat. Dec. Aids standards)
	5 TEST Testing the concept	
	6 FINALISING Finalising and obtaining approval	
	7 DISSEMINATION Dissemination and application	
	8 OWNERSHIP Management and revision	

For patient versions of guidelines, the patients' information needs together with the subject of the guideline will form the basis for the content of the patient version; the guideline itself should be the most important source of information. Rather than assuming just one guideline as a starting point, this situation might mean that multiple guidelines will need to be integrated and translated into a single patient information document, as this process will more effectively address the desires and perceptions of the target group. Or, alternatively, it might mean that only a limited number of guideline modules will be applied in creating patient information documents. A need to develop one or more patient decision aids is especially indicated when one or more of the guideline's key recommendations are preference-sensitive in nature.

Box 2: *The guidance. A brief description of each step for the development of patient information on a guideline or a patient decision aid (PDA) connected to specific guideline recommendation(s).*

1 TEAM The team composition is discussed with the relevant patients' and professional associations. The team has an independent chair and a process support member/secretary, along with at least one patient (-representative) with first-hand experience (acquired by the patients' organisation). Membership of the team is approved based on written Declarations of Interests. An editor with experience in writing copy for a non-expert audience will be involved in the team. If the development of the tool is part of a guideline project, the team will (ideally) be commissioned by the guideline working group itself, which has budgeted the developmental work.

2 SCOPE The team checks the availability of existing tools, and establishes the objective, the target group and the rough form of the tool.

Patient information: Determine where the guideline is failing to meet patients' information needs. After all, guidelines for practice are typically drawn up from the perspective of the care provider. Whenever possible, address the major underlying questions patients have about the guideline, as well as the key recommendations.

PDA: Select one or more recommendations from the guideline that have to do with the decision at hand, and that are preference-sensitive in nature.

3 NEEDS There are multiple ways to identify the needs of patients: a review of the literature, and/or additional qualitative or quantitative methodologies for collecting data, such as focus groups or questionnaires.

Patient information: Concerns any additional needs that have not yet been elaborated during the guideline development, e.g. with regard to multimorbidity, ethnic minorities, alternative interventions, self-management.

PDA: Involves questions the patients and their proxies may have when faced with taking a specific decision. Which needs, preferences and attributes influence a given patient's decision-making? This might involve information needs and psychosocial needs, along with important strategies for self-management in connection with the illness or condition, and should also include the variations between patients.

4 CONTENT For both type of tools describe:

- The target group and medical condition/symptom/healthcare topic.
- The guideline(s) serving as the basis (in part) for the creation of the information on evidence, etc.
- The source of funding, who has ownership, year of publication and expiry date (if applicable).
- The interests of each member of the development group (conflict of interest).

Patient information:
Describe the guideline recommendations on which patients would want to be informed in terms that a layperson can understand. Mention frequently-used examples of professional jargon so that patients can become familiar with them. The patient information will additionally indicate the following aspects:

- Point out where aspects have consciously been omitted and/or emphasis has intentionally shifted (if applicable), as compared to the guideline.

PDA:
Describe the situation/decision at hand and the relevant recommendation(s) from the guideline, in terms that a layperson would understand. The PDA will describe the following aspects (at minimum):

- An explanation that the patient has a choice; that he/she is facing a preference-sensitive decision.
- A description of the medical/care options, including the option to wait and see (if applicable) and an explanation of the procedure for each medical/care intervention.
- The desired and undesired outcomes (side effects) of the medical or care options, and the burden of treatment.
- The likelihood and risks of the outcomes, expressed as numeric data with equal denominator of population in natural frequencies and an identical length of time; preferably displayed in population diagrams; framed both positively and negatively (chances of both survival and fatality, for example); and in the case of risk reduction presented, at minimum, in terms of absolute (and potentially relative) risk reduction.
- An evidence table in which the medical/care options are summarised and compared in terms of a few key aspects.
- Ensure explicit mention of the attributes found in step 3 that are important for patients to keep in mind as they consider their options and elicit their values. These attributes must contribute to the key aspects described in the evidence table.

5 TEST The development team will present the draft to the relevant professional, scientific and patients' associations for the purpose of obtaining feedback. The parties will assess whether the patient perspective is sufficiently reflected, ensure understanding of people with low literacy, and if the medical content is accurate. If the guideline working group is still active, the draft will be presented to that group for feedback as well.

6 FINALISING The development team establishes the final knowledge tool and presents it to the relevant professional, scientific and patients' associations for approval. This regards approval at the process level, i.e. concerning the creation of the knowledge tool. Ownership is determined and formally established.

7 DISSEMINATION The tool will ideally be submitted to the national Health Care Institute as a section of the relevant guideline(s). The knowledge tool becomes accessible to the public and is preferably made available at a central location, including points for attention to facilitate the actual application/implementation in healthcare practice.

8 OWNERSHIP The owner(s) of the knowledge tool will manage the tool and determine when the information is due to be revised: in any case when the expiry date has been reached. Ideally, the need for revision of the tool will be considered when the guideline as a whole is revised.

Discussion

We successfully collaborated as a consortium of researchers and end user representatives, with patient participation realised at the highest level of involvement, to achieve formal support from national stakeholders on a set of minimum criteria for the development process, content and governance of patient-directed knowledge tools related to clinical practice guidelines. What we provide is not a detailed 'recipe' for development but rather a series of recommendations based on the 'state of the art' and feasibility considerations.

A number of potential limitations should be mentioned. Our project was explicitly embedded in the guideline context, we did e.g. not include patient versions of systematic reviews. The guideline context may be a limiting context for developing patient-directed knowledge tools. As the starting point of a clinical practice guideline is predominantly the clinicians' perspective, important issues for patients may not be covered in the guideline. The assignment from the National Health Care Institute was aimed specifically at guidelines in the context of curative health care. While the literature is unclear in this regard, it is possible that the content of the guidance might have been different had representatives from public health, long-term and palliative healthcare been included. One strength of this project is the systematic approach

and involvement of all national stakeholders, from patients to policymakers, with patient representatives in a co-leading role. We believe that the involvement of all stakeholders from the writing phase of the project proposal contributed to the successful collaboration. Another strength of the project is that the guidance was developed with prospective feasibility checks parallel to the nine ongoing development projects.

The relevance of patient-directed knowledge tools being publicly available has also been acknowledged in the UK, with one of the main institutions developing guidelines committed to develop patient decision aids based on clinical guidelines[28]. The relevance of this process was recently underpinned by empirical evidence in the Netherlands. The Dutch College of General Practitioners launched a non-commercial public website in March 2012 that provides easy access to patient versions of guidelines. Since its launch, the website has grown to become one of the most visited Dutch healthcare websites. Healthcare usage in primary care seems to have decreased by 12% after the launch of the website[29].

We expect the criteria to evolve over time as they are further tested through developers using patient versions of guidelines and patient decision aids, as well as by adding new tools to the guidance. The next challenge will be the effective implementation of the guidance as a further step towards ensuring the development of high-quality, reliable and publicly available patient-directed knowledge tools with the support and acceptance of professional associations (and alliances), scientific associations and patients' organisations. The main stakeholders (the Dutch Federation of Patients' Organisations, the Dutch Association of Medical Specialists, the Dutch College of General Practitioners and the Dutch Nurses' Association) continued in working together to translate the guidance into a web-based practical version, and to arrive at consensus on a sustainable model for the development, publication, governance and financing of patient decision aids. An important follow-up step is to crosslink this guidance to the guidance for developers of clinical practice guidelines[1].

Formal steps towards accreditation have not been taken yet, the question being whether this procedure is needed, and is warranted given the current level of evidence. In December 2016, the USA National Quality Forum released national standards for the certification of patient decision aids[30]. The certification criteria are meant to be used for 'complete' patient decision aids, which are standalone, independent tools for patients facing a clinical decision. Our guidance, although not formulated along the lines of certification criteria, is highly comparable with the USA criteria in terms of content. The only USA criterion that we do not cover is that the patient decision aid should report readability levels.

We believe that this study can be seen as an inspirational example for other countries that are facing the same challenges with regard to the development and governance of clinician- and patient-directed knowledge tools such as guidelines, guideline summaries, patient versions of guidelines and patient decision aids.

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  - Integrating guidelines and SDM: Paediatricians reflecting on CPG Palliative Care for Children;
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  - Unravelling chaos: a modified RAND Delphi to limit the number of knowledge tools in the Netherlands and to define them at a national level

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- Workshop, G-I-N 2009, Lisbon, Portugal:
  - Designing and testing a programme for multidisciplinary guideline development


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Dankwoord

Tijdens mijn leven ben ik zoveel lieve en aardige mensen tegengekomen. Alle contacten en vriendschappen hebben gemaakt tot wie ik nu ben. Hoe doe ik die recht in mijn dankwoord? Ik heb daarom even overwogen een ieder met naam en toenaam te noemen. De gedachte dat je uiteindelijk toch iemand over het hoofd hebt gezien, heeft me doen besluiten er van af te zien. Een poging tot die lijst staat echter wel in mijn laatste PhD-notitieboekje en die koester ik; deze brengt dierbare herinneringen te weeg aan wie ik allemaal ontmoet heb, ken en wat we allemaal hebben meegemaakt.

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Dit zit erop, tijd voor iets nieuws! Bedankt allemaal! x


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About the author

Born in Maastricht on 9th February 1972, the last day of carnival. And every eleven years, my birthday takes place on the last day of carnival. Carnival enthusiasts recognise the significance. I grew up in Maastricht except for a five year stint in Born and Sittard ('t Kleesj). After finishing Gymnasium ß at 't Stedelijk, I chose to start with the brand-new studies Commerce and Business Economics at Hogeschool Zuyd (1994). Because on the one hand I was dreading the 'crowdedness' of university, and on the other hand this new study offered the opportunity to spend a year abroad. During that year abroad, I did an apprenticeship at Douwe Egberts UK (London) and got introduced to techniques retailers use to influence buying behaviour of customers. Which was also the subject of my thesis.

Triggered by the course 'intercultural communications', I decided to follow-up with a master study that was more human interest oriented: social cultural sciences at Vrije University in Amsterdam (1998). During my last year at university, I got employed by Boots the Chemist Ltd. A pharmacy/chemist chain that was seeking a foothold in continental Europe. As Merchandising & Marketing executive health care, this was my introduction in the world of (commercial) health care. After opening five shops in the Netherlands, I switched to the Ministry of Health, Welfare and Sports where I was involved in the project pharmaceutical care. Still not having found my niche, I left the government after two years to start as a consultant with Accenture (2000). That was a rollercoaster ride, peeking into kitchens of very different organisations such as AkzoNobel, KLM, Child Welfare Council, Betuweroute (knowing quit early on that its deadline would not be met) and spending most my time with energy supplier Essent (regarding transition of the energy market). My project involvements were mainly change management.

After five years, I decided it was time to return to health care as I wanted to make sure it is in tip top shape when I'm old. However, when applying for jobs I was told that my days in health care were too long ago, so I took up a new master study at Erasmus School of Health Policy & Management (formerly iBMG) in Rotterdam (2005). And also starting a new consulting job with CQ-procesmanagement that mainly worked with mental healthcare organisations. The subject of this thesis concerned factors influencing people choosing home care.

Preferring a job that sees to the end of the projects I was involved in, I applied with ZonMw (2006), Netherlands Organisation for Health Research and Development. My terms and discussions negotiations took place on the shores of the peninsula Snæfellsness (Iceland) waiting for the ferry. I was programme manager for three programmes: Disaster management in hospitals (Ziekenhuisrampenopvang-plannen, ZIROP), Multidisciplinary guideline development (Kwaliteit, Kennisbeleid Curatieve Zorg) and Every day diseases (Programma Alledaagse Ziekten (PAZ); programme together with the Dutch College of General Practitioners) before I was outsourced to a new advisory board for the minister of health; Councill for the Quality of Care (2009). Finally finding my niche: knowledge tools, knowledge translation and quality of care. Some feats of the Council of which I am proud: Guideline for Guidelines (working group), Glossary of quality health care, and the new edition of the 'manual' for evidence-based guideline development.

Due to the merger of the Council with other advisory boards, I came to work with the new National Health Care Institute (Zorginstituut Nederland) (2012) and was responsible for the long-term agenda for clinical practice guideline development and implementation in the Netherlands (also known as Meerjarenagenda). Not agreeing with the direction the institute was taking, I returned to ZonMw (2014). This time, as work package lead of the EU Joint Programming Initiative Antimicrobial Resistance (JPI AMR). In this capacity I contributed to the booklet Antibiotic resistance; what if antibiotics are no longer effective? Feeling I was drifting away from my PhD subject, I asked around within my network what a suitable working place would be for a person such as me. I 'ended up' at the Knowledge Institute of Medical Specialists (2015), as senior advisor and team lead.

At the beginning of the guideline programme at ZonMw, I was interviewed and the article inadvertently referred to me as having a PhD. When rectifying this with the programme committee, some members said that they would welcome me if I ever wanted to do a PhD with them. In 2011 an opportunity arose when committe member Trudy van der Weijden was appointed professor at Maastricht University. Coming full circle, back in my home town, I started my PhD in summer 2012 and my PhD thesis was accepted in spring 2020.

Still a proud *Mestreechteneer*, but living happily together with her tough Scot Andrew McBride, and kittens Zoomer & Loki in happening The Hague.

Het is miech gelök!

Eus Mestreechter taol

De zon sjijnt sjoen
Sjeng en dien sjeun zien erreg sjiek,
bove de riviere klink dat get kemiek.
De waor steit in de kiekoet, zèt de kenkee noe mer lieg,
'n knievel op dien lip beteikent haor op die geziech.
'ne Groete bavvie is gewoen 'n groete moul,
e look in de grónd, jao dat neume veer 'n koul.

Refrein:
Ze is neet breid, ze is neet breid.
Mer ze is laank, mer ze is laank.
Eus Mestreechter taol, 't sjoens vaan allemaol.
En veer trèkke ze laank, want dat gief zjus de klaank.

Tappesere doen veer mèt tepiet,
leef medam, eur humme is te wied.
Lammentere is gewoen gezeik,
lómmele verköp ste aon 'de Reik'.
'n Kachel in de keuke hèt bijj us 'ne kwiezenjaer,
en al deez leuke wäördsjes höb iech oet d'n diksjenaer.

Teks: D. Vangarde & J. Innemee
Melodie: "Vive le douanier Rousseau"
Zaank: De Drei Köp