

**Towards improved decision quality in person-centred healthcare:
exploring the implications of decision support
via Multi-Criteria Decision Analysis**

PhD Thesis

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List of included papers [I-V]

Paper I

Kaltoft MK. Nursing Informatics AND Nursing Ethics: addressing their disconnect through an enhanced TIGER vision. *Studies in Health Technology and Informatics*, 192 (Medinfo 2013), pp.879–883.

Paper II

Dowie J, Kaltoft MK, Salkeld G, Cunich M. Towards generic online multicriteria decision support in patient-centred health care. *Health Expectations*. 2013 Aug 2;192.

Paper III

Kaltoft MK, Cunich M, Salkeld G, Dowie J. Assessing decision quality in patient-centred care requires a preference-sensitive measure. *Journal of Health Services Research and Policy*. 2013. 19(2):110–7. First published on December 12, 2013

Paperr IV

Kaltoft MK, Nielsen JB, Salkeld G, Dowie J. Increasing User Involvement in Health Care and Health Research Simultaneously: A Proto-Protocol for “Person-as-Researcher” and Online Decision Support Tools. *JMIR Research Protocols*. 2014 Jan;3(4):e61.

Paper V

Kaltoft MK, Nielsen JB, Salkeld G, Dowie J. Who should decide how much and what information is important in person-centred health care? *Journal of Health Services Research and Policy*. Doi: 1355819614567911, first published on January 10, 2015

List of abbreviations

AHP Analytic Hierarchy Process

Anti-TNF (TNF=Tumor Necrotic Factor)

API Application Program Interface

BEAN/s Best Estimate/s Available Now

CCF Colitis-Crohn Foreningen (Danish patient organisation for IBD)

CD Crohn's Disease

CSV comma-separated value

CQI Dutch Consumer Quality Index

DDKM Den Danske KvalitetsModel (Danish Quality Model)

DQI Decision Quality Instrument

DQM Danish Quality Model (DDKM Den Danske KvalitetsModel)

EQ-5D EuroQol-5 Dimensions (European Quality of Life Questionnaire)

EVIDEM Evidence and Value: Impact on Decision Making

IBD Inflammatory Bowel Diseases

ID Identification or Identifier

IPDASi International Patient Decision Aids Standards Instrument

HTA Health Technology Assessment (Danish: Medicinsk Teknologi Vurdering (MTV))

JD Jack Dowie (PhD project supervisor)

LUP Den Landsdækkende Undersøgelse af Patientoplevelser <http://patientoplevelser.dk/lup>

MCDA Multi-Criteria Decision Analysis

MCDD Multi-Criteria Decision Deliberation

MI Motivational Interviewing

MyDecisionSuite (MDS)

MyDecisionQuality (MDQ)

NEM-id 'easy – id' Danish national electronic mail communication

NECCO Nursing European Crohn's and Colitis Organisation

NHS National Health Service for England and Wales

OUH Odense University Hospital

PREM Patient-Reported Experience Measure

PROM Patient-Reported Outcome Measure

PEQ Patient Experience Questionnaire

PSA Prostate Specific Antigen

RCT Randomised Controlled Trial

RPAH Royal Prince Alfred Hospital (Sydney)

RSD Region of Southern Denmark

PI Principal Investigator

PICOTS Populations, Interventions, Comparators, Outcomes, Timings, and Settings

SDM Shared Decision Making

SDU University of Southern Denmark

SMDM Society for Medical Decision Making

SMART Simple Multi-Attribute Rating Technique

St Marks St. Mark's Hospital and Academic Institute (London)

STROM Student Reported Outcome Measure

SOuRCe Surgical Outcomes Research Unit

SURE Sure of Myself; Understand information; Risk-benefit ratio; Encouragement

TIGER Technology Informatics Guiding Educational Reform

Tiabimia Taking Into Account and Bearing In Mind

UC Ulcerative Colitis

VLE Virtual Learning Environment

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1.0 Aim and Outline of the thesis

The overall aim of my thesis is to contribute to the moves towards increased decision quality in health and healthcare, specifically by exploring the potential of individualised online support for clinical decisions based on the technique of Multi-Criteria Decision Analysis (MCDA) following accomplishment of the necessary conceptual and developmental work.

The empirical aim was to investigate the feasibility and practicality of online home preparation designed to improve the quality of a decision arrived at in a forthcoming consultation. The users would be outpatients with Inflammatory Bowel Disease (Crohn's Disease and Ulcerative Colitis) where a change in disease management would be considered. One secondary aim would be to assess the acceptability to patients and clinicians of the decision support. Another secondary aim would be to explore the effect of the intervention on the MyDecision Quality (MDQ) instrument's score. (MDQ having been developed in the initial phase.) A third secondary aim would be to explore the concordance between clinician and patient when the clinician was able and willing to complete the clinician version of MDQ.

The thesis shows how the attempts at implementation led to a sequence of revised aims and adjustments in methods in pursuit of the original aim. Then, how, in the light of the lessons learned, major reconceptualisations of the way the overall aim might be better pursued emerged.

The *Background* to the original thesis proposal is established first, followed by a chapter that clarifies, at greater length than above, the *Objectives* and proposed *Methods* as they were at the outset. What happened in the pursuit of these objectives is then described in a series of seven subchapters, under the overall heading of *Results, Findings, and Outputs*. Included in these subchapters are explanations of how and why the original objectives were either achieved, or adapted, or postponed for future accomplishment.

Five of these seven subchapters introduce and summarise the research reported in the **5 included publications**. Some of what might be interpreted as the detailed background for particular studies and publications is postponed until the relevant subchapter reporting on the relevant *Results, Findings, and Outputs*. Otherwise it would need to be repeated in order for the reader to follow the presentation and it is preferable to keep it until the point of use.

Paper I: **Nursing Informatics and Nursing Ethics: addressing their disconnect through an enhanced TIGER vision** introduces the framework provided by the metaphorical map of the world of judgement and decision making that is used to locate the developed MCDA-based aid and decision quality instrument, emphasising their distinct features for health professionals who have not come into contact with them.

The development and implementation of a generic MCDA-based decision support template is then reported in paper II: **Towards generic online multicriteria decision support in patient-centred health care**. This is followed by the development of the 'dually-personalised' instrument for measuring decision quality, MyDecisionQuality (MDQ) in paper III: **Assessing decision quality in patient-centred care requires a preference-sensitive measure**.

The following two subchapters focus on the empirical research on implementation in the (out-patient) context of Inflammatory Bowel Disease (IBD) in London and Sydney, and the pre-piloting of MDQ as a possible web-based enhancement of the national patient experience survey in Denmark (LUP). Despite numerous adaptations in the spirit of action research, these subchapters record limited empirical success, mainly in the form of proof of method. But they also report substantive developmental achievement, insofar as technically well-functioning online programs with embedded MCDA-based aids were produced, ready for deployment in the near future. A rich body of interview materials remains to be exploited, but requires some supplementation to ensure anonymity for those who have contributed their experiences thus far. The lessons learned in regard to implementation prompted fundamental rethinking. This resulted in the subchapters introducing and summarising the final two submitted papers IV: **Increasing user involvement in health care and health research simultaneously: A proto-protocol for “Person-as-Researcher” and online decision support tools** and V: **Who should decide how much and what information is important in person-centred care?**

The *Discussion* looks back to explore the broader messages of the research experience, including an assessment of whether external developments in the literature and practice since those reported in the original background, have changed the significance of the results and findings. In *Conclusions and Implications for Future Research* we summarise what we see as the wider implications of the detailed studies, and the whole research experience. The process is seen as confirming the importance of remaining open to conceptual innovation within action research, especially in complex settings that are experiencing rapid change of all sorts, usually under severe resource pressures. Future work using the protocol and tools developed will build on the reconceptualisations and include translation into the Danish context.

For reasons explained in the appropriate subchapter, three papers are currently on hold pending the resumption of the interrupted and/or revised research, after completion of this thesis. Their tentative titles are:

- *Cross-cultural action research for translational health: ‘patients-as-researchers’*
- *Reflections on decision making and decision quality during my IBD journey: patient narratives*
- *MCDA-based decision support for IBD sufferers: from clinical shared decision making to open community access*

1.1 The Changing Context

The studies that resulted in the five peer-reviewed publications included in the thesis were undertaken in a period of extremely rapid change in the technical infrastructure of healthcare access and delivery. Continuous innovation was occurring in both the underlying hardware and software and in the communication opportunities offered by the expansion of the internet and mobile computing.

The original 'Moore's Law', which predicted the doubling, year after year, in the number of circuit components that could be economically packed on an integrated chip, may be failing (Cumming et al. 2014) but the integrated circuit continues to change many aspects of life, including healthcare and the social and environmental factors impacting on health, at exponential pace (Mack 2015). One important consequence for researchers seeking to implement standard methodologies has been the resulting tension captured in

Buxton's Law - 'It is always too soon to evaluate, until suddenly it's too late' (Buxton 1987). This law has never been more relevant than in the last few years of electronic e-health and mobile m-health expansion and the urgent need for techniques and attitudes in research, as well as practice, to adjust, is argued with increasing urgency (Baker et al. 2014).

Buxton's law is not quite as applicable to thinking about healthcare, but ideas have had to respond to the technological changes as well as to the associated changes in population expectations. There have been rapid changes in how both individuals and institutions conceptualise their roles and tasks, with major rethinking about the 'humanware' of healthcare and how the various parties and stakeholders involved are regarded and talked about. The rise of 'user involvement' and 'patient and public engagement' in both healthcare and healthcare research has been a feature of the study period. All of the terms in this discourse will always be problematic in one way or another (McLaughlin 2009) but it is now widely accepted that patients are an important source of knowledge in relation to their condition (Pols 2013) and that their preferences, as *persons*, demand respect. It is symptomatic of our own participation in this change, that the early papers use the term 'patient-centred', whereas the later ones reflect our conscious adoption of the term 'person-centred' (Miles & Asbridge 2014). There is a good case for rephrasing this as person-focused, but we stay with the usage which is currently conventional.

The studies reported here are therefore very much of their time. The major developments in our thinking during the research period - of myself and the team within which I have been working - are clearly reflected in the contents of the five papers presented. The sequence is testimony to the need for a flexible, reflective approach and philosophy to research that engages with person-centred health decision making and is ultimately focused on its improvement, whether within or without the healthcare or healthcare research settings. Not one approach or analytical technique can fully address the ethical, spiritual, religious, existential and emotional complexities of health and healthcare as dimensions of life and living (la Cour & Hvidt 2010). Nevertheless we are committed to the virtues of balancing what Kahneman calls 'fast and slow thinking' (Kahneman 2012) in the health-related decisions faced by all persons and all communities. We see MCDA, the technique chosen as the foundation of the research, as making possible the context-sensitive balancing of intuition and analysis - of science and art - in decision making. Simultaneously it offers protection against the dangerous confounding of beliefs and values present in most 'isms', including 'healthism' (Skrabanek 1994).

My research was conducted in the context of a collegial team, including an international set of supervisors. This poses some problems in terms of mode of address. I have used the first person only when it seems desirable. Otherwise the 'royal we' is used, partly to signify that my research has been carried out within this collegial setting.

The multiple concepts and terms used in the thesis and papers are introduced as they become relevant, rather than being listed out of context here.

1.2 Related papers [A-G]

A number of peer-reviewed papers besides the included five were published in the course of my research. In all cases it was felt my contribution warranted first author status. The seven related papers all drew on the same MCDA/Annalisa-based approach and software as those included in this thesis. They are introduced briefly at the end of the thesis to give an indication of the wider scope of the research undertaken during my PhD period.

- [A] Kaltoft, M.K., Nielsen, J.B., Eiring, Ø., Salkeld, G & Dowie, J., 2015. Without a reconceptualisation of “evidence base” evidence-based person-centred healthcare is an oxymoron. *European Journal for Person Centered Healthcare*. (Forthcoming)
- [B] Kaltoft, M.K., Nielsen, J.B., Salkeld, G. & Dowie, J. 2014. Enhancing informatics competency under uncertainty at the point of decision: a knowing about knowing vision. In C. Lovis, ed. *e-Health - For Continuity of Care*. 192:879-883.
- [C] Kaltoft, M.K., Nielsen, J.B., Salkeld, G. & Dowie, J., 2015. Can a Discrete Choice Experiment contribute to person-centred healthcare? *European Journal for Person Centered Healthcare*. (Forthcoming)
- [D] Kaltoft, M.K., Turner, R., Cunich, M, Salkeld, G, Nielsen, J.B & Dowie, J, 2015. Addressing preference heterogeneity in public health policy by combining Cluster Analysis and Multi-Criteria Decision Analysis: Proof of method. *Health Economics Review*, 5:10.
- [E] Kaltoft, M.K., Nielsen, J.B., Salkeld, G., Lander, J. & Dowie, J, 2015. Bringing feedback in from the outback via a generic and preference-sensitive instrument for course quality assessment. *JMIR Research Protocols*, 4(1), e15.
- [F] Kaltoft, M.K., Nielsen, J.B., Salkeld, G. & Dowie, J. 2015. Health informatics can avoid committing symbolic violence by recognizing and supporting generic decision-making competencies. *Studies in Health Technology and Informatics* 218: 172-177.
- [G] Kaltoft, M.K., Nielsen, J.B., Salkeld, G. & Dowie, J. 2015. Enhancing both provider feedback and personal health literacy: dual use of a decision quality measure. *Studies in Health Technology and Informatics* 218: 74-79.

2.0 Background

The wider motivations for my research were concerns about health and healthcare arising during the preceding years of course work, and research and practice in multiple healthcare systems since WHO Health for All 2000 (launched in 1984) and international definitions for public health. The WHO Health Promotion Glossary defines Public Health as:

The science and art of promoting health, preventing disease, and prolonging life through the organized efforts of society (This is adapted from Acheson's report 1988) and it adds to this definition:

Public health is a social and political concept aimed at improving health, prolonging life and improving the quality of life among whole populations through health promotion, disease prevention and other forms of health intervention (WHO 1998, p.3)

While 'Public Health' is defined here without the word decision, this is in contrast to 'Empowerment for health':

In health promotion, empowerment is a process where people gain greater control over decisions and actions affecting their health' (WHO 1998, p.6)

The Aarhus Convention has taken up the call for public participation in decision making in environmental matters as a human right issue and been adopted since 2001 (<http://www.unece.org/env/pp/treatytext.html>)

The approach in my research would accordingly have to have the potential to advance the cause of person-centred healthcare in the context of the many social determinants of health and well-being, beyond and across beliefs systems and dominant paradigms (De Leeuw & Hussein 1999). The approach would not only respect the multiple considerations relevant to the person in their health and healthcare decisions, but also ensure that the options presented to them were not restricted to the pill or the surgeon's knife, but embraced nutrition, exercise, and other lifestyle and environmental sources of personal and public health (Aarhus Convention (UNECE) 1998).

On the basis of courses undertaken long before the formulation of a PhD proposal I had come to the belief that judgment and decision making is a relatively under-emphasised and under-researched source of individual and social problems in relation to health and healthcare, and that higher quality decision making can contribute to ameliorating well-recognised and important problems (Meehl 1986; Gigerenzer & Gray 2011). Challenging decisions characterised all levels from the micro-individual (Should I be screened for chlamydia? Should I take statins or change my lifestyle?), through the meso-institutional (Should we introduce handhelds for nurses? Should we merge these two hospital departments?), to the macro-regional/national/international policy issues (Should we curb antibiotics use more aggressively? How should we allocate resources across competing service priorities?)

Too often it seemed these questions were framed, researched and communicated in conceptual isolation from each other, without the unifying insights a generic decision analytic framework and approach might bring. As a result of exposure to the courses and publications of my project supervisor Jack Dowie I was already aware of, and had some formal familiarity with, a theoretical framework and applied technique that seemed to have the potential to improve decision quality at all levels and in all settings. One of the main ways they would do this would be by providing a common map and language to facilitate cross party, cross-border, and cross-disciplinary

communication and translation - by being prescriptive, not descriptive, and by using numbers and not words to quantify magnitudes.

After introducing this framework and the Multi-Criteria Decision Analysis (MCDA) technique I will note how their application could help address three of the most prominent current questions in academic and policy discussions about health and healthcare, in Denmark, as well as internationally:

- The translation question: How can research evidence be translated into improved healthcare and public health?
- The involvement question: How can users of health services be better involved in decision making relevant to their health and healthcare?
- The feedback question: How can providers (professionals and organisations) know whether they are contributing to improving healthcare?

Subsequently, I will provide the background to the choice of Inflammatory Bowel Disease (IBD) as the case study for decision support.

2.1 Mapping the world of Judgment and Decision Making: Judemakia

The background framework would be provided by the metaphorical map of the world of Judgment and Decision Making called Judemakia (Dowie 2013) which built on his earlier portfolio theory approach to health behaviour (Dowie 1975). The map resulted from combining Hammond's psychological Cognitive Continuum Theory (Hammond 1996b; Hamm 1988), in which different modes of cognition are seen as appropriate for different task structures, with normative Decision Theory, with its prescription that beliefs (evidence/knowledge) and preferences (values), need to be established and processed separately, in order to minimise 'mutual contamination', prior to their necessary synthesis in a decision.

Hammond's title *Human Judgment and Social Policy: Irreducible Uncertainty, Inevitable Error, Unavoidable Injustice* neatly sums up the case for exploring the cognitive basis of decision making in all contexts.

In his Cognitive Continuum diagram (Figure 1) current health and healthcare decision making is located mainly at the first two modes of intuitive and peer-aided judgment. The present research would explore the case for moving more of it to the next level, called 'system-aided judgment' by Hammond.

An old and good idea, according to author/scientist/statesman Benjamin Franklin in 1772:

When these difficult Cases occur, they are difficult chiefly because while we have them under Consideration all the Reasons pro and con are not present to the Mind at the same time... To get over this, my Way is, to divide half a Sheet of Paper by a Line into two Columns, writing over the one Pro, and over the other Con...

...And tho' the Weight of Reasons cannot be taken with the Precision of Algebraic Quantities, yet when each is thus considered separately and comparatively, and the whole lies before me, I think I can judge better, and am less likely to take a rash Step...

- Benjamin Franklin, American author, scientist, and statesman (1706-1790)

Letter to Joseph Priestley, Sep. 19, 1772 <http://www.procon.org/view.resource.php?resourceID=005356>

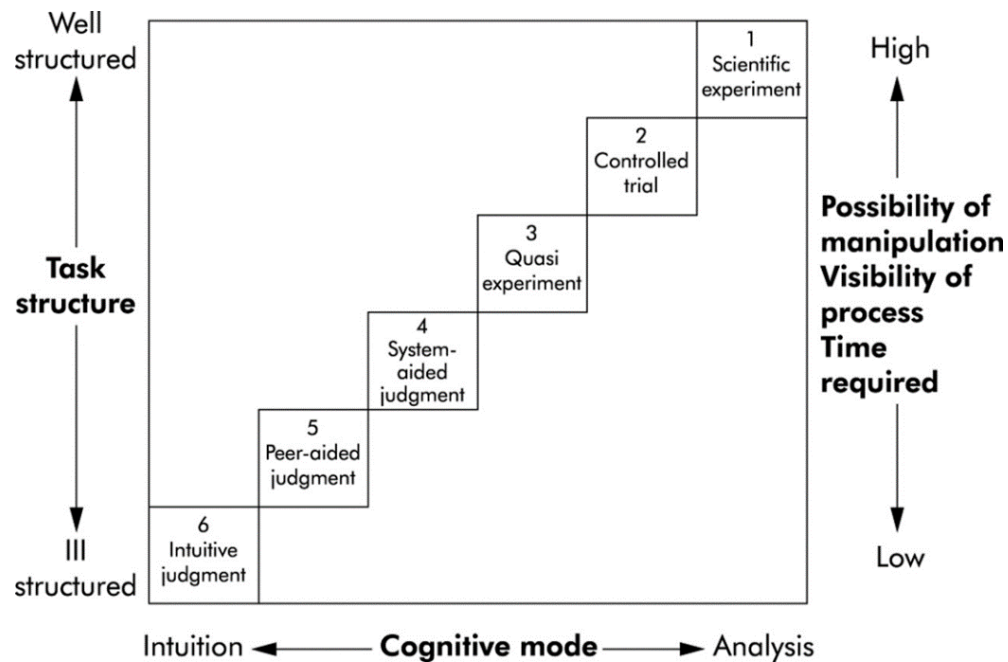


Figure 1: Hammond's Cognitive Continuum (Hamm 1988) in (Dowie & Elstein 1988)

This would involve moving northwards towards the equator in the Judemakia map included in the poster (Figure 2). The map, with its distinct continents (to separate beliefs, preferences, and decisions) and provinces (to reflect the main analysis-to-intuition ranges), can help locate border disputes and the obstacles to coordination, collaboration, cooperation and coherence resulting from operating at different balances of what Kahneman has called 'fast and slow thinking' (Kahneman 2012). Disagreements about evidence and ethics separately, and particularly disputes which involve both, as do most decisions (Dowie 2001), can be located by their latitude and longitude and given visual representation. Quality is a third dimension and is, metaphorically, altitude.

The poster (reproduced with permission) presents the map and also draws its implications for the challenges of decision making in both practice and research. The magnets metaphorically represent the pressures on practitioners and researchers to be more certain than is warranted and more certain than can be achieved at the equatorial balance of analysis and intuition. The map is introduced more fully in subchapter 4.1 and Paper I.

Knowledge of the Cognitive Continuum Theory has been found highly relevant to understanding the decision making tasks and processes of health professionals in the clinical environment (Cader et al. 2005; Bucknall 2003; Randell et al. 2009; Thompson & Dowding 2009). I specifically wished to explore a decision support approach based on the balancing of intuition and analysis that characterises the system-aided judgment level in Hammond and the equatorial level in Judemakia where analysis and intuition are in balance.

While we talk of 'balancing' there is no suggestion that the elements of these need to be measured in a rigorous way for the current purpose and it is made clear by Hammond and Dowie that the implicit scales (i.e. those for defining and measuring intuition and analysis) would be multi-criterial in nature.

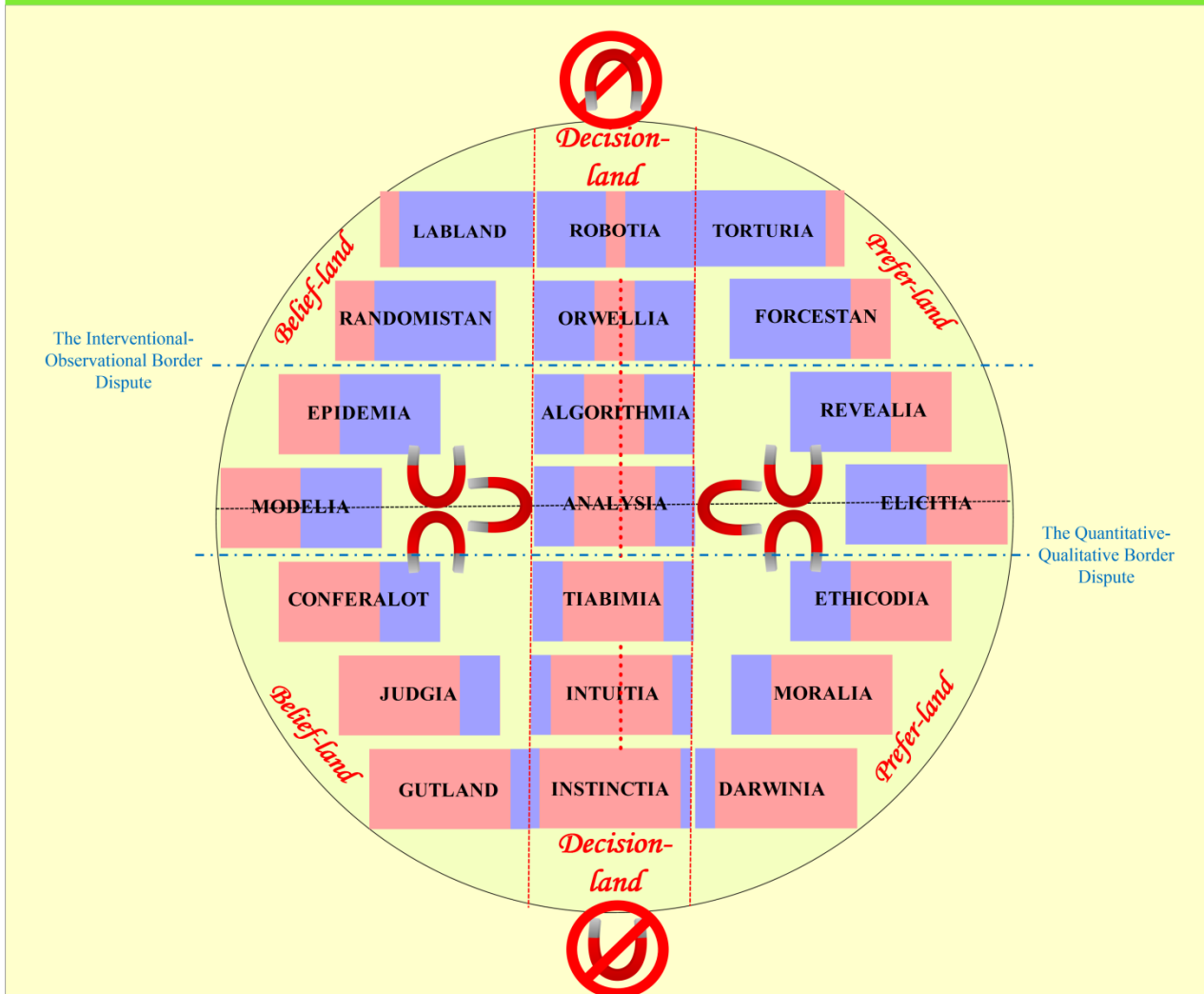
Mapping the Translation Challenge

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JUDEMAKIA

the world of Judgement & Decision Making



Longitude

Bayesian Decision Theory requires separate numerical judgements and syntheses of beliefs (generated in the continent of Belief-land) and preferences (generated in that of Prefer-land) and their integration into a decision/opinion by a specific mathematical rule (in Decision-land)

Latitude

Hammond's Cognitive Continuum Theory proposes that all judgement and decision making tasks can be undertaken at varying balances of **intuition** and **analysis**. Seven regions which embody broad differing balances exist in all 3 continents.

The Translation for Decision Problem

The pulls from the polar magnets reflect excessive reliance on the scientific method (north pole) and personal expertise (south pole), resulting from disciplinary interests on the one hand and psychological biases (especially uncertainty aversion) on the other, creating major obstacles to Translation for Decision.

The Translation for Decision Solution

These polar pulls need to be offset by new equatorial magnets in both Belief-land and Prefer-land, needed to produce input syntheses that balance analysis and intuition and in a language equally accessible to all; supplemented by epicentral magnets to pull the two input syntheses into Decision-land at 0° 0° - the centre of Judemakia, where translation challenges (distances) from all regions of all continents are minimised.

Figure 2: Judemakia and the interpretation of the translation challenge based on it (Dowie 2013)

2.2 Multi-Criteria Decision Analysis (MCDA)

As a health visitor with experiences with and within multi-ethnic communities across the life- and healthcare services spectrum I wanted an approach to decision support which would be visual, on one-screen, interactive and transparent.

It would therefore take advantage of the latest e- and m-health innovations including translation tools for non-native speakers. The decision-making tool for Family Planning Clients and Providers (WHO 2005) provided an excellent example of how the MCDA-approach could be achieved on paper, but it was necessarily offline and not interactive. The colour coding reflects the developers’ threshold ratings for this option being a ‘top choice’ or ‘good choice’ for this need. There is no provision for weighting the needs, this cognitive burden being left to the user, along with the synthesis of the weightings and the ratings into a decision. This is what any implementation of MCDA provides. The Annalisa implementation of MCDA, which will be used in this thesis, had already been used in the context of sexual and reproductive health to produce the open access My Contraception Tool (French et al. 2013) and for counseling in genetic testing in pregnancy (Erenbourg et al. 2013).



Figure 3: WHO matrix decision-making tool for Family Planning Clients and Providers

The thesis focuses on the exploration of the way the prescriptive technique of MCDA might be used to improve decision quality. It is not concerned with evaluating alternative non-MCDA-based approaches to achieving this goal, simply noting its fundamental difference with the vast majority of the description-based aids and tools on offer. Description-based tools are based on, and seek to work within, the ways humans *do* make decisions - or have been theorised as doing. Prescription-based tools are based on theories of how humans *should* make decisions, given acceptance of a set of normative assumptions concerning the ideal decision maker, but adapting these to practical circumstances. The case is made for adding MCDA-based aids to the portfolio of available tools, to be evaluated against the alternatives by those tackling the meta-question of ‘deciding how to decide’ in a specific decision context.

However, MCDA can only be applied through some software implementation of the technique. Again, this thesis is not concerned with evaluating alternative implementations. It simply utilises the Annalisa© implementation of MCDA, as embedded in the Elicia© survey program, and notes its fundamental differences from the alternatives, most of which involve greater complexity and resource requirements. The case is made for adding Annalisa-based tools to the portfolio of MCDA-based decision aids, to be evaluated against the alternatives by the stakeholders 'deciding how to decide' *in a specific decision context*.

The reader will find the basics of Annalisa introduced in 4.2 and the relationship between Annalisa and Elicia explained in 3.2, where it is needed in order to clarify the research for my PhD, which was carried out in a collegial setting. (The software is used by courtesy of the University of Sydney, School of Public Health.)

The use of a single clinical criterion, or narrow set of such criteria, in treatment decision making is a likely source of low decisional concordance between clinician and patient, and subsequent limited adherence to prescribed management pathways, in the form of poor persistence and compliance with medications or behavioural recommendations. The applicability of *Multi-Criteria Decision Analysis* (MCDA)-based decision support in a shared decision making context had already been well demonstrated (Dolan, Boohaker, et al. 2013a; Dolan 2008; van Til et al. 2008; Dolan 2008). It had also proven feasible in clinical practice using an early version of the template for a patient-specific MCDA-based aid, which was further developed as part of my research (Masya et al. 2009; Cunich et al. 2011) and had already been used elsewhere (Erenbourg et al. 2013; French et al. 2013).

Following carrying out a pre-thesis systematic review on handhelds for nurses within a mini-Health Technology Assessment framework (Kaltoft & Dowie 2010), I was able to begin my PhD study by contributing to the later stages of the development of the Annalisa implementation of MCDA. This was an implementation of the technique which appeared to have great potential to impact on the 'real world' of the ordinary person, because of the flexible trade-off between rigour and practicality it permits. More ambitiously it could be a candidate for the generic template needed to allow all actors and stakeholders along the translation pathway from research to practice - and return - to use a common and visual grammar and vocabulary in their decision making.

Could the translation, involvement and feedback questions identified earlier, benefit from being approached through the Judemakian framework and MCDA technique, implemented in an accessible fashion in Annalisa?

2.3 The translation question

A major focus in the world of healthcare research and practice for most of this century has been the increased demands for more effective 'translation' of research evidence into practice and 'knowledge into action' (Ward et al. 2009). Modeling the process by which this translation is hindered by various 'barriers' or 'blockages', has dominated the relevant literature. Since the ultimate destination of the research is the health of the patient it is crucial how their interests, including their preferences, are dealt with during the process. From surveying the available models we found the Callard version of the 'bench-to-bedside' model (Callard et al. 2012) the most pertinent one to person-centred healthcare and health care research.

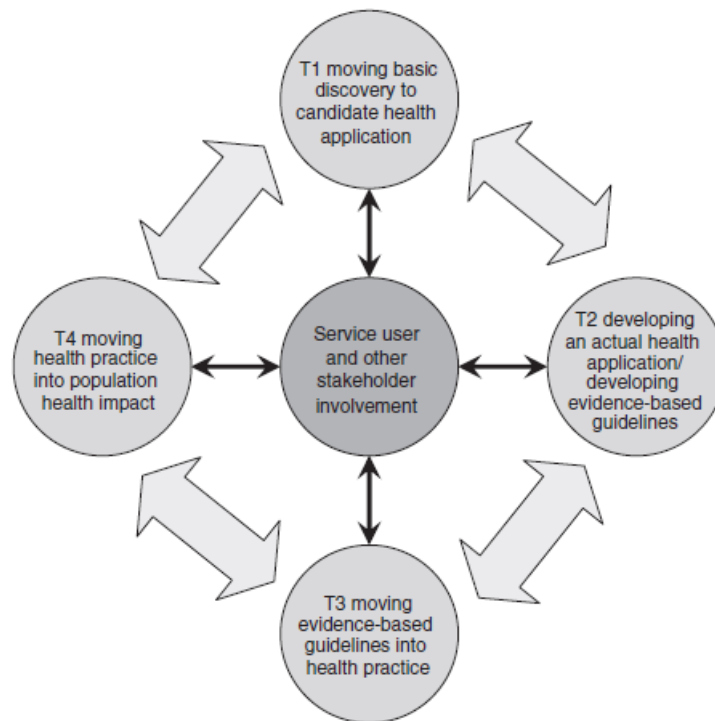


Figure 4: Callard, Rose and Wykes translation model (reproduced with permission)

It places the user (whether conceptualised as person, patient, citizen, consumer, or other stakeholder) at the centre of the translation process, rather than, as in all other models, either at one end of a linear process (Glasziou & Haynes 2005; Sung et al. 2003; Westfall et al. 2007; Wilson, K. M. et al. 2011) or at one point in a cyclical one (Graham & Tetroe 2007; Greenhalgh & Wieringa 2011; Ogilvie et al. 2009). As a result of this central positioning the user is directly involved and can contribute at all stages and nodes in any ‘knowledge to action’ change pathway.

2.4 The involvement question

Early on in my research it was decided that the focus would be on clinical decision making, rather than community policy formation, despite the relevance of the framework and technique for both.

There have been worldwide moves to increase patient involvement in decision making on health and user involvement in policy development and research in healthcare. These movements have been based on patient rights grounds (Berwick 2009), their health consequences for patients, and institutional efficiency ones. Groene suggests there are three simple arguments for a patient-centred approach : improving patients’ rights, improving health gain and contributing to organizational learning (Groene 2011).

It is taken for granted that the amount of ‘shared decision making’ should be increased (Col et al. 2011) (Coulter A & Collins A 2011; Stiggelbout et al. 2012), that it is increasing, though only slowly and with many qualifications (Gionfriddo et al. 2014), and that decision quality should be improved through the provision of explicit decision support and fuller ‘perfected’ informed consent (Nelson & Clay 2011). The establishment of the

Patient-Centered Outcomes Research Institute (PCORI), by the Affordable Care Act ('Obamacare') represents a major commitment by the US government in this direction (Selby & Lipstein 2014).

The latest Cochrane review provides a convenient summary of what is known about patient decision aids:

Findings show that when patients use decision aids they: a) improve their knowledge of the options (high-quality evidence); b) feel more informed and more clear about what matters most to them (high-quality evidence); c) have more accurate expectations of possible benefits and harms of their options (moderate-quality evidence); and d) participate more in decision making (moderate-quality evidence). Patients who used decision aids that included an exercise to help them clarify what matters most to them, were more likely to reach decisions that were consistent with their values. However, the quality of the evidence was moderate for this outcome, meaning that further research may change these findings. Decision aids reduce the number of patients choosing prostate specific antigen testing and elective surgery when patients consider other options. They have a variable effect on most other actual choices. Decision aids improve communication between patients and their health practitioner. More detailed decision aids are better than simple decision aids for improving people's knowledge and lowering decisional conflict related to feeling uninformed and unclear about their personal values. Decision aids do not worsen health outcomes and people using them are not less satisfied. More research is needed to evaluate adherence with the chosen option, the associated costs, use with patients who have more limited reading skills, and the level of detail needed in a decision aid. (Stacey et al. 2014, p.3)

The literature on implementation of decision support is almost as dominated by the metaphors of barriers and blockages as the translation literature above. The barriers were relatively easy for researchers to identify and to list individually: time and resource constraints, commitment to the existing way of doing things as best practice within the specific disciplinary or practice setting, belief that while maybe of general merit the approach and/or aid did not match this particular patient population's needs, lack of awareness of, or interest, in alternative ways that would be disruptive and call for changes in attitudes and competencies not included in existing professional capital. However, the most appropriate way to address the complex mixture of barriers present in any specific clinical setting was more difficult to establish, beyond acceptance that tackling one successfully would not necessarily guarantee overall progress (Légaré et al. 2008).

The extensive background in relation to decision support is well covered by Elwyn where such interventions are classified into categories:

- 1: Those that are used by clinicians in face-to-face encounters.
- 2: Those that can be used independently from clinical encounters, either after an initial consultation with advice to return for further discussion or ahead of clinical encounters, so that patients arrive better informed and prepared for greater involvement in decision making. (Developers) generally stipulate that these interventions should be viewed as adjuncts to clinical encounters. Yet, in our view, the assumption also exists that the interventions should be capable of serving as the basis for autonomous decision making. Whether these interventions, or their developers, carry liability for patients who might act on

the basis of the information which they contain, has never been tested legally, but it is a matter of increasing interest as many open-access web-based interventions become available.

3: Those that are mediated by more interactive and social technologies. Most patient decision support interventions in this category have been mediated by telephone-based encounters, typically between patients and nurses who have been trained in the use of either a decision support protocol or tool, a service often called decision coaching. The nurse (usually) provides and discusses information with the patient, guides them to find other resources, helps explain the issues and supports the deliberation process (Elwyn et al. 2010, pp.703–4).

(Our intervention fits best in 2. It was initially conceived as 3, and can also be used in 1.)

While this Elwyn paper provides an excellent background for the whole field of decision support for our project its relevance lies in its almost complete dismissal of the approach we adopt, an approach based on prescriptive MCDA and ultimately on normative decision theory (Lipshitz & Cohen 2005; Riabacke et al. 2012).

This means that the MCDA-supported technologies in Figure 5 are largely ignored.

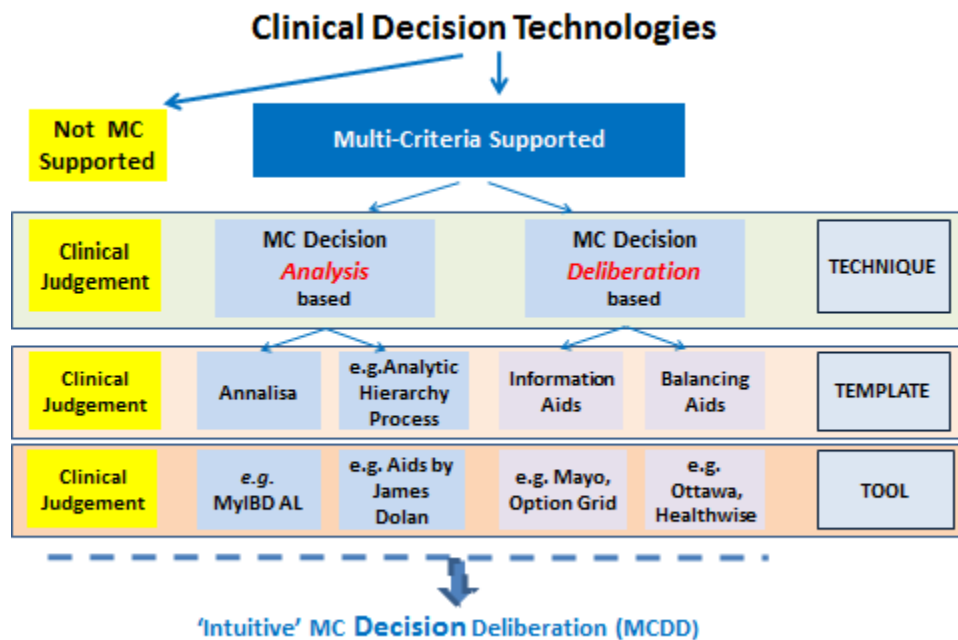


Figure 5: A taxonomy of clinical decision technologies (Reproduced with permission of Dowie)

The dismissal is puzzling, given the claimed openness of the writers and concern about the lack of theory-based interventions. Here and elsewhere in their writings (Elwyn, Stiel, et al. 2011) Elwyn and colleagues lament the large 'theory–practice gap' that exists, noting there is little explicit use of decision making theory in the design of decision support interventions. They acknowledge that few interventions are explicit about how they have translated theory into intervention design and outcome measure specifications. They admit that the deliberative

processes they favour for supporting decision making remain poorly understood, and accept it may be too early to propose interventions which aim to improve the process. But within this humility they are remarkably clear about one thing:

Optimization-based normative theories are viewed as not adding value to the process. (Elwyn, Stiel, et al. 2011, p.572)

[Though they do not] make concrete suggestions as to ‘how to make decisions’, the results resemble the imposition of a ‘deus ex machina’ – an external intervention that is often at odds with the outcome of a personally accomplished determination. Other, more descriptive, theories aim to understand and describe how humans make decisions ...

Sadly they acknowledge that these more descriptive theories

... have not yet moved to consider how to systematically *improve the process* of decision making. (italics in original) (Elwyn et al. 2010, p.709)

What we find here is either misunderstanding or misrepresentation of prescriptive theories, coupled with a total lack of any evidence for their rejection as the basis for decision support, apart from a repeatedly stated *opinion*.

This theory relies on the premise of unbounded rationality, a premise that has since been viewed as inconsistent with how people actually make decisions and as an unrealistic way to try and guide and support decision making (Elwyn et al. 2010, p.708)

It is not the aim of a prescriptive theory to be consistent with how people actually make decisions. What is the citation provided for the claim (made in 2010) that optimization-based normative theory is viewed as an unrealistic way to try and guide and support decision making? The answer is the same authors, writing 10 years earlier (Elwyn et al. 2001).

It is clear that those writing in this vein are mostly trained in descriptive disciplines, such as psychology, or ones without formal training in decision making, like medicine. The statements are repeatedly repeated by the same group of authors and built into their guidelines and canon, without any evidence apart from this collegial agreement. And, most importantly, without any recognition that logically one cannot derive an ought from an is. No amount of descriptive theorising can provide the necessary prescriptive basis for improvement (Dowie 2004).

The misrepresentation, based again on 'general agreement', extends to the cognitive demands of decision analysis

... analysing the trade-off between accuracy and frugality could be central to the practice of evidence-based medicine in the real world of busy professionals with limited time. Although it is important to explore how patients and clinicians might have used decision analysis, there is general agreement that technology does not provide a way forward (Elwyn et al. 2001, p.574)

In its prescriptive, as opposed to idealised normative, form, MCDAnalysis does not rely on a totally irrelevant ‘unbounded’ rationality any more than does MCDDeliberation. It is completely compatible with very different trade-offs between accuracy and frugality and Annalisa was designed specifically to be flexible in this regard. (Paper II)

This rejection of the approaches of the sort we adopt simply avoid the challenge of setting up the rigorous empirical test that would usually be demanded for interventions and is insisted on for those within their descriptive paradigm. A level playing field would require that the primary outcome criterion (a good decision) not be defined as one requiring the sort of deliberative process they mandate. Since such proper comparative empirical evaluation appears unlikely to happen, we would prefer to see our approach acknowledged as one contribution to a portfolio of approaches. Nothing said here is therefore intended to deter pursuit of description-based approaches to improving decisions - when the need for some prescriptive input is accepted.

One of the most interesting issues to resolve in such a comparison is whether it is the function of decision support to produce a clear verdict in favour of one option, and to penalise it if it does not, as happens in the case of the Decisional Conflict Scale (O'Connor, A.M. 1995) and its short form SURE. (Legare et al. 2010). A numerical approach such as MCDA may establish the existence of genuine decisional equipoise, given the evidence and the patient's preferences. We argue that penalising an aid for producing an opinion that the decision is a 'toss up' (Pauker & Kassirer 1981) is unacceptable and encourages a 'false clarity' bias (Kaltoft, Dowie, et al. 2014).

The comprehensive report on 'Helping people share decision making' (da Silva 2012) does not contain the word 'multi-criteria' or any cognate and neither do the title of any of the 976 references cited. The later report on 'Helping measure person-centred care' (da Silva 2014) acknowledges the concept is 'multi-dimensional' and 'multi-faceted', but again we find it significant that there is not even peripheral mention of an analytical technique specifically designed to address decision making within person-centred care in the report or in the titles of its 1221 references.

A physician-administered online patient self-aid assessment and communication tool has proved successful in helping control 'flare-ups' in Inflammatory Bowel Disease (IBD) and avoiding costs of hospitalisation (Elkjaer, Shuhaibar, et al. 2010; Elkjaer, Burisch, et al. 2010; Munkholm et al. 2010). Online self-aid tools are in increasingly being made available by pharmacological companies producing new medications. A number of Danish patient-support groups have already seen the potential of the national domain www.sundhed.dk with its secure log-in (NemID) [<https://www.nemid.nu/dk-en/>] for patient-to-patient support, including disease management. (OUH Operational Excellence and IT 2013). The challenges to health care providers include how to handle 'your Google-patient' in general practice and in general (Dybdal 2014). The suggestion that Google is shut down is not the answer. The relevant fact is that none of these initiatives, including Google, while offering extensive information resources, explicitly aid the decision process needed for preference-sensitive decision making and fully informed consent. Information provision, surveillance and monitoring, and professional or peer support to patients, do not address the fundamental question of individual patient involvement in decision making, their self-rated decision quality, or the documentation of the decision and consent processes.

2.5 Health decision literacy

We see decision aids in the wider context of general health decision literacy, this being reflected in the generic template which is the basis of our condition-specific tools. According to an 'all inclusive' definition of health literacy in an EU report (Sorensen et al. 2015) (Sørensen et al., 2012) four types of competencies are required: accessing, understanding, appraising and applying information. Access refers to the ability to seek, find and obtain health information. Understand refers to the ability to comprehend the health information that is accessed. It is a feature of this literature that health literacy is defined as possessing

... the knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life throughout the course of life (Sørensen et al. 2012, p.3)

But there is no follow-up in terms of how the judgments should be made or the decisions taken. In other words, of how the appraisal and application are to result in judgments and decisions. There is no separate concept of health *decision* literacy as the ability to use alternative ways of making decisions.

2.5 Decision quality and concordance

The importance of evaluating decision quality as opposed to ‘satisfaction with decision’ is increasingly accepted. (Institute for Healthcare Improvement 2012). However, we note that most of the existing instruments reduce to measures of the information state of the patient (Sepucha, Fowler Jr. et al. 2004; Sepucha, Levin et al. 2008; Sepucha and Mulley 2009) and/or penalise decision aids which leave the decision maker in a state of warranted equipoise, as previously mentioned. Expressed ‘satisfaction’ may mask an underlying lack of concordance between patient and professional, which is commonly found when their preferences are separately elicited and compared, as in Inflammatory Bowel Disease (IBD) (Johnson et al. 2007; Baars et al. 2010; Baars et al. 2009; Johnson et al. 2009).

To improve decision quality there is a need for decision support that embraces the multiple criteria that are relevant to the individual patient (Siegel et al. 2008; Corey A Siegel 2010; C A Siegel 2010; Siegel 2009; Baars et al. 2009; Siegel et al. 2011; Siegel 2012).

This support must respect the heterogeneity of patients as human beings, whatever their biological homogeneity. ‘There is no average patient fitting the boxes’ was expressed by the nurse during a local (Svendborg) pilot of ‘Map of Medicine’ at the rheumatoid outpatient clinic (Jakobsen; personal communication 2009). (Kolbæk 2012) addresses the next generation and two local PhDs followed (Sorknæs et al. 2011; Danbjørg et al. 2014). This trend is bringing the decision support aspects of informatics into closer focus, including nursing informatics (McCormick, K.A. et al. 2007; Matney et al. 2011; Technology Informatics Guiding Educational Reform (TIGER) 2007). ‘What Every Nurse Should Know about Computers’ was translated (‘Hvad enhver sygeplejerske bør vide om datamater’) by the Danish Council of Nurses, three years after its 1984 US publication (Walker & Schwartz 1984).

2.6 The feedback question

How could providers provide better care? The answer requires knowing both how good is their current provision, and establishing what would improve *overall* performance, since improving one sector at the expense of others would not necessarily constitute improvement.

National initiatives for quality in health and healthcare are now universal and these are increasingly accompanied by systems which elicit the views, *ex post*, of a random sample of patients concerning their satisfaction with participation in decision making and other aspects of care. In Denmark 2012 this was achieved through the Danish Quality Model’s (DQM) standards of care, with corresponding patient satisfaction survey questions. This generates hospital and department specific updates for quality development, based on input from approximately 250.000 patients annually (<http://patientoplevelser.dk> LUP: Den Landsdækkende Undersøgelse af

Patientoplevelser (The national survey of patient experiences)). The major focus is on communication, including the amount of involvement in the clinical decision making, but little is known about the relative importance a patient attaches to the questions asked, or the relation to the quality of the clinical decision making and communication process. Nor indeed whether the patient appreciated that a decision was taken or that they had given their informed consent to anyone about anything.

Hillingsø noted that

LUP is used as direction for action renders it an enormous impact on health care professionals' motivation. Because the contract is not clear, a manipulation takes place, and cream-skimming is favored by the survey, because it only examines one perspective of quality, which is patient perceived quality, whereas the rest of the criteria, concerning pathway are related to organization and structure which is attributable to the principal, and therefore is not controllable for the professionals. It is part of the accreditation process, which is regulative, and does not make professional sense in the way it is implemented, due to an excess registration, that is not evidence based.

Quality has become an institutional myth and isomorphism is prevailing due to the institutionalization of the quality improvement organization. This fact is further underlined by the lack of an efficient electronic patient paper to support registration and research. In a political environment with a lot of double communication like "remove all bureaucracy, but register everything, save but it must not affect quality", it is increasingly hard for the line leader to motivate the healthcare professionals, also due to the fact that the registration is beyond meaningfulness, and their primary motivation factors professional pride, social recognition, and autonomy are not respected through the publication of surveys and they are further subdued to control by the accreditation structure that does not make professional sense, because it is only a benchmark of perceived quality to be used politically and not a reliable instrument for quality improvement or related to treatment specific indicators. <http://studenttheses.cbs.dk/handle/10417/3120> (Hillingsø 2012)

Riisskjær et al. see patient surveys as a possible source of organisational change, conditional on their having sufficient validity, the feedback being detailed, and their having practical implications:

By involving the professionals in both the design and evaluation of these surveys, the results could be more customized to the specific needs of the relevant wards and departments, and be more accepted as organisational diagnostic data. This may increase the probability that results are transferred into changes for the good of the patients (Riisskjær et al. 2010, p.401)

This adopts the view of the health professionals and stresses the need for them to perceive the results to be useful. In terms of practicality, the viability of an online MCDA-based survey in Denmark has been demonstrated in a population with a mean age of 66 years, where the subject was alternative medications for diabetes (Henriksen 2009, personal communication) (Bøgelund et al. 2011). The research on extending routine feedback to include decision quality reflects the assumption that online surveys are a viable way forward.

2.7 Case study: Inflammatory Bowel Disease (IBD)

The proximate cause of my choice of IBD was a set of workplace professional contacts, but the condition also met another very important criteria, that of a chronic disease with major public health impact. IBD, comprising largely Crohn's Disease (CD) and Ulcerative Colitis (UC), is a source of much suffering and huge consumer of health service resources. International collaboration among 26 IBD patient organisations has in an online European survey documented wide disparities in care, treatment and quality of life effects for people with IBD. Of the (4990) respondents the majority report an overall negative impact on their life. Four of ten report IBD has prevented them from pursuing intimate relationships, and almost the same number 34% that IBD being a reason for ending one. 66% worry about the ready availability of a toilet when visiting a new place and the low general knowledge of IBD in the wider community. IBD is recognised as a public health problem in all European countries with an estimated and increasing European prevalence of 2.5-3 million, with a direct healthcare cost of 4.6-5.6 billion Euros/year (Burisch et al. 2013). The latest Danish evidence, comparing the periods 1995-1998 with 2009-2011, shows increasing incidence rates per 100.000 for Ulcerative Colitis from 14.4. to 23.2 for women and 13.8 to 23.4. for men; and for Crohn's Disease from 7.8 to 10.3 for women and 5.6.-8.9 for men (Nørgård et al. 2014). Essential validation of diagnostic IBD codes is ongoing (OPEN 2015). The European survey confirmed that many patients have concerns about their disease management, as well as the impact of the condition on many aspects of quality of life, education, work, and general well-being (Wilson, B.S. et al. 2011).

Acknowledging IBD is of unknown origin with no current cure, and involves complex interaction between genes and the environment, including smoking, nutrition, our gut microbiota (Wu et al. 2013) and is sex dependent (Bolnick et al. 2014) the European-wide EpiCom inception cohort seeks to capture the impact of an East-West gradient in IBD incidence including public health initiatives in 23 European countries (Burisch et al. 2011). This includes vaccinations and birth-delivery modes, and the extent to which IBD specialist nurses are used to elicit the attitudes and perceptions as to the quality of health care and support available. <http://www.epicom-ecco.eu/start.dll/EXEC>. The expenses for diagnostics and medical and surgical treatment during the first year after diagnosis of this inception cohort in Europe exceeded four million Euros.

An early and more aggressive treatment using biological Anti-TNF agents was noted as a trend towards a 'top-down approach', and the 'era of mucosal healing' is seen as a contributing factor. However, the inception cohort could not, due to the short follow-up, confirm previous suggestions that this would decrease the need for surgery, and Burisch could also find no benefit to early azathioprine treatment in terms of remission rates and risk of surgery in a RCT of severe CD. On this basis he suggests that some patients with IBD have a phenotype that will ultimately require surgery and that this is inevitable given the present treatment strategies (Burisch 2014).

In other words, uncertainty is rampant, in addition to clinical equipoise in many situations, each decision is highly preference-sensitive in relation to the individual, whether just diagnosed or having lived with IBD for decades. We could hardly find a more complex arena in which to explore the use of an MCDA-aid. The wider issues are effectively communicated in the daily e-newsletter videnskab.dk e.g. (Christensen 2014) including nutrition and fecal transfusion of healthy gut microbiota as promising future alternatives to the present portfolio of treatments for IBD. The media help address the general knowledge – health literacy – and can at times make true and important impact e.g. Lesley Stahl's *60 Minutes* report "Sex Matters" aired May 15, 2014 forced FDA to take action including legal response by requiring animal research should include females <http://www.cbsnews.com/news/60-minutes-helps-pave-way-for-change-at-nih-fda/> and maybe paved the way for

adopting the mixed methods approach in the Road Map <http://www.meddeviceonline.com/doc/fda-publishes-new-strategic-roadmap-emphasizes-regulatory-science-0001> and help expose when scientific misconduct takes place (Seife 2015).

The arrival of expensive innovative pharmaceutical technologies is adding to the complexity of decision making for patients and clinicians and hence, there is a well-established case for decision support. IBD specialist nurse involvement is developing internationally, including at my own hospital in Denmark, learning from institutions such as St Mark's Hospital in London.

Extensive networks are beginning to provide informational exchange and emotional support and decision aids have been developed by Healthwise and the Option Grid collaboration (<https://www.healthwise.net/cochrane/decisionaid/Content/StdDocument.aspx?DOCHWID=uf4785>) (http://www.optiongrid.org/resources/crohnsdiseasetreatments_grid.pdf). However, neither IBD specialist nurses, support networks, nor decision aids are designed to provide an opinion on major changes in disease management during the entire life course. The nurses are typically restricted to giving advice within the current medical regime. And the decision aids on offer leave the patient with the ultimate task of 'making up their mind', without being offered a personalised preference-based opinion. Or having it made up for them, by the clinician, often no doubt at their own request.

IBD is a complex arena to navigate for patients, relatives and health care professionals alike. It presents challenging complex and preference-sensitive decisions throughout the patient pathway, affecting life-style, work, and quality of life. Extensive patient involvement in decision making has long been advocated within the healthcare system. However a discrepancy between official ideals of patient involvement in decision making and actual practice in Denmark has been documented in a Health Technology Assessment by the National Board of Health (Jacobsen 2010; Jacobsen et al. 2008). New approaches are called for.

Ever-increasing cost and resource constraints have affected healthcare delivery in the chronic conditions and expanding the roles and functions of nurses is seen as a major opportunity in this regard (Younge & Norton 2007; Walker & Faan 2010; Reid et al. 2009; Bager 2014; Marín et al. 2011; Malik & Coulson 2011). It was therefore desirable to explore the involvement of nurses in the delivery of analysis-based decision support, including the use of telemedicine and mobile technologies (Kaltoft & Dowie 2010). There is considerable attention to the role of nurses as patient advocates, but no specific mention of decision making processes in a review (Barello et al. 2013) or in the Nursing European Crohn's and Colitis Organisation (NECCO) guidelines (O'Connor et al. 2013).

It is highly relevant, not least from the resource point of view, whether IBD patients would be able and willing to prepare themselves at home prior to a consultation. This has been successfully trialed in the case of health promotion in primary care using an online decision aid (personal communication, Lyndal Trevena 2011).

My case study would be focused on MCDA/Annalisa-based home decision preparation for an upcoming clinical out-patient consultation for IBD.

2.8 The resources: the bottom line

Underpinning all issues in health, and health care research decision making are costs and resourcing questions. In the context of IBD, the cost and resource implications of treating the average patient on the basis of average results has been highlighted by Baslund commenting on Bendtzen (Baslund 2010). And a review by Danish pharmacists (Rossing et al. 2009) draws attention to the impact of lack of concordance on patient safety and cost issues, including overmedication. Supply induces demand (Bech 2010). The PhD thesis by Burisch reporting on the Epi-Com inception cohort includes material on IBD costs in Denmark (Burisch 2014).

Incorporating costs in an MCDA is possible, but this thesis is not concerned with the costs or cost-effectiveness of the interventions it develops and seeks to implement. The clash between the individual preference-sensitive effectiveness mandated by person-centred care and cost-effectiveness at a community level is not easily addressed. What is clear is that any assessment of the cost-effectiveness of decision support will be crucially dependent on the metrics used for costs and effectiveness. A major issue arising from our work is whether decision quality should be treated as a Patient-Reported Outcome Measure (PROM), measured at the point of decision, because the decision is the outcome of a decision making process. Or whether decision quality also should include reference to the downstream consequences of the decision taken.

Any concern with resources and costs as fundamental drivers needs to remember that these also include the incomes of stakeholders. Material interests are a major feature of professional life, as well as other occupations. Proposed changes to the way of doing things may threaten the human capital built up and embedded in the structures of the status quo. Difficulties of 'walking the talk' in relation to improving care provision have long been a feature of the healthcare landscape and their frequent attribution to 'communication problems' masks a reluctance to question the bases of the difficulties in the existing arrangements in incentive and reward structures for professional individuals and groups. More efficient and effective ways of doing things from one perspective may represent painful disruption to the lives and incomes from another. MCDA is particularly prone to exposing the existence of hidden criteria and trade-offs. While this thesis does not engage with these issues in any direct way it is important to establish that the research was critically influenced by the way MCDA represents a challenge to the existing way of doing things, even if it was not initially appreciated as being a 'paradigmatic' challenge.

Against these various backgrounds the objectives of the research and the methods to be adopted were established. They are outlined in the following chapter 3.0.

3.0 Objectives and Methods

While the overall goal was enhanced decision quality and health decision literacy at a generic level, the research would need to be carried out in a specific context, albeit with generalisable potential. Workplace professional contacts led to the case of Inflammatory Bowel Disease (IBD), comprising largely Crohn's Disease (CD) and Ulcerative Colitis (UC).

IBD has been established in the previous background chapter as a major source of patient suffering and huge consumer of health service resources. All sources confirmed that there is major anxiety and distress among patients about their disease management, through the impact of the treatments, as well as the condition, on their quality of life. We have already noted the existence of efforts to respond to these needs in the form of decision support tools, mostly for use in the shared decision making context. However, where they did exist and were in clinical use, these aids were not developed within the MCDA approach outlined earlier.

3.1 Aims and Objectives

An increasing number of aids are being developed for patients that are increasingly suspected of simply inducing 'information overload' in the absence of the decision support needed to make sense of the information at the point of decision.

The related set of problems I sought to address were: to ensure that the multiple considerations patients regard as relevant to their current decision are dealt with, and documented, fully and transparently, in a way that increases the quality of the decision from their point of view; that their self-ratings of decision quality become part of the clinical process; that the requirements of 'perfected' informed consent are met; and that the degree of non-concordance, if any, between patient and professional is established and explored.

The primary aim of this study is to investigate the feasibility and practicality of online home preparation designed to improve the quality of a decision arrived at in a forthcoming clinical consultation using interactive decision support based on Multi-Criteria Decision Analysis (MCDA). The users are out-patients with IBD (Crohn's Disease and Ulcerative Colitis) considering a change in disease management. One secondary aim is to assess the acceptability to patients and clinicians of the decision support. Another secondary aim is to explore the effect of the intervention on the MyDecisionQuality (MDQ) instrument's score. A third secondary aim is to explore the concordance between clinician and patient when the clinician is able and willing to complete the clinician version of MDQ.

The original objectives were:

1. After completion of the necessary generic template, to deliver and explore an IBD-specific online decision support tool, based on MCDA, that would help patients prepare for an upcoming consultation with a gastroenterologist/colorectal surgeon located in (a) an out-practice setting in London (multi-disciplinary team, including IBD specialist nurses) and (b) in Sydney (two independent consultants with hospital appointments).

2. To develop and assess a generic instrument to measure decision quality in a dually-personalised way, that is one in which the index score reflects the quality criterion weights of the individual concerned as well as their ratings of a decision based on those criteria; and use this in the assessment of the IBD aid.
3. To pilot the decision quality instrument via an online survey in a Danish population to establish its feasibility as a component of the national patient experience survey (LUP); and to use the Satisfaction with Decision instrument to explore the relationship between satisfaction and the quality of decisions so measured.

Ambitiously, the proposed study would have a substantial international dimension in order to gain insights into the ways in which attainment of the objectives might be affected by national and cultural differences, organisational, and professional. It would benefit from the synergistic collaboration between the three clinical IBD settings (London, Sydney, OUH Svendborg/Nyborg) made possible by their participation in the project. Denmark could, in the future, bring to this collaboration its well-established informatics structure, including the CPR-numbers that facilitate long-term follow-up and the potential for patient-to-patient support networks via e.g. OPEN http://www.sdu.dk/en/om_sdu/institutter_centre/klinisk_institut/forskning/forskningsenheder/open and www.sundhed.dk. (OUH Operational Excellence and IT 2013). It was not possible to pursue objectives 1 and 2 in Denmark, the necessity to develop the IBD condition-specific aid in English being the trumping consideration. The MCDA-based software was available via my affiliation to SSPH and project supervisor Jack Dowie (JD) who was joint software developer.

The objectives would be pursued while avoiding the danger, latent in many aids being developed for patients, of inducing 'information overload' without offering of the decision support needed to make effective use of the information at the point of decision. Additionally, there was full awareness that the research objectives should not jeopardise the care of the patient or their relationship with their health care clinicians. In each setting this was ensured by the Principal Investigator (PI) of the study. Given the complexity of the tasks involved, the original objectives were consciously formulated within an action research approach. Action research accepts the challenge of change (Bradbury-Huang 2010; Titchen & McCormack 2010; McLean et al. 2013; Cresswell et al. 2007) and acknowledges that not only may one need to modify the strategies to achieve the original research objectives in their pursuit, but also that the original objectives may require transformation as a result of the unfolding research experience.

3.2 Methods

A mix of quantitative and qualitative methods would be essential in the pursuit of all three objectives (Mayoh et al. 2012; Dibley et al. 2010; Norton et al. 2013; Dibley et al. 2014; Malterud 2001; Norton & Dibley 2013). Patients engaging with the IBD aid (including MDQ) - to be introduced in later chapters - would generate a very large downloadable csv spreadsheet file, containing not only details of their responses within the aid, but also much process ('web-log') data, such as the time they spent on particular pages within the program (Joseph-Williams et al. 2010) and the links they clicked on. Descriptive statistics, broken down by characteristics, would be the main output, accompanied by such correlation and regression analyses as justifiable, given the respondent numbers successfully recruited, completing, and submitting. The online decision support program would also ask for written feedback in the form of both closed and open questions on the aid experience and various aspects of the process, both conceptual and technical. These would be supplemented by interviews with patients who agreed to be taped, either in person, or by phone or Skype. The resulting tapes would be transcribed and analysed by methods for qualitative data (Malterud 1996), notably pragmatic thematic analysis (Norton & Dibley 2013).

There would be concurrent fieldwork at St. Mark’s Hospital in London (involving IBD specialist nurses operating a telephone advice-line), and at Royal Prince Alfred Hospital in Sydney (private consultants attached to the hospital). In London the clinician would open the aid, as completed by the patient at home, at the start of the consultation. In Sydney the consultant would access the home-prepared opinion of the aid after a normal consultation with the patient - as a second opinion. Following initial identification of potential participants by the clinician’s invitation to participate would be by letter from the consultant, noting that the researcher would be the point of contact regarding the aid from the point of provisional acceptance. Consent would be given online on an opt-in basis after provision of a unique ID and password, known only to the researcher (and, later, for relevant parts of the elicitation program, to the clinician who was the P.I. for each of the respective studies).

The studies would be funded by Danish resources, and would use the Annalisa and Elicia software courtesy of the Sydney University School of Public Health. The development of the IBD aid would be carried out in conjunction with my project supervisor and where appropriate with the clinicians concerned. Maldaba® the software developers, would assist where needed. They were continually enhancing the software throughout the thesis period. The findings would feed into a protocol for a study of home-based support in a Danish context. The context-specific studies would require ethics approval in the UK in the case of the IBD aid but not in Denmark in the case of the anonymous MDQ-focused survey. Agreement to the storage of all data from the studies, behind the University of Sydney server firewall was essential to using the software. The Helsinki Declaration was adhered to throughout.

To ensure that the account of the research methods adopted from the start is clear and relevant it is important to clarify my responsibilities within the wider team working on MCDA/Annalisa-based projects. This necessitates establishing the relationship between the various components of the decision support tool and the software platform in a more detailed way than has been provided thus far. The overall tool uses the generic MyDecisionSuite (MDS) program layout reproduced below (Figure 6).

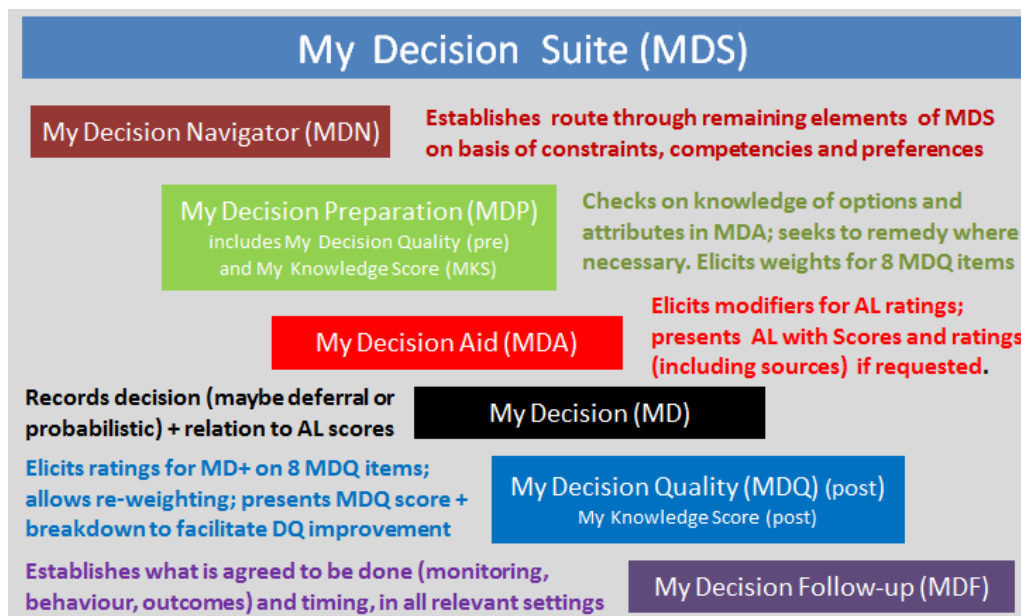


Figure 6 MyDecisionSuite (MDS)

MyDecisionSuite (MDS) is implemented within the Elicia survey software. At the heart of MDS is the condition-specific decision aid itself built within the generic template provided by the Annalisa software. The Annalisa aid is embedded in the Elicia program through a bespoke API (Application Program Interface).

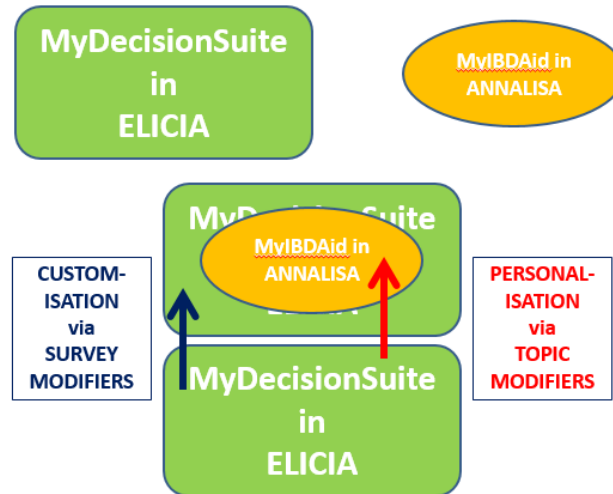


Figure 7: Relationship between the Annalisa and Elicia software components

Each patient has an individualised experience as a result of the *customisation* and *personalisation* functions offered by the Annalisa-in-Elicia software package. As pictured in Figure 7, the items (questions, text, Annalisa/s) the individual patient encounters in progressing through MDS are *customised* on the basis of the responses to questions entered by either themselves or the clinician. The customisation occurs by rules that are referred to as Survey Modifiers. For example, if the patient says they are in remission or in a mild disease state, all the items from the IBD aid (designed for those in moderate or severe state) are disabled and do not appear. If they say they are currently experiencing moderate Crohn's Disease and are on a thiopurine medication, they see only the Annalisa/s relevant to that combination. If they are not referred for surgery, the section of the program relating to a surgical consultation is disabled.

Quite separately, the programme takes the responses to questions such as these and *personalises* the options and performance ratings in those Annalisa/s which the individual patient sees after customisation. The personalisation occurs by rules that are referred to as Topic Modifiers.

It is now possible to clarify my precise responsibilities in relation to the objectives of the IBD and associated projects. As a member of the Sydney team I contributed substantially to the later stages of the development of the generic Annalisa-in-Elicia template. I was jointly responsible for the design of the generic MDS layout to be used for condition-specific aids, such as the one for IBD. And I was jointly responsible for the decision quality instrument (MDQ) which is a key component of MDS.

While I took a close and supportive interest in the process, I had no formal responsibility for the embedded Annalisa IBD model in terms of its structure (options and criteria), or for eliciting the performance ratings for the options on the criteria. These tasks were the responsibility of my project supervisor Jack Dowie (JD) and the

collaborating clinicians. I was mainly responsible, in collaboration with JD and the clinicians concerned in both London and Sydney, in developing the IBD implementation of the MDS program with which the patients would engage. This included ensuring, by intense iterative testing and checking, that it functioned technically correctly in terms of customisation and personalisation, as well as communicating well with the participants in their online situation. It also included the development of videos with the clinicians for inclusion in the MDS program.

Finally, I was responsible for all the procedures and arrangements for piloting the aid in the two clinical settings, including seeking ethics approval [London: Ethics Committee (EC) No.:12/LO/0152. Sydney: Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. Protocol number X12-0287]

It is important to note that it was established from the beginning that, while often onsite, much of my involvement would also be at a distance, and that this was appropriate insofar as it was important that the aid delivery was tested in the actual clinical situation, not one artificially enhanced by my constant presence as an additional resource. The online nature of the aid made this a realistic option, though difference in the time zones between Sydney and Europe did cause some problems.

In relation to the piloting of the Danish survey to explore the feasibility of incorporating MDQ into a routine feedback instrument such as LUP (Christensen & Engel 2014), I was responsible for all aspects, including the Danish translation and the arrangements for its dissemination. The RSD Scientific Ethics Committee confirmed that a Danish survey without biological data does not require ethics approval. A query was sent to those locally responsible at OUH as to whether registering to the Danish Data Protection Agency was required. I was assured that anonymous surveys are exempt. I included an open text field for comments or e-mail address if interested and willing to take part in future studies. While no IP address was accessible, it was therefore possible to enter person-identifiable data if the respondent wished. Accordingly, I filled out the project description and layman report and the study was registered and approved prior to its start (Umbrella permission 2008-58-0035 health science research RSD (Sundhedsvidenskabelig forskning i Region Syddanmark)). (The Danish Council of Ethics/Det Ethiske Råd 2015).

A mix of methods, as outlined earlier, would be employed in relation to the results, although in this case quantitative analyses of the downloaded survey results would predominate.

4.0 Results, Findings, and Outputs

The following series of subchapters report on the outcomes from my research. Subchapter 4.1 presents the framework and technique underpinning the developmental work reported in 4.2 and 4.3, the empirical work on implementation reported in 4.4 and 4.5, and the resulting reconceptualisations introduced in 4.6 and 4.7. While chronologically the published paper on which 4.1 draws, and reports, was written after the developmental work, it is placed first in order to provide the reader with an accessible introduction to the topic, as was offered to a specific health professional audience.

Five of the subchapters draw extensively on the relevant included paper, and the reader is referred to that paper for further details and elaboration of the argument.

4.1 The framework and technique

I: Nursing Informatics & Nursing Ethics: addressing their disconnect through an enhanced TIGER vision

Coming from a nursing and health visiting background the most novel and striking feature of Multi-Criteria Decision Analysis (MCDA) was its insistence on a complete separation of the assessment of how well options performed on relevant criteria from the weighting of those criteria, these processes preceding their being brought together in a decision. It became clear during production of our review for a mini-HTA on Handhelds for Nurses (Kaltoft & Dowie 2010) that most academic nursing concentrated on either the informatics aspects of nursing, or the role of values and preferences considered from an ethical point of view. This prompted a simple search on Medline and Cinahl (from 2000). It returned hundreds of hits for 'nursing informatics' and 'nursing ethics' individually, but combining the searches with an 'AND' returned zero results. Some of the papers with 'nursing ethics' as title/ abstract keyword addressed 'informatics issues' from the ethical perspective and some with 'nursing informatics' addressed 'ethical issues' from the informatics perspective. But few, if any, focused on the decision itself, since both fields clearly saw themselves as providing decision *support*, by way of information inputs and ethical insights respectively. Each of the distinct communities had reasons – ideological, professional, institutional - for maintaining this *supportive* construction of their function, but it could be seen as a significant source of the disconnect between them, including within multi-disciplinary teams, since both are held back from fully engaging in the point-of- (care)-decision (American Medical Informatics Association 2008).

Given the increased pressure for the translation of 'evidence-based' research findings into 'ethically-sound', 'values-based', and 'patient-centered' practice, this disconnect was of concern. It suggested the need for rethinking of the model implicit in conventional knowledge translation, informatics practice and ethical training in nursing and indeed all health professional disciplines (McCormick, K.A. et al. 2007). MCDA could contribute to this revised model of how evidence and values could be better integrated in transparent patient/ person-centred decision making. This proposition constitutes the 'red thread' linking this and all the subsequent subchapters.

4.1.1 Decision technologies and their location

Judemakia (Figure 8), a metaphorical map of the world of judgment and decision making, can help us understand the nature and magnitude of the task of making decisions, and hence to both identify and meet the challenges of connecting ethics and informatics in a transparent and coherent way (Dowie 2013).

Judemakia has two bases, one longitudinal and one latitudinal. The longitudinal base reflects the assumption that decisions (which are always taken in the central Decision-land) require inputs from the two distinct flanking and supporting provinces of Belief-land (where we address the question the probability of something, such as an adverse event, happening) and Preference-land (where we address and assess the question of the desirability of something, such as the adverse event). (Its underlying Bayesian philosophy (Dowie 2006) leads to the use of the terms ‘beliefs’ rather than ‘knowledge’ or ‘evidence’ and ‘preferences’ rather than ‘values’.)

Hammond’s Cognitive Continuum Theory suggests that a variety of possible balances between intuition/fast thinking and analysis/slow thinking exist in relation to any judgment and decision making task (Hammond 1996b). Applying that idea in all three ‘lands’ creates a set of regions within which one can locate various activities and methodologies on the basis of their analysis-to intuition ratio. For example, these range from Gutland to Labland in Belief-land. The map is the result of a prolonged search for a way of communicating the intrinsic complexities of decision making at different levels, and depicting the multiple locations relevant in an increasingly multi-cultural clinical landscape. (Figure 8 is reproduced with permission of Dowie)

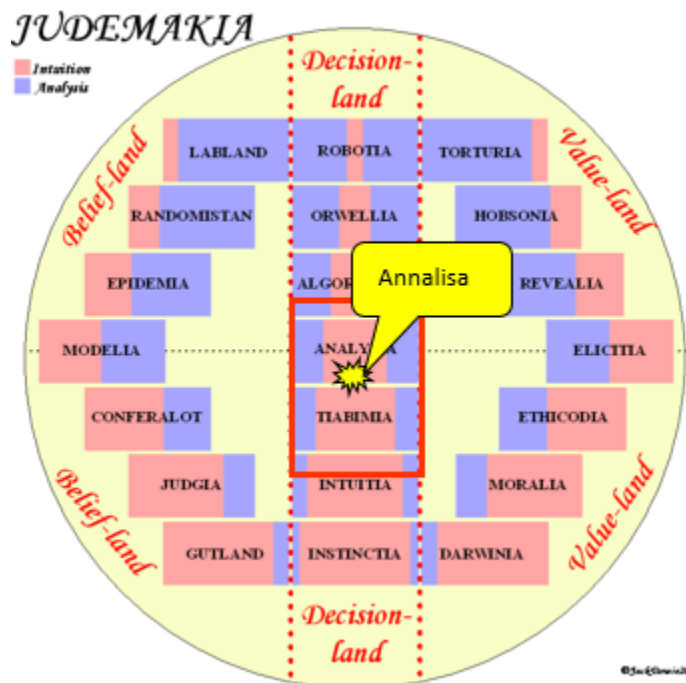


Figure 8: Judemakia showing location of Annalisa program. (Available at <http://bit.ly/judemakiatext>)

The synthesis and integration of the evidence/judgements and values/preferences relevant to a decision can be carried out in three main ways, as well as in various combinations of the three. One, in Intuitia, is *clinical or professional judgment*. The second (in Tiabimia (Taking Into Account and Bearing in Mind) is currently the dominant form, and takes the form of verbal argumentation or deliberative discourse that processes the benefits and harms (the ‘pros and cons’) to arrive at a conclusion, most often in a social or interpersonal setting. It is useful to characterise this way of making decisions as ‘*verbal multi-criteria decision deliberation*’, since then it can be clearly differentiated from the third method, *numerical multi-criteria decision analysis*, which arrives at a conclusion through calculation, albeit one based on extensive deliberation about the inputs, often qualitative in

nature. The use of ‘verbal’ and ‘numerical’ reflects the fact that both are necessarily concerned with magnitudes and in this sense both are quantitative. Words matter, numbers count.

4.1.2 Connecting informatics and ethics

We can now see that the problem of connecting informatics and ethics requires two things: (i) focusing on the decision in Decision-land and (ii) ensuring that the essential informatics inputs from Belief-land and ethical insights from Prefer-land enter Decision-land in a way that enables them to be synthesised transparently and coherently. At the moment, this is being done in the ‘Taking into account and bearing in mind’ decision technology of deliberative discourse, in Tiabimia. Whatever its advantages, this location perpetuates the disconnect since the informatics inputs are coming from different and (at least normatively) much higher analysis-to-intuition ratios than the ethical ones. Attempts to address the disconnect exclusively in Tiabimia seem unlikely to achieve the necessary synthesis with desirable transparency. Thus the portfolio of competencies of the health professional and inter-professional team needs to be extended ‘north’ to include a technique like Multi-Criteria Decision Analysis (MCDA), located at the equatorial balance of intuition and analysis. The map (Figure 8) shows the location of the Annalisa implementation of MCDA, in Analysisia but as close to the border with Tiabimia as possible.

In order to communicate the central idea of MCDA to health professional audiences unfamiliar with it, we use the sandwich as a metaphor (Figure 9). By combining the bread (the evidence) with the filling (the preferences) one produces the sandwich, or decision. One does not have a sandwich (decision) without both. The clear implication from this construction is the need for a prime focus on the sandwich-making/decision making process with the supportive/input supplying activities operating in a way that is decision-driven (What should we do?) not only-evidence driven (What do we believe?) or value-driven (What do we prefer?). It follows that we need a ‘*decisionics*’ discipline to complement the *informatics* discipline and a transformation (or expansion) of the ethics discipline into a ‘*valuematics*’ one, in order to ensure that the resulting decision is of high quality. A high quality decision would be transparent, as well as logically *coherent* and empirically accurate (‘*correspondent*’) in relation to both beliefs and preferences (Hammond 1996a; Hammond 1996b).

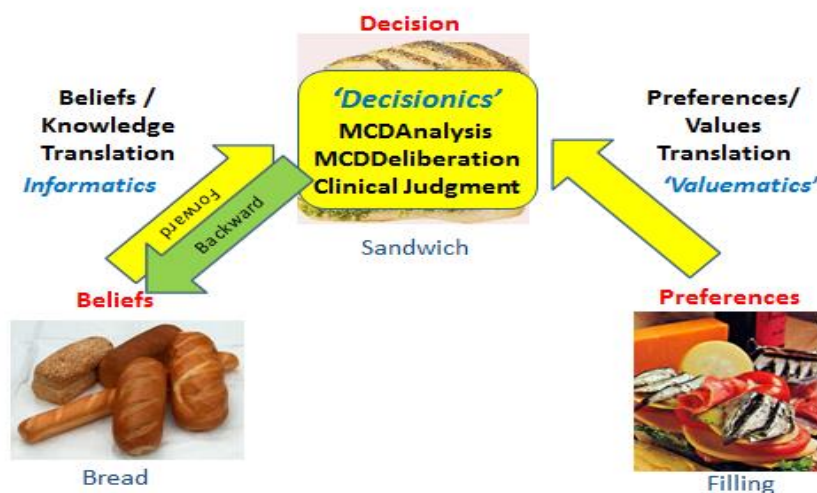


Figure 9: Sandwich as a metaphor for a decision

It is indicative of the considerable resistance to increasing the analytical content of decision support and decision making that a recent essay (De Vries et al. 2013) suggests only intuition and deliberation need to be considered. They survey the strengths and weaknesses of these two, without considering an analytic technique such as MCDA as a candidate for ‘decisionics’.

4.1.3 An example: the disclosure dilemma

The power of MCDA lies in the way health professionals, either individually or as part of a care team, are required to assess the impact of the options on the criteria (produce their performance ratings) separately from assessing the relative importance of the criteria (their importance weightings), and then explore the effect of both - and variations in them - on the desirability of each option.

We find an effective illustration of the way MCDA can help in addressing both the informatics and ethics communities, is provided by the decision faced by most health professionals deciding how to respond to questions of parents or other caregivers concerning the prognosis for a child or increasingly ill and demented relative. In the hypothetical example the prognosis is known to be very poor. The specific details of any such case will vary enormously and its framing will always be influential, but a number of ethical principles are always in play - beneficence, non-maleficence, justice, autonomy, veracity, and confidentiality, to name the six used by (Page 2012) adding the last two to the traditional four (Dowie 1994).

Given its numerical inputs and calculation requirements the implementation of an MCDA-based approach will normally require computer-based implementation, preferably online. (See 4.2 for the development of the template used in our research.)

To keep the example simple, the options are limited to two: disclose the prognosis fully, or in some way deny possessing significant information about it. Using purely *hypothetical* ratings and weightings, some combinations may favour ‘denial’ (Figure 10), some ‘disclosure’ (Figure 11). (The figures are screen captures from the Annalisa implementation of MCDA. A video link in the included Paper I shows the example ‘live’. Fuller details as how the scores are calculated appears in the following subchapter 4.2 (Paper II).

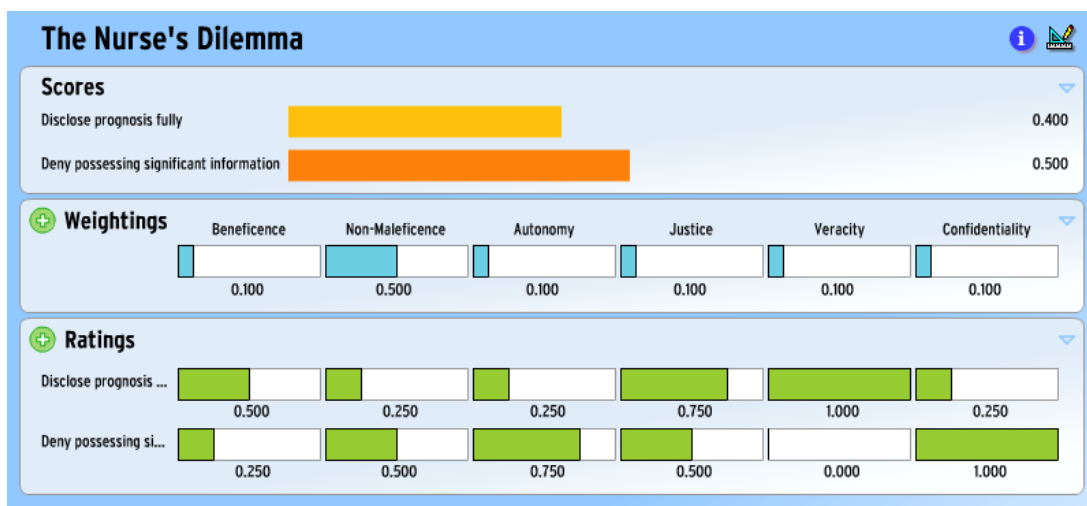


Figure 10: Annalisa screen with ‘Deny possessing significant information’ favoured

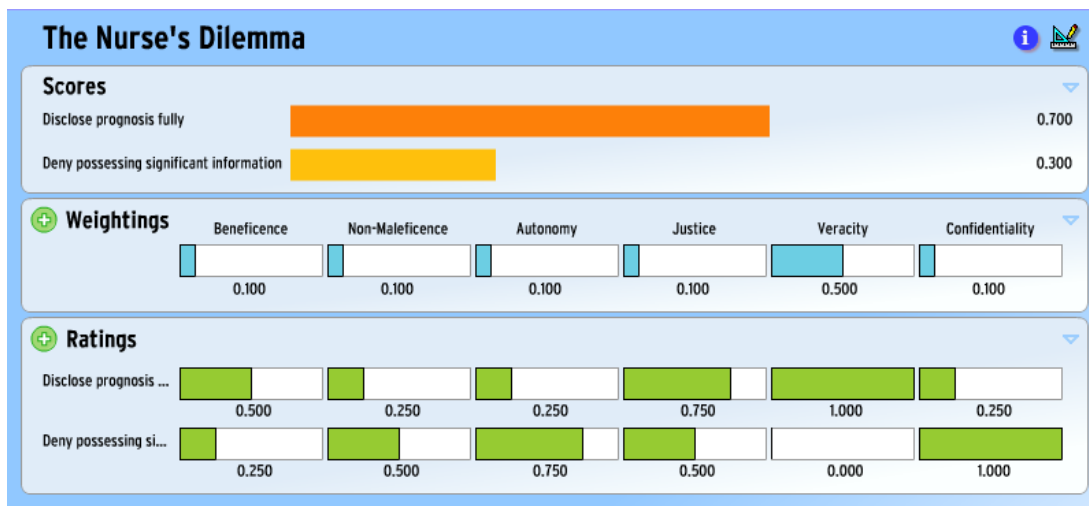


Figure 11: Annalisa screen with 'Disclose prognosis fully' favoured

An MCDA-based aid cannot simply be thrown into an existing decision process. A framework for evaluating and documenting the decision process, as well as aiding it, is needed and this is the aim of the MyDecisionSuite template (Figure 6). It comprises a set of elements that provide navigation and preparation segments - the latter providing the opportunity for a variety of multimedia links- before the aid, and decision quality assessment and follow-up elements after it. The framework is adaptable to any specific set of organisational circumstances, healthcare provider arrangements, and patient's preferences regarding decision style.

4.1.4 Implications for training and practice

Knowledge of Cognitive Continuum Theory has been found highly relevant to understanding the decision making tasks and processes of nurses in the clinical environment (Cader et al. 2005; Bucknall 2003). But this still leaves most of the decision making challenge remaining since 'decisionics' focuses specifically on the Point of Decision rather than on knowledge translation (synthesising, exchanging, disseminating) mechanisms on the one hand, and ethical discourses on the other, each of which acts to *support* the decision process. Practice curriculum and resources such as TIGER's Virtual Learning Environment (VLE) (Technology Informatics Guiding Educational Reform (TIGER) 2007; American Medical Informatics Association 2008), will need to introduce the three main 'decision technologies' – (clinical) judgment, multi-criteria decision deliberation, and multi-criteria decision analysis – as essential components of the professional's competency portfolio. They vary significantly in their intuition-analysis balance and all three should be available for deployment, depending on the decision setting and task structure.

A shared 'decisionics' framework and language with common grammar and vocabulary, can enhance the performance of multidisciplinary health professional teams, since each individual participant, provider or user, can make an optimal input to, and have optimal impact on, the decision, including giving 'voice' to frequently speechless users such as many patients. Being online, MCDA-based aids can also include those who cannot attend due to distance by providing access in their own home setting. For those who can express themselves only via trained computers e.g. if they have speech difficulties such as aphasia, this offers an excellent solution. The 'medical home' provides a possible setting (Berwick 2009). Alternatively they can be seen, to anticipate sub-chapters 4.6 and 4.7, as part of a process which 'flips healthcare' (Bisognano & Schummers 2014).

Again it is important to stress that MCDA/Annalisa approaches are not seen as a panacea, but simply as adding to the portfolio of available techniques to deal with the inevitable dilemmas in health and care. For example, when focus groups – physicians and nurses - are discussing hypothetical cases (Holm et al. 1996), when pre-graduate nurses are training for future inter-disciplinary teamwork (Pollard et al. 2012), perhaps exploring the forces of creativity via Edward de Bono’s 6 thinking hats (Kenny 2003). Or when moral judgments are discussed on the basis of religious beliefs (Shariff et al. 2014), and the importance of meta-ethical beliefs for understanding individual differences are highlighted (Piazza & Landy 2013).

Having established the framework and basic case for developing MCDA-based decision support we proceed in the following two sub-chapters to elaborate on the developmental work undertaken.

4.2 Developing a decision aid template within the MCDA technique

II: Towards generic online multicriteria decision support in patient-centred health care

This subchapter reports on the template within which the IBD aid was constructed, knowledge of which is essential to understanding the theoretical and technical bases of that aid, and its practical application in the research reported in succeeding subchapters. It draws on the included Paper II, which supplies additional detail.

We begin by briefly rehearsing the case for adding MCDA-based decision support to the existing body of tools, usually based on some form of what we have called Multi-Criteria Decision Deliberation (MCDD). (See the taxonomy of clinical decision technologies Figure 5).

The explicit aim in MCDA, and in fact of any version of decision analysis, including its cost-effectiveness and cost-utility forms, is to arrive at a result – an *opinion* is our preferred term – by analytical calculation on the basis of numerical judgments (Belton & Stewart 2002). The process of arriving at those numerical judgements does almost always involve extensive verbal, non-numerical elements and hence deliberation, in the same way that the second major type of decision technology, deliberative discourse or MCDD, must always contain judgments of magnitudes, including some expressed numerically. Deliberation, however, is an interpersonal process where the provenance of the emerging conclusion inheres in the social process adopted and the arguments of the participants involved in it (Witt et al. 2014; Elwyn et al. 2010). Unless the deliberation is structured as an MCDA (Proctor & Drechsler 2006) the conclusion cannot be detached from the process and presented in the form of a graphic summary, or equation, or set of numerical option scores. For these reasons we do not find ‘Verbal Decision-Analysis’ appealing (Larichev & Brown 2000).

It might be asked why the distinction is expressed as a ‘verbal/numerical’ contrast, rather than a ‘qualitative/quantitative’ one. This is because MCDD is replete with the quantification of magnitudes. This quantification is simply done in predominantly verbal ways. This applies in relation to the performance magnitude judgements, for example, of the extent to which different medications reducing the probability of pain, where terms such as ‘low probability’, ‘low risk’, ‘good chance’, and ‘very likely’ are used to characterize the probabilities of the criterion being met for this patient. It also applies to the relative importance judgements, for example of the importance of pain reduction relative to medication side effects, where again a variety of terms such as ‘paramount’, ‘trivial’ and ‘major’- or simply ‘very important’ and ‘not very important’ - are deployed.

In MCDA both types of inputs, coming from opposite sides of Judemakia, need to be mapped on to a numerical 0-1 ratio scale (0% to 100%), in order that their integration into an opinion on the same scale can be carried out. It is important to note that the use of this numerical scale does not *per se* imply any particular level of precision. Numbers however give greater clarity and thus provide and enhance cross-disciplinary/cultural communication.

We see the analysis-based prescriptive approach embodied in MCDA as having one compelling advantage in the provision of patient/person-centred care and genuinely shared decision making. In its multi-criteria form, decision analysis provides a generic approach to all decisions, that is, it is not condition-specific and does not require expertise in reasoning or knowledge in the particular area (e.g. a disease) of the sort needed to follow and share expertise-based prescriptions. As long as expertise-based prescription is the basis of the clinical encounter, serious patient involvement and empowerment will be a very difficult and demanding task. An MCDA-based

approach, on the other hand, allows the person/patient to input their preferences as importance weights for criteria in a straightforward manner and to have them transparently combined with the published evidence and the clinician’s ratings expertise.

4.2.1 The target: a practical generic MCDA template

The challenge in the research was not to defend MCDA as a possible basis for a decision aid, though it remains controversial because of its prescriptive grounding in normative decision theory, but to develop an implementation which would give it practical potential as a decision support system in any setting at any time.

This subchapter accordingly reports on the particular software template, Annalisa developed as a practical and person-centred implementation of MCDA. It is suitable for use not only at the individual level, such as in a clinical consultation, but also in the community, in relation to the formation of policies on such things as screening and drug reimbursement. It is a ‘one screen fits all - and fits all’ template, in that the complete decision can be visualised on one screen, and generic in that it can cope with any decision in any setting. It offers the common decisional 'vocabulary' and 'grammar' necessary to overcome the communication problems produced by disciplinary and silo-specific languages, doing so at the equatorial balance of intuition and analysis in the map of Judemakia (See Figure 8).

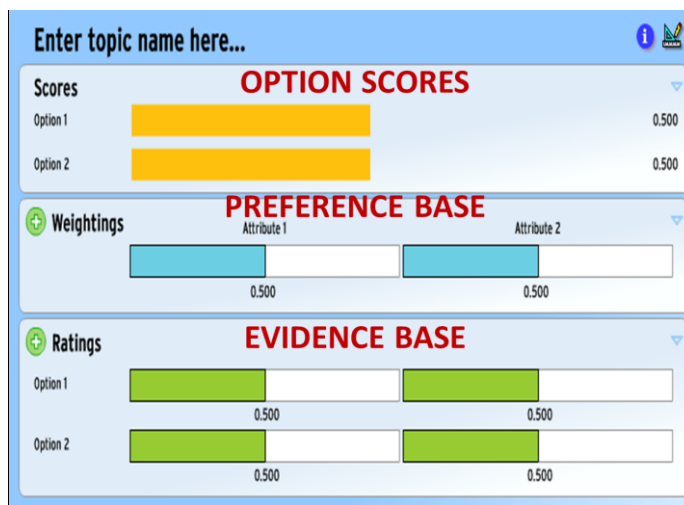


Figure 12: The one-screen generic Annalisa template with default settings

The template has panels for Scores (Option Scores), Weightings (Preference Base) and Ratings (Evidence Base).

In the illustration of a generic health care application (Figure 13) there are three options (Medication, Surgery, and Lifestyle Changes) and three criteria (Maximise Length – and Quality of life, and Minimise Treatment Burden). Tools developed in the template should combine the Best Estimates Available Now (metaphorically and acronymically the BEANs) for each option on each attribute/criteria (entered in the Ratings panel) with the user’s own values and preferences (entered as importance weights for the criteria in the Weightings panel). The user can indicate the relative importance or weight they wish to attach to each criterion or attribute by dragging the cursor on each bar to the left (lower weight) or to the right (greater weight). The top panel Scores are the

summed multiplication of ratings by weighting, and indicate the opinion from the aid as to which option is best for the user, *given the two sets of inputs*. Again, as with the previous examples, the numbers are all hypothetical.

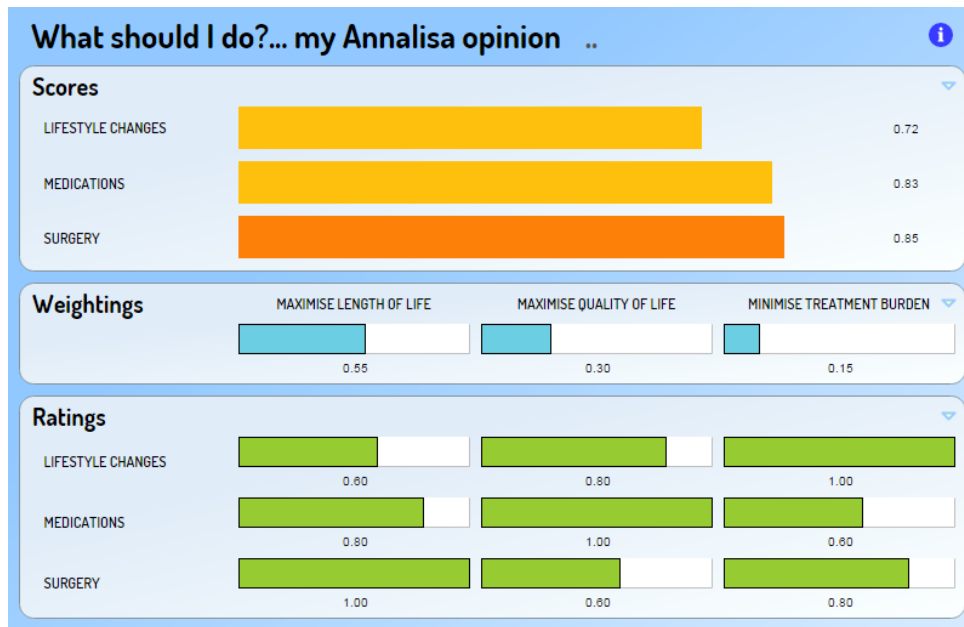


Figure13: A generic application of the Annalisa template: ‘What should I do?’ in a healthcare context

Annalisa adopts the simplest and most colloquially familiar form of MCDA. In the decision matrix ‘weighted-sum’ approach, all attributes exist at the same level (there is no hierarchy of criteria and sub-criteria); the performance of each option is directly rated on each attribute; the importance of each attribute is directly weighted in relation to that of all the other attributes; and the option Scores are calculated by summing an option’s ratings on the attributes multiplied by the attribute weightings. In other words, Annalisa deliberately implements the simplest, compensatory ‘weighted-sum’ version of the MCDA technique, and so is not at all innovatory as a decision model. It is, in essential respects, an enhanced interface for any SMART (Simple Multi-Attribute Rating Technique)-type decision matrix (Velasquez & Hester 2013). Such decision matrices can easily be developed in a spreadsheet, but Annalisa provides enhanced interactive online capability by way of the numerous customizing and personalizing functionalities provided in the survey program Elicia, into which an MCDA/Annalisa file itself is embedded when it functions online.(Figure 7).

Paradoxically it is the failure of Annalisa to provide alternative and/or more sophisticated and complex methods for key tasks, including those for determining the criteria and eliciting weights that we regard as a positive virtue. It thereby generates the potential for much wider use, offering a different trade-off between scientific rigour and operational practicality from the alternatives, notably the Analytic Hierarchy Process (AHP) (Dolan, G.J., 2010; Dolan, Boohaker, Allison, & Imperiale, 2013b; van Til et al., 2008) and the Evidence and Value: Impact on Decision Making (EVIDEM) framework (Goetghebeur et al. 2008; Tony et al. 2011). The recent growth of product comparison websites and recommender systems within e-commerce (Laffey & Gandy 2009; Tsafarakis et al. 2010; Manouselis & Costopoulou 2007; Venkatesh et al. 2003) is a clear sign that multi-criteria analysis is accessible to large sections of the population, but only at an appropriate level of complexity.

To anticipate, in subchapters 4.6 and 4.7 we suggest how this existing form of decision literacy can be exploited to overcome some of the obstacles associated with low functional literacy.

4.2.2 The key principles

Annalisa is designed to embody a set of practical principles:

1. It should be possible to undertake an analysis within a very short time, such as the 5–10 min often available in time/resource-pressured situations, to ensure that the possible benefits of even a modicum of ‘slow thinking’ should not be lost (Kahneman 2012). This is in no way intended to prevent weeks or months being devoted to generating the detailed structure and performance rating inputs, if the time and other resources are available.
2. Irrespective of the time available at the point of decision (and therefore including 5–10 min), the decision owner should ideally not be asked to make the necessary trade-offs among more than 7 (plus or minus 2) criteria (Miller 1956; Higgins & Green 2011). Annalisa can display a maximum of 10 criteria.
3. All the elements of the decision (preferences and evidence) and the outcome (best option) should be simultaneously visible on the screen, providing a complete picture of all elements of the decision, with the effects of varying any weighting or rating dynamically visible in real time. It must be possible to close the Scores screen while any such changes are being made so that the possibility of gaming to make a pre-preferred option the winner is minimised.
4. Pop-ups on the screen should provide access to additional information, especially the provenance of the option performance ratings (including external links where appropriate); as with the rest of a MyDecisionSuite (MDS) formatted aid most information should be provided on an opt-in basis in order to avoid overload problems.

4.2.3 The visual picture provided by a completed Annalisa

An illustrative example of a completed Annalisa screen is provided in Figures 14 and 15. These might be seen as either those for two different patients, or those of the same patient at two points of time (where Figure 14 is produced at Time 1 and Figure 15 is produced at the next encounter i.e. Time 2). In the ratings panel of both instances, we can see that new treatment is better at maximizing the main effect benefit than current treatment (0.70 vs. 0.50), is better at minimizing the treatment burden than the current treatment (0.80 vs. 0.70), but is worse at minimizing side effects (0.20 vs. 0.50). (Longer bars mean the particular option does better in the sense of achieving a higher score.) The two are equally good in relation to minimizing adverse event (both 0.90). Given the relative weightings of the four attributes in Figure 14, new treatment emerges with the highest score in a simple expected value calculation, as provided below the figure.

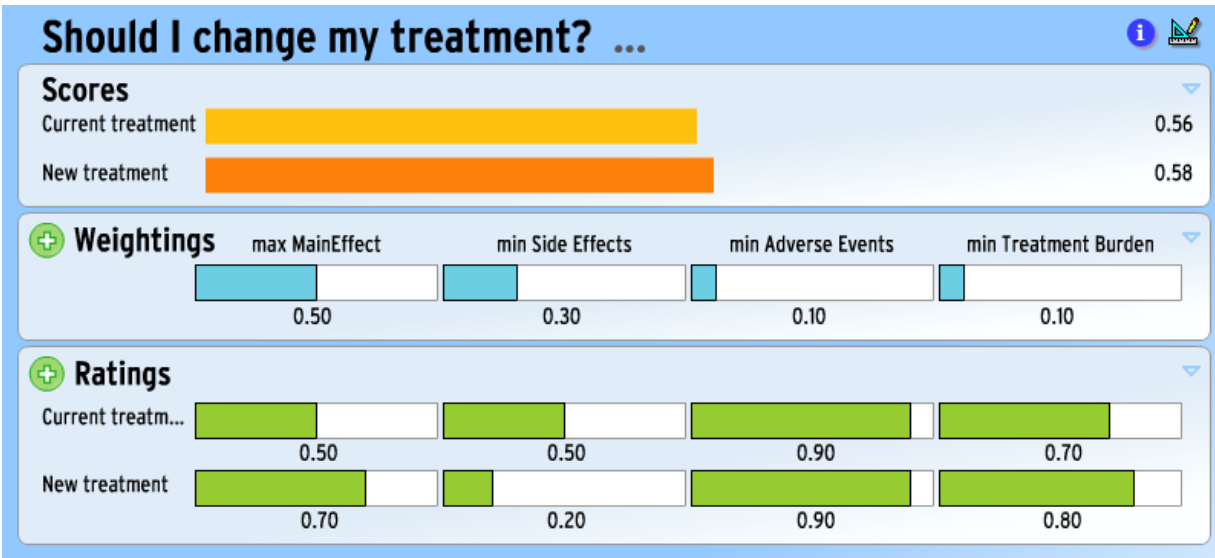


Figure 14: Annalisa with original weights (time point 1).

The score calculation, illustrated for Figure 14, is as follows:

Score for CURRENT treatment $(0:50 \times 0:50) + (0:50 \times 0:30) + (0:90 \times 0:10) + (0:70 \times 0:10) = 0.56$

Score for NEW treatment $(0:70 \times 0:50) + (0:20 \times 0:30) + (0:90 \times 0:10) + (0:80 \times 0:10) = 0.58$

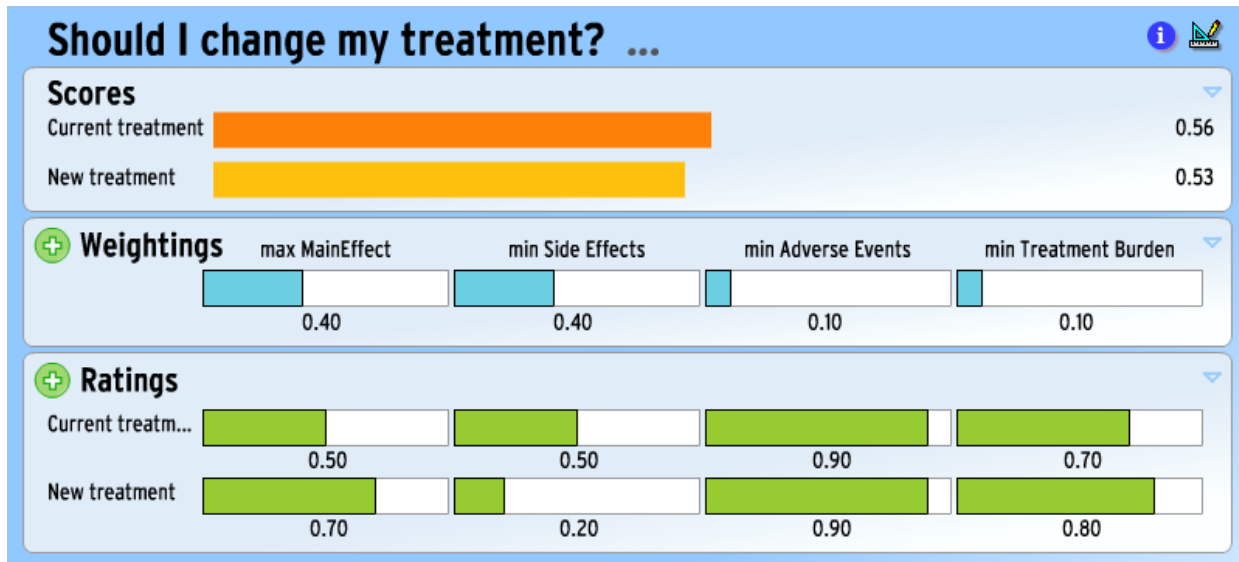


Figure 15: Annalisa with changed weights (time point 2)

The figure of time point 2 now presents the scores when the weight assigned to minimizing side effects is increased, with correspondingly reduced weight to maximizing main effect benefit. (The weightings for the set of attributes must sum to 1 or 100%). Current treatment now has the highest score, which means we interpret this option as the opinion emerging from the Annalisa.

High weights were assigned to relevant practical considerations in both development and delivery, in full recognition and awareness that these may lead to poorer ratings on other criteria, pre-eminently ones concerned with normative rigour. We do not see rigour/relevance and practicality/normativity as dichotomies, where one must make binary choices, but rather as matters of weighting and hence preference-sensitivity. Annalisa, as with any implementation of MCDM including MCDD, embodies a particular view as to the criteria and weights to be used in the meta-decision of ‘deciding how to decide’ (Montis et al. 2001).

In moving from the generic template to a decision specific tool or aid, such as the one for patients suffering from IBD outlined in subchapter 4.5, taking into account considerations for the specific condition and setting is imperative. But given that this is clinical decision support, they must include the basic resource requirements, such as the time and cognitive effort and commitment required from all parties, as well as any financial implications for them.

The term 'Annalisa' is used in multiple ways, with the context making clear which meaning it has. Annalisa is alternatively:

- A simple software template with some basic functionalities hard-wired (e.g. the expected value algorithm to calculate option scores) but no labels or data, other than defaults. We might say 'We could use Annalisa in this study'.
- An instance of Annalisa which contains data for a condition-specific decision. We might refer to 'the IBD Annalisa'.
- A person-specific instantiation of the latter. We might say to a patient with Crohn's Disease ‘This is your Annalisa’, meaning the screen produced as a result of the patient interacting with the condition-specific Annalisa built within the Annalisa template.

4.2.4 Evaluating decision aids

It is essential that any comparative evaluation of alternative decision support systems makes the theoretical basis of each aid and process very clear to all respondents and decision stakeholders. In the context of person-centred care, this comparison will involve multiple criteria, of which the paradigmatic basis of the aid or process is a crucial one (Lipshitz & Cohen 2005). The choice will be preference-sensitive, with the criteria weightings sometimes leading to an instantiation of MCDD emerging as the best way of deciding, and at other times to an implementation of MCDA. There can be no one answer to a preference-sensitive question, so asking simply whether an MCDA/Annalisa-based decision aids are better or worse than alternatives, such as Option Grids (Elwyn, Lloyd, et al. 2013; Marrin et al. 2014), makes no sense if a ‘yes’ or ‘no’ answer is expected.

However, given a commitment to transparent decision making one cannot abdicate from the task of measuring decision quality. The generic, MCDA-based instrument for measuring decision quality, that was developed to evaluate the decision aids, is introduced in the following subchapter.

4.3 Developing a measure of decision quality

III: Assessing decision quality in patient-centred care requires a preference-sensitive measure

The development of a generic decision aid template based on MCDA was preliminary to the production of decision tools for patients facing decisions specific to their condition. In the case of this thesis the condition was Inflammatory Bowel Disease (IBD) (Crohn's Disease and Ulcerative Colitis) and the development of the decision support tool for this condition and our experiences in pursuing its implementation in two clinical settings are the foci of subchapter 4.5.

The explicit aim of these condition-specific aids, built within a generic template, is to improve the quality of decisions. This means that a generic index measure of decision quality is needed to serve as the primary outcome in any evaluation of the use of such aids. Since quality is clearly accepted to be a multi-criterial concept MCDA was clearly a candidate to be the basis for such a decision quality instrument. And if MCDA were to be used, the issue of what, and whose importance weights, would be entered arose, because decision quality would, because of its multi-criterial definition, be preference-sensitive. Given a commitment to patient/person-centred care, the use of the individual person's importance weights was an obvious possibility. If the person also *rated* the decision just taken about their care on the same criteria they *weighted*, a self-reported, 'dually-personalised' measure of decision quality would result.

4.3.1 Assessing decision quality

We took then, and take now, the view that decision quality– defined tautologically as the goodness of a decision– does not exist and should not be defined in a positivistic way. 'Decision quality' is a multi-criterial construct and, given the necessity to assess it, one can only propose a set of items that appeal to our – and others' – value judgements as to what should be included. In this respect it parallels many other constructs in the health arena, like 'health-related quality of life', where instruments such as EQ-5D simultaneously define and measure the construct (Brooks & de Charro 2003).

What did the existing relevant instruments offer? An assessment of the available instruments for evaluating decision aids– mainly those on the Ottawa website (<https://decisionaid.ohri.ca>) – was undertaken to establish whether any of them generated *a generic and preference-based index of overall decision quality*. They would not meet these criteria if they were: (i) condition-, setting- or decision-specific; (ii) measured one or more possible aspects of decision making, such as preferred involvement in decision (Elwyn et al. 2003) satisfaction with the decision (Holmes-Rovner et al. 1996) or decision conflict experienced (O'Connor, A.M.1995) rather than yielding an overall index measure of decision quality; (iii) did not weight their multiple components to produce an index measure (i.e. were profile instruments only); or, if they did involve weighting, did not elicit weights from the specific patient on the specific decision occasion.

None of the instruments identified in the search constituted such a personalized preference-based measure of decision quality. The only instruments uncovered that used the label 'decision quality' *per se* were those developed by Sepucha and colleagues (Lee et al. 2010; Sepucha et al. 2008; Sepucha et al. 2011; Sepucha, Feibelman, et al. 2012). Their condition-and decision-specific decision quality instruments (DQIs) included items that assessed (i) knowledge – the extent to which the patient was 'well-informed', (ii) concordance – the level of agreement between the patient's goals and concerns and their treatment, and (iii) involvement – the

extent to which the patient was involved in decisions about their care. In addition to the fact that they are not generic, these DQIs are not preference-based. The scores that are produced relate to particular segments of the DQI and are not aggregated, by weighting, into a single overall index measure of decision quality for the individual patient on the specific occasion. Moreover, the score for the concordance element can be calculated only for a sample of a patient population, through a delayed survey, not for any and every specific patient at the point of decision. Essentially, they are designed only for evaluating decision aids in population studies, not for clinical use in individual decisions at the point of care.

4.3.2 MyDecisionQuality (MDQ)

The instrument which resulted from our development, MDQ is a generic dually-personalized DQI based on MCDA and currently implemented in the Annalisa/Elicia package. (In principle it could be implemented in any form of online spreadsheet). MDQ is generic in the sense that the criteria are phrased without reference to any particular decision or context. Information relating to the specific decision (such as one in a particular health-care setting and population) is to be provided outside the MDQ instrument, but in the larger decision support system (e.g. MyDecisionSuite) in which MDQ will usually be situated (Dowie et al. 2013).

In MDQ the assessor (e.g. patient) is responsible for not only (i) weighting the criteria of decision quality in terms of their relative importance, but also (ii) rating the quality of a decision just made on the criteria. MDQ combines the set of importance weights for the multiple criteria with performance ratings for each option on these criteria and calculates the overall score as the expected value of these components. It has two parts which can be administered separately or together, and in either sequence. (There are researchable questions here, under consideration for future study.) However, it was felt *a priori* that initial piloting should involve the patient's weightings for the criteria being elicited as early as possible in the decision making process. Their ratings of how well the made decision performed on these criteria, would be elicited as soon as possible after it was made. The instrument could, in principle, be applied again at any time point 'downstream' of the decision, but in our research we have used it only at the point of decision, in order to provide an assessment of the decision and decision process unaffected by subsequent events.

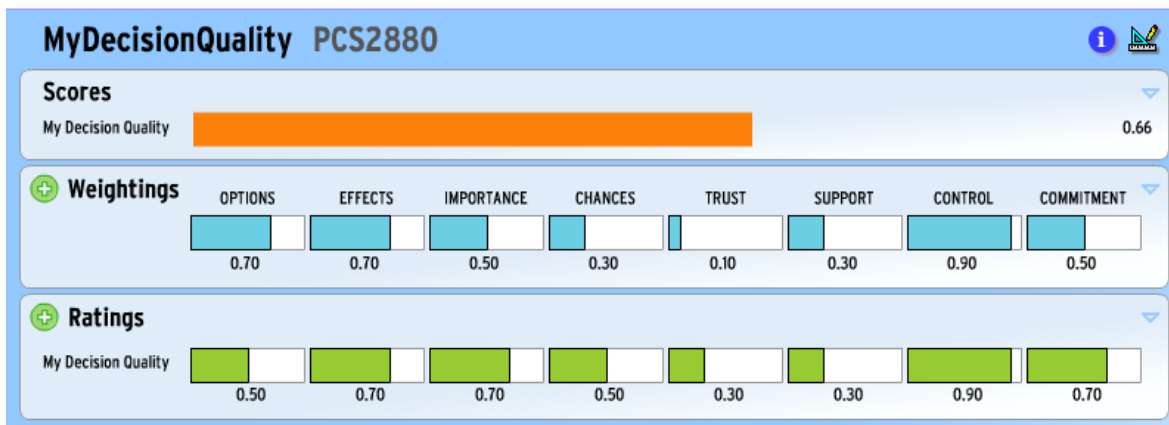


Figure 16: Screen capture of MDQ with un-normalised Weightings, Ratings and Scores for Patient (PCS2880 in a trial of decision aids for the PSA screening decision (Cunich et al. 2011))

The MDQ Score, unique to the patient and to the particular occasion, is automatically calculated as the summed multiplication of criterion weightings and ratings. A worked example is provided in Figure 16. The patient can easily access an explanation of the expected value score calculation, similar to that provided in the previous sub-chapter.



Figure 17: Screen capture of MDQ with normalised Weightings, Ratings and Scores for Patient

This summary picture of the decision quality assessment can be printed and/or downloaded as an image for later use, including sharing and formal clinical documentation in electronic health records.

4.3.3 The criteria

The central issue in the development of the instrument was clearly the criteria to be included. The desire to make MDQ practical in pressured situations, such as a healthcare clinic, influenced the number of criteria included. The number that an individual could realistically be asked to weight and rate, at the time of decision making was initially set at 10. Given that the instrument was to be preference-sensitive, construct and face validity would be the pre-eminent considerations, since eliminating criteria simply on the grounds of statistical correlation or redundancy at the population level would threaten that principle.

A review of the commonly used instruments relating to patient involvement and participation in health decision making helped generate a list of candidate criteria. This list was reduced to 10 on the basis of either conceptual redundancy or inappropriateness for inclusion in a *generic* decision quality measure. These 10 included six items which remained when it was later concluded that eight was the maximum number of criteria that a user could reasonably be asked to weight and rate at the time of decision making. Hence it was the maximum number of items to include in a decision quality measure. This number is within Miller’s magical number (seven plus or minus two) (Miller 1956) and is endorsed in the Cochrane Handbook (Higgins & Green 2011).

The shorthand labels for these six criteria are: ‘Options’, ‘Effects’, ‘Importance’, ‘Trust’, ‘Control’, and ‘Commitment’. Of the remaining four items in the original 10, an Uncertainty criterion was subsumed in a ‘Chances’ criterion and an Emotional Support item in a general ‘Support’ criterion.

Figure 18 presents the Weightings part of the MDQ instrument as it appears to the respondent, with the shorthand label for each criterion followed by a brief elaborating statement. (Early use of a five-point Likert

scale was abandoned on the ground that this required a numerical mapping on to a 0 to 1 ratio scale to be imposed. These would be better elicited directly from the respondent, albeit on the more familiar 0 to 10 scale.)

My Decision Quality (1)											
How important to YOU is each of these criteria in making a decision?											
0 = of NO importance ... 5 = of MODERATE importance ... 10 = of EXTREME importance											
	0	1	2	3	4	5	6	7	8	9	10
OPTIONS Importance of being clear about the possible OPTIONS for me and what they involve	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EFFECTS Importance of being clear about the possible EFFECTS and outcomes of each of the options for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IMPORTANCE Importance of being clear about the relative IMPORTANCE of the different possible effects and outcomes for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CHANCES Importance of being clear about the CHANCES of the different effects and outcomes happening to me, including the uncertainties surrounding the best estimates of them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TRUST Importance of being able to TRUST the information I was given was the best possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SUPPORT Importance of feeling I received the level of SUPPORT and consideration I wanted throughout the decision process, especially in regard to communicating at my level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CONTROL Importance of feeling I was in CONTROL of my decision to the extent I wished	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COMMITMENT Importance of feeling COMMITTED to acting on the decision taken	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure 18: MyDecisionQuality Weightings elicitation screen

The equivalent items of the Ratings part of the instrument, rephrased in past tense, are as follows:

OPTIONS: I was clear about the possible options for me and what they involve

EFFECTS: Importance of being clear about the possible effects and outcomes of each of the options for me

IMPORTANCE: I was clear about the relative importance of the different effects and outcomes for me

CHANCES: I was clear about the chances of the different effects and outcomes happening to me, including the uncertainties surrounding the best estimates

TRUST: I trusted the information I have been given is the best possible

SUPPORT: I was satisfied with the level of support and consideration I received throughout the decision process, especially in regard to communicating at my level

CONTROL: I felt in control of the decision to the extent I wish

COMMITMENT: I was committed to acting on the decision.

After internal discussions and testing on convenience samples of colleagues, we uploaded an online survey incorporating the initial MDQ on the Facebook page of the Shared Decision Making (SDM) group, and emailed an invitation to comment to all those on the lists of the Society for Medical Decision Making (SMDM) and Society of Judgment and Decision Making in mid-December 2011. Allowing for crossover, we estimated that this provided us with a few hundred potential respondents. Twenty individuals completed the questionnaire (the latest in mid-January 2011) and nine also provided comments on the MDQ screen. Their feedback was incorporated in the re-development of the MDQ, whenever it was compatible with the underlying framework and

construct. The suggestion that MDQ weightings be elicited as part of the pre-consultation preparation was accepted. One respondent rejected the instrument immediately because of its prescriptive basis.

Of the eight criteria in the current version of MDQ the first four match the structural requirements for any MCDA implementation in any context (Options, Criteria, Weightings and Ratings) as is needed for a fully informed consent. These criteria also appear, in one form or another, in all checklists for developing decision aids for health decisions, including those produced within the IPDASi guidelines. The last four criteria relate to other aspects of the decision process and are also explicitly or implicitly included in most checklists for decision aids. The 'Commitment' criterion is included primarily because of its relevance to perceived quality at the point of decision, but it creates the possibility of investigating concordance at the point of decision (see below) as well as correspondence with future actions and outcomes if this is undertaken.

As with the existing instruments referred to earlier there is no intention in MDQ to capture or assess the subjective experience of the patient (fear, anxiety, etc.). The patient expresses their views as to the support they received in relation to their feelings and emotions - and all other aspects of the decision experience - by their weighting of, and rating for, the Support criterion.

4.3.4 Priorities for decision quality improvement

One feature of the thesis journey was the continuing developments in the functionalities of the underlying software. Enhancements meant that it became possible to perform more extensive calculations for the individual patient in real-time. It was always possible to present the respondent with a visual breakdown of their score, encouraging them to identify highly-weighted but lowly-rated criteria as the prime potential source of improvement in future decisions. The software enhancements gave us the ability to deliver instant feedback in the form of the Incremental (Expected) Value of Perfect Rating (IVPR) or, less jargonistically, the Gain from Improved Rating. The IVPR for a criterion indicates the amount by which the patient's overall MDQ Score could be increased, given their weighting for that criterion, if they achieved a perfect rating on it.

Percentaging the gains for each individual criterion produced a suggested prioritisation in relation to future consultations. In the case of the illustrated patient (PCS 2880 as in Figures 16 and 17) this would suggest priority be given to improving the Rating for Options, followed by those for Effects and Support. He should devote (Figure 19) about 25% of his available efforts, time and resources to becoming clearer about his Options. (In many cases, such as this, we turn the numbers in Annalisa off, leaving the impact purely visual, acknowledging that numbers shown are not easy to convey). The IVPR of a criterion is the normalised weight for the criterion multiplied by (1-the provided rating for the criterion) e.g. if the normalised weight for the 'Option' criterion for PCS 2880 is 18% and the provided rating is 50% then the IVPR for that single criterion is 0.18 multiplied by $(1-0.5) = 0.09$. This number is not shown, because we work out IVPR for all 8 criteria and then percentage them in order to provide a prioritisation allocation across the criteria for future decisions.

Another result of the software enhancement during the research was the possibility of calculating and presenting a decomposed measure of the concordance on decision quality that existed between patient and clinician - if the clinician was willing to complete a version of MDQ that registered their perceptions of the patient's Weightings and Ratings. The limited application of this possibility in Sydney established its feasibility as recounted in 4.5.

We are focusing on the concordance/discordance (LeBlanc et al. 2009) between the patient and the clinician. But the software permits this concordance/discordance to be established between any two parties, for example a child and its parents (Vetter et al. 2012).

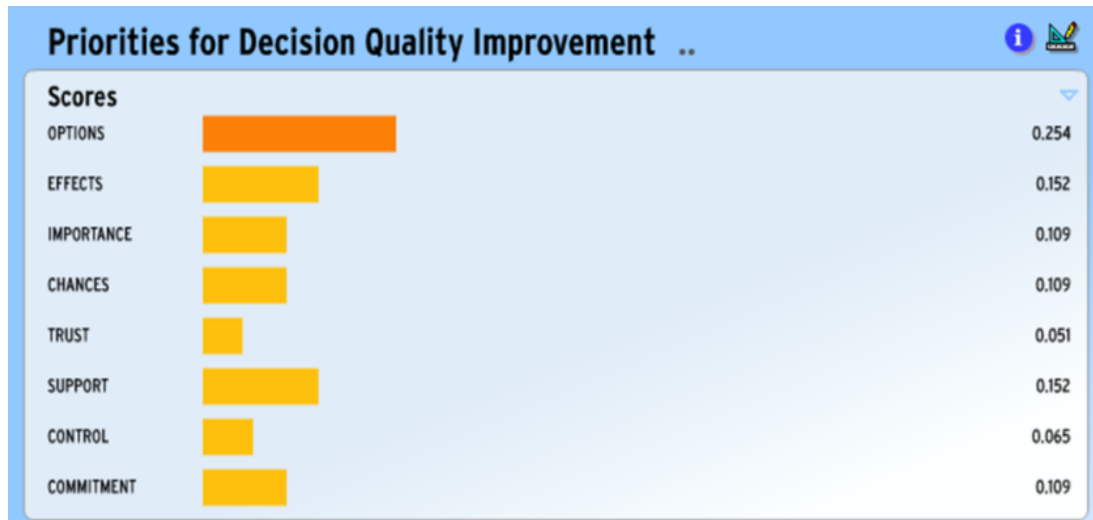


Figure 19: Screen capture of Priorities for Decision Quality Improvement of Patient PCS2880

4.3.5 MDQ as a generic decision aid

When the Weightings part of MDQ is administered early in the decision making process it constitutes an intervention in itself, whether or not any other intervention (e.g. decision aid) is involved before the Rating part is administered. We report in 4.5, and subsequently, how MDQ came to be interpreted as a generic decision aid, as well as but as distinct from a Patient-Reported Outcome Measure (PROM).

It is not at all clear what should be the primary outcome, in terms of decision quality, of a trial of MDQ-supplemented decision making and standard practice. The challenge of validating a patient-specific, preference-based instrument such as MDQ does not appear to have been addressed in the literature, and we continue to seek advice and assistance in this respect. Given the personalized character of MDQ, we are particularly interested in exploring the use of n-of-1 study designs (Kravitz et al. 2008; Duan et al. 2013; Gabler et al. 2011).

4.3.6 Conclusion

As we move towards person/patient-centred care it is important that we respond positively and wholly to patient heterogeneity in the value aspects of decision making. MDQ represents a step in that direction but the impression should not be left that MDQ is seen as the finished article. The value of a self-reported and dually-personalised instrument based on a prescriptive principle will always be contestable, even when offered as here simply as an addition to the instruments relevant to the task of assessing decision quality. While not initially proposed as such, we now see MDQ as a valid Patient-Reported Outcome Measure (PROM), when the outcome of a decision process is interpreted as the decision. How such a dually-personalised measure can be used beyond a clinical context remains to be determined. Its possible use in such wider context is the subject of 4.4 which follows.

4.4 MDQ as a component of routine feedback to providers

The empirical research reported in this and the following subchapter occurred during, as well as subsequent to, the developmental work described in the preceding ones. The accounts are necessarily selective and, in metaphorical terms, reflect both the glass half full and half empty perspectives on what was achieved.

Interpreted one way the results can be seen as largely negative, insofar as the implementation achieved fell far short of that hoped for. This reflected not only the challenges faced in setting up the fieldwork in the three settings (in particular in obtaining ethics approval in London), but also the ongoing modifications and enhancements of the underlying MCDA software that were produced for reasons unconnected with my particular research. An important consequence was that the clear separation between development and implementation envisaged in the research design and protocol became blurred. This called for even more adaptations in the spirit of action research than had always been accepted as inevitable in the context of such an innovatory approach.

However, seen from an alternative perspective a great deal was achieved in terms of program development. It was clearly established why the approach adopted was unlikely to succeed, echoing the experience of others (Wyatt et al. 2014), and hence prompted the fundamental reconceptualisations reported in chapters 4.6 and 4.7 and in related paper A.

In the previous subchapter the development of the dually- personalised measure of decision quality MDQ was set in the context of its use as an outcome measure for the evaluation of a clinical decision support tool. In 4.4.1 below we report on its additional use as a generic decision aid in the clinical context. But from the beginning it was also envisaged as a possible means of enhancing the feedback obtained from individual patients about the care they had received from a health care provider. Specifically in the case of Denmark, the third research objective would be to test the feasibility of MDQ as a possible component of the national patient experience survey in Denmark care known as LUP <http://patientoplevelser.dk/lup>. As a result of the interruption to the pursuit of that objective reported below, the objective has been widened and the rest of this subchapter therefore sets out the basics of the revised research that will be undertaken in the post-thesis period, rather than simply reporting on the very limited results from the initial piloting.

4.4.1 Feedback in healthcare systems

Those responsible for health services at a community or national level have long sought feedback from patients viewed collectively, as a whole or as members of subgroup. Anonymised feedback in the form of satisfaction surveys has been the traditional source and these are now becoming even more prominent, while undergoing the technical revisions that take advantage of web-based technologies and rapidly increasing access to the internet. However, most bodies now accept that self-reported 'satisfaction' is not an appropriate concept and are replacing it with requests for reports on the person's experience of specified events or actions. In recent years these wider surveys have been accompanied by efforts to increase 'user involvement' in top-level organisational and research settings, with representatives of patients or patient groups, or lay persons, being invited to the table (Barber, 2014; Boote, Wong, & Booth, 2012; Kaltoft, Nielsen, Salkeld, & Dowie, 2014). Citizen juries, focus groups, and similar community-based arrangements, provide an intermediate mechanism, giving the possibility of deeper, if narrower, feedback than a survey (Mooney, 2005).

Surveys seeking patient feedback or assessments of patient experience typically suffer from at least three limitations from the perspective of person-centred care.

First, they are typically confined to eliciting ratings on a number of indicators. If these are weighted to produce an overall index, rather than being left as a profile, the weights are supplied by the instrument developers. They are quite often simple equal weights as in the Patient Experience Questionnaire (PEQ) (Pettersen et al., 2004), subsequently cluster-analysed in (Bjertnaes et al. 2013). Only those built within the Dutch Consumer Quality Index (CQI) framework incorporate patient weightings into the assessment (Delnoij et al. 2010). The condition-specific CQI instrument (Van Der Veer et al. 2012) is in fact two instruments. CQI Experience elicits ratings on each item and CQI Importance elicits importance weightings for each item, both employing four-point Likert scales. The percentage of respondents giving the lowest Experience rating to an indicator is multiplied by the percentage giving it the highest Importance weighting to produce a Quality Improvement Score for use in prioritisation according to the authors. These are clearly group-level results and we learn nothing about the individual level relationship between experience and importance.

Second, most surveys give relatively little attention to the person's participation in decision making. Remarkably neither the PEQ nor Bjerknaes papers contain either the word 'decision' or the word 'preference'. They reflect a largely passive and disempowered patient who is to be 'informed', 'communicated with', 'have things explained clearly', 'listened to attentively', 'treated with respect', and 'taken seriously'. The foregoing are all items in the dialysis CQI (Van Der Veer et al. 2012) and are typical of those in the other instruments. The two items (of 45) in that instrument which include the term decision are 'Nephrologist providing information to enable shared decision making' and 'Nephrologist giving opportunity for shared decision making'. So even here we are in a provider-driven situation.

The third limitation involves the restriction to patients' treatment experience within an illness context. This means omitting invitations issued to persons regarding screening, vaccination, and other preventive actions. Our protocol, which has been developed in response to the interrupted piloting reported below, involves dissemination to the community as well as patients, and so rectifies this.

Apart from these general limitations (Institute for Healthcare Improvement 2012) there were well-established specific concerns with the value of the Danish LUP (Boolsen et al. 2013; Riiskjær et al. 2010; Jensen et al. 2010; Riiskjær 2014).

4.4.2 The piloting experience

Objective 3 was stated as being to pilot the MDQ decision quality instrument in a Danish population to establish its feasibility as a component of a national survey of patient feedback on their hospital care, in collaboration with the IBD patient organisation (www.ccf.dk) (linking to the survey on their website) and to use the Satisfaction with Decision instrument to explore the relationship between satisfaction and the quality of decisions measured by MDQ.

The sub-objectives were

- to elicit Danish patient's self-rated perceptions about, and desires for, decision involvement and support and informed consent, by means of an online pilot survey (including a Danish translation of MDQ);

- to establish the extent to which responses to decision-relevant LUP questions are related to responses to a decision quality instrument (MDQ);
- to establish the feasibility of administering an online survey including a decision quality instrument (MDQ) to Danish patients/respondents.

The piloting would be via all patients at department of Medicine (M), OUH Svendborg Hospital and the Danish IBD patient organisation (CCF) the latter reflecting the choice of IBD as the case study for chronic disease, and their agreement for the invitation to participate being posted on their website (Bente Buus Nielsen, personal communication.)

Originally planned for a two month period during 2012, all patients leaving each unit in department M would be handed an invitation (with url and password) to complete when back in the community. On the basis of 3 years data the estimated populations would be 140 gastroenterological patients overall, and some suffering from IBD.

The survey had three introductory questions asking the respondent to recall whether a specific decision was made on their recent visit (if not, they should exit the survey); and respond to the four decision-related LUP questions; and then complete the decision quality instrument, in which they weight the 8 criteria in MyDecisionQuality, as well as the widely-used Satisfaction with Decision instrument as a comparator (Holmes-Rovner et al. 1996; Wills & Holmes-Rovner 2003). The basic background LUP information would be requested (age group, sex, general health using Short Health Scale, educational level, and region). Whether they had ever taken part in the national LUP survey was also a question, and for the respondents logging on due to the link at www.ccf.dk whether they had taken part in a national survey on IBD (Nikolajsen 2012).

Descriptive statistics, including those on completion rates by characteristic, would be complemented by cross-tabulations and regression analyses to explore the relationship between the responses to the LUP questions and the items of the decision quality instruments, by patient characteristic and setting.

4.4.3 Results

Provisional translation of MDQ into Danish was by the present author, followed by reference to colleagues with high bilingual competencies and involved in such work on a regular basis. It was pointed out that the Lix readability index was high in both English and Danish (Claire Gudex, personal communication). However, it was essential to maintain the construct validity of the items while making them as accessible as possible. A number of words led to extensive discussions about the most meaningful rather than literal translation. As examples, Commitment became Forpligtelse (from intention or beslutsomhed), Effects became Virkninger (from effekter), and Chances became Sandsynligheder (from udfald). Figure 20 shows the MDQ Danish Weightings items. Figure 21 is an example of the Danish MDQ result screen (MinBeslutningsKvalitet). The weightings displayed are non-normalised (and add to more than 100%) but the score is always normalised and in this case it is 54.8% of the maximum. (For the effect of normalising the un-normalised weightings see Figures 16 and 17.)

VALGMULIGHEDER Vigtigheden af at være klar over mine VALGMULIGHEDER, og hvad de indebærer
VIRKNINGER Vigtigheden af at være klar over de mulige VIRKNINGER, hver valgmulighed har for mig
BETYDNING Vigtigheden af at være klar over den relative BETYDNING, de forskellige virkninger har for mig
SANDSYNLIGHEDER Vigtigheden af at være klar over SANDSYNLIGHEDER i forhold til de forskellige virkninger i min situation, incl. den usikkerhed de angives med
TILLID Betydningen af at have TILLID til at den information, jeg har fået, er den bedst mulige
STÅTTE Betydningen af at modtage ønsket STØTTE og forståelse i beslutningsprocessen, specielt i forhold til at tale med mig på mit niveau
KONTROL Betydningen af at føle KONTROL over min beslutning i den udstrækning, jeg ønsker
FORPLIGTIGELSE Betydning af at føle mig FORPLIGTET til at handle på den trufne beslutning

Figure 20: MDQ Danish Weightings items

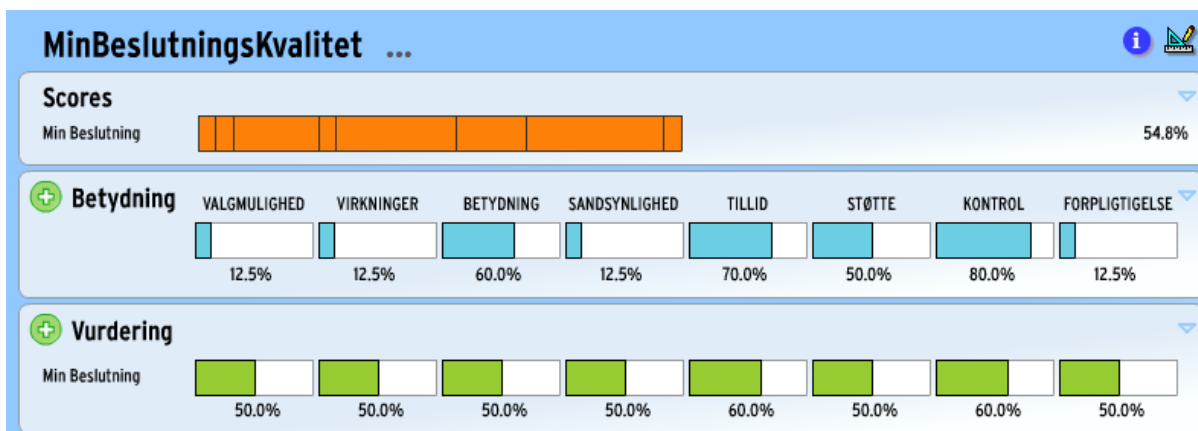


Figure 21: Example of Danish MDQ result screen (MinBeslutningsKvalitet) displaying non-normalised weights

The numerical response was disappointing especially from the hospital route where summer timing and ongoing reorganisation undoubtedly contributed to the very limited distribution as well as to the poor response rate. The possible contribution of respondents experiencing difficulties with the concepts in Danish can be examined in the future research.

There were 29 responses made as a result of the CCF link and five from the hospital distribution. We could see that many more started the survey but did not submit their answers. Either they did not want to, or they found the exercise too complex, or they did not understand the translated instruction on how to press 'submit your answers' which was embedded in the hardwired instruction in English. (The Danish letters æøå were not enabled in the software at this time). Of the 34 respondents, 29 completed both parts of the MDQ instrument as well as the Satisfaction With Decision (SWD) instrument (Holmes-Rovner et al. 1996). Little of significance could be

learned given these numbers, but as proof of method we were able to plot the relationship between MDQ and SWD instruments.

The 6 questions of the SWD responded to on a 5-point Likert scale [1strongly disagree -5 strongly agree] are:

1. I am satisfied that I am adequately informed about the issues important to my decision.
2. The decision I made was the best decision possible for me personally.
3. I am satisfied that my decision was consistent with my personal values.
4. I expect to successfully carry out (or continue to carry out) the decision I made.
5. I am satisfied that this was my decision to make.
6. I am satisfied with my decision.

The 29 completed sets established the feasibility of collecting the required information, but also allowed an exploratory look at the relationship between MDQ and the SWD instrument. As a provisional conclusion it appears from the fact, that given a correlation coefficient of 0.7 means only about half the variance is explained, MDQ is probably measuring something different from SWD, without being completely unrelated.

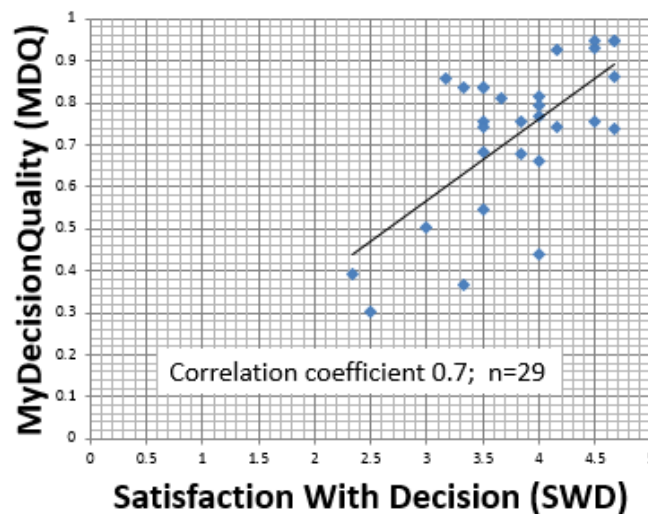


Figure 22: MyDecisionQuality and Satisfaction with Decision correlation

The reason why this research was not followed up lies in the revision of LUP, which was announced at this time. There was no point comparing MDQ with decision-related items which might not survive or be similar to those in the new national LUP. Unfortunately the LUP revision process took over a year. The revised items have only recently become available, along with a description of the methods for their development (Christensen 2015).

The major positive result from this stage of the empirical work is the existence of a technically fully-functioning survey, with embedded MDQ in Danish and updated LUP items. A video in Danish has also been prepared ready for user testing and dissemination in the future. This will enable the limited proof of method established on the small number of condition-specific patients reported above to be expanded to patients with all conditions in all 5 regions of Denmark. Statistically significant comparison of the results from MDQ with the SWD instrument will be sought, as well as the relationship between MDQ and the responses to the decision-focused items used in the

revised LUP. The existence of MDQ as a possible future key Patient-Reported Outcome Measure on decision quality at a national level we see as a positive achievement, even if the bulk of the task remains to be done.

The following study protocol, which emerged out of the interrupted piloting exercise, is now based on the assumption that the individual can not only contribute to the higher-level feedback process but also and simultaneously benefit personally. This dual strategy is designed to minimise both cost and respondent fatigue and maximise the return to healthcare provider and person in relation to decision making quality. It can also be seen as input into ‘flipping healthcare’, embracing the primary and secondary sectors, and using e- and m-technologies.

4.4.4 Outline of a protocol for the revised and resumed research

In this proposed pilot study we seek to establish the feasibility of using a web-based survey to simultaneously supply healthcare organisations and agencies with feedback on a key aspect of the care experience they provide, and increase the generic health decision literacy of the individuals responding. The focus is on the person's involvement in decision making, an aspect of care which is under-represented in current surveys from the perspective of person-centred care. By engaging with an instrument to assess decision quality the person can, in the one action, provide a retrospective evaluation of a past decision making experience in a specific provider context, and enhance their competency in relation to future decision making in any provider setting. We seek to combine organisational and educational health informatics in a context-sensitive way. See related paper G.

The protocol has been developed for the Danish context, where we already observe large scale and successful efforts in making Patient-Reported Outcome Measures (PROMs) the centre of an integrated electronic system (Hjollund et al., 2014). But we see this Danish study as just one application of a higher level 'proto protocol', adaptable and sensitive to other countries and settings, through translation to the professional, legal and ethical circumstances in the jurisdiction. In the Danish piloting we will offer both Danish and English versions of the ‘DQ4ALL’ (DecisionQuality for All) survey, which contains the MyDecisionQuality (MDQ) instrument.

4.4.4.1 Objectives

To explore the feasibility and acceptability of the MDQ instrument to persons in the community (as residents, citizens or persons) in order to (i) provide feedback to providers on self-rated dually-personalised decision quality as an important aspect of the person's health and healthcare experience, and (ii) increase the health decision literacy of the person concerned in relation to both evaluating past decisions and preparing for future ones.

4.4.4.2 Methods

The ‘DQ4ALL’ survey will establish some basic socio-demographic details of the respondent and then ask them to recall one healthcare decision, taken in a hospital setting, or a primary care/community setting, or in relation to a recommendation or invitation from a health care agency (e.g. a screening invitation). They are asked approximately when this recalled decision happened and whether it was about testing (including screening), treatment (initiation, change, and discontinuation), rehabilitation or prevention (e.g. vaccination, lifestyle/behaviour change).

Next they are asked to respond (on a four point scale) to the two decision-related items from the recently revised LUP survey (Enhed for Evaluering og Brugerinddragelse 2015):

- Questions 9/10: The patients/relatives have an opportunity to take part in decisions about treatment
 Questions 9/10: Patienterne/pårørende har mulighed for at deltage i beslutninger om behandling

They then respond to the MDQ instrument in respect of the recalled decision, experiencing the instrument in its full form, including the production of priorities for future improvement in decision quality.

A final set of questions asks whether completing MDQ in relation to a recalled decision has helped evaluate or re-evaluate that decision, and/or increased their perceived ability to engage in future decision making processes more fully and competently. Their aim is to establish whether their perceived health decision literacy has been enhanced, by the implicit nudge from MDQ of how to think proactively and more slowly about decision making and the quality of their decisions.

It will be made clear that the focus of this survey is on decision making and informed consent and is not related to the increased efforts to gain patient feedback on safety-threatening mistakes or ‘near misses’ in the implementation of decisions or carrying out of procedures (Ministeriet for Sundhed og Forebyggelse 2015a; Hansen 2014; Slot 2014; The Danish Institute for Quality and Accreditation in Healthcare IKAS; Christensen & Engel 2014). We will consider approaching the Danish Knowledge Center for User Involvement in Health Care (ViBIS) to undertake a feasibility and acceptability study among their panel members for adding the two-part MyDecisionQuality instrument to LUP or other relevant surveys. ViBIS was established (after the start of the PhD May 2012) in November 2013 to gather, share and develop knowledge about methods for and experiences of user involvement from both Denmark and abroad, and to make this knowledge available to health professionals, managers and decision-makers in the Danish health care system (<http://vibis.dk/english>). ‘The user involving hospital’ is a Danish protocol for 2014-18 outlining ongoing research (ViBIS et al. 2014)). Once more user testing for comprehension and usability has been performed, launching on national level can use media such as Videnskab.dk, an e-newsletter including reporting on ongoing research projects, to achieve a wider distribution of the survey among the residents of Denmark, including migrants, who might be accessed via <http://denmark.dk>

4.4.4.3 Ethics

Since the survey is being distributed to persons in the community rather than patients, consent is by opting into its completion, and all data is anonymous, we expect no ethics approval will be required. However, the issue of data storage is currently under examination of different sorts so the obtaining of anonymous responses of the kind outlined above will need approval (The Danish Council of Ethics/Det Ethiske Råd 2015).

The software used for the research is by courtesy of the University of Sydney School of Public Health, with the data stored behind their firewalls, and this will also require approval. This will be possible through my current status of honorary affiliate and part of the Sydney research team employing the Annalisa/Elicia software as the basis of a decision app <http://www.healthdecisions.org.au/>.

4.4.4.4 Conclusion

Using the MyDecisionQuality (MDQ) instrument we seek to show how the individual can, in one online survey, simultaneously contribute enhanced feedback to providers on past decisions and benefit personally from the increased generic health decision literacy that may improve the quality of their future health decisions.

4.5 MCDA-based decision support for IBD patients

The first objective in the original protocol was to develop a decision support tool within MyDecisionSuite (MDS), based on the Annalisa implementation of MCDA. The support would be for IBD patients preparing for an upcoming consultation in which a major change in disease management might be considered. MDS for IBD would include the MyDecisionQuality (MDQ) measure developed in fulfillment of the second objective.

The resulting story is complex, partly as a result of the ambitious attempt to provide a comparison between implementation in two different institutional settings, as well as two continents. It is difficult, even in hindsight, to establish precisely how the London and Sydney projects interacted, but the main elements of each story are clear and can be told largely separately.

In this subchapter we recount, necessarily somewhat selectively and in hindsight, how the implementation of both the IBD aid and MDQ instrument became one of almost continuous adaption to the realities of clinical practice, and, in London, eventually to abandonment. But it is also the story, of how the limited, but different achievements in the two settings, yielded important insights into the type of research that can be done and should be attempted. The research from the Sydney setting has left us with a fully-functional decision support tool that will be disseminated - with the endorsement of the clinicians- in a much less restricted and provider-dependent way in the near future. The recent rewriting of the underlying software in JavaScript will extend its reach compared with the Flash basis of the one used in the research. (iOS is the dominant platform in the local OUH/SDU context).

4.5.1 London

The story starts at St Mark's Hospital, where the renowned gastroenterology department includes an IBD nursing team led by Marian O'Connor with two colleagues of IBD specialist nurses operating a telephone Advice line as well as seeing patients in their clinics. The original intention to involve these IBD specialist nurses in the delivery of the IBD decision aid had to be quickly revised. In order that a credible and acceptable decision aid could be constructed and delivered in clinical practice - and justify the time involved in its delivery - it would have to relate to a major change in disease management. At that point, as now, one major management issue was whether to move patients on to one of the new anti-TNF biologics from an immunosuppressant.

A number of decision support tools had attempted to address this decision (Siegel et al. 2011; Corey A Siegel 2010; Siegel 2012; Johnson et al. 2009; Siegel 2009). Such a change in management was not, however, within the power of the IBD specialist nurses to deliver and so it would be necessary for the consultant to be involved.

In any case, it became clear that the nurses had no time to deliver the aid, so it was agreed they would mainly be involved via the Advice line in recruiting and then supporting those patients who consented to engage with the web-based aid. The initial patient engagement with the decision aid would be online in the patient's home, some days before the appointment with the consultant in which the major change in management might be considered.

The development of the Annalisa part of the aid was clearly distinguished from its proposed implementation and was undertaken by my project supervisor in collaboration with the consultant who was PI of the study. Regrettably from my personal viewpoint the structure was narrowed to contain only medical options, later

expanded to include two surgical ones as a by-product of the involvement of the colorectal surgeon in Sydney, but still excluding non-medical/surgical options, such as lifestyle changes as formal alternatives.

The criteria for the aid went through a process of successive refinement, which included the merging of two criteria ('mucosal healing without clinical remission' and 'clinical remission without mucosal healing') which had been advanced as clinically meaningful by others (Sandborn et al. 2012), were felt unlikely to communicate with most patients by the clinicians, and would require an endoscopy to establish the patient's state in this respect. They were therefore merged into 'Mild Disease'. The seven criteria which emerged from the literature and informal discussions with IBD patients (including colleagues) were agreed by the clinicians as equally applicable to Crohn's Disease and Ulcerative Colitis. The 7 criteria were *avoiding* Mild, Moderate and Severe Disease, Side effects, (Life-threatening) Adverse events, Treatment burden, and Relationship impact. Relationship impact was added at a late stage following patient discussions. A check of transitivity in response would be provided by the importance of avoiding Severe Disease being not less than that of avoiding Moderate Disease, and that of avoiding Moderate Disease being not less than that of avoiding Mild Disease. Assistance in relation to weighting the outcomes was provided in videos produced by us (JD and myself) with the respective Principal Investigators.

The iterative development of the St Mark's Annalisa became intertwined with my research on the MDS in which it would be embedded, even though as indicated earlier, neither its structure, nor the performance ratings were my responsibility. However, in implementing a decision aid in a software program, it became obvious that aspects of 'development' become intertwined with aspects of 'delivery' and it is difficult sometimes to separate 'the dancer from the dance'.

4.5.2 Sydney

The professional contacts of my supervisors in Sydney, along with the fact that the software to be used in all settings was located on a server at the University of Sydney, School of Public Health, had presented me with the potential to deploy the same aid in a very different institutional setting from the NHS context of St. Mark's Hospital in London. In Sydney the gastroenterologist and colorectal surgeon operated as private consultants, but held appointments at the Royal Prince Alfred Hospital. Both were involved in highly relevant research in patient quality of life outcomes through the Surgical Outcomes Research Unit (SOuRCe) (Byrne et al. 2014; Byrne et al. 2007) (<http://sydney.edu.au/medicine/public-health/source>)

The idea that exactly the same IBD aid could be used in both London and Sydney had to be quickly dismissed. The Sydney gastroenterologist wished the options in the aid to be in line with the clinical alternatives he considered reasonable, even if he did not prescribe them himself. While the seven criteria would be the same in the two settings, the number of options (including two surgical ones) was considerably greater than in the St. Mark's aid, consisting of 31 options for Crohn's Disease as against 11, and 25 as against 11 for Ulcerative Colitis. The consultant undertook the task of producing the resulting judgements (the BEANs) for a patient in only Severe or Moderate Disease state and on a specified medication currently being in one of the four states (Remission, Mild, Moderate, or Severe Disease) in six months' time, for each alternative possible medication option. He also supplied the Side effect and Adverse event probabilities (the BEANs), which he felt would be the same for both CD and UC and would, on average, be unaffected by the patient's current or future disease state. As in London, early suggestions from the clinicians that the ratings might be different for males and females, was rejected when the elicitation task began, and it was also decided that age effects could be given meaningful

expression only in the clinical situation. The translation of clinician experience-‘the art’ - into BEANs proved to be a challenging task.

To repeat what was made clear in 3.2, these Annalisa-based parts of the process were not part of my research, though it was necessary to pay close attention, since I was involved in the production of the MDS program with which the patient and clinician would engage. A great amount of time and effort was accordingly devoted to bug-detection to ensure that all the possible permutations were correctly programmed, so as to provide an efficiently *customised* program that asked the patient only questions which were relevant to their current disease state and medication, and presented them with a correctly *personalised* Annalisa. See Elicia/Annalisa Figure 6.

4.5.3 The standard implementation route

The patient interacts with the aid at home, following the MDS sequence. Having entered their ratings for the Treatment burden and Relationship impact criteria, where they are the expert, they provide their criterion weightings. This immediately generates and presents the full Annalisa result screen, illustrated in Figure 23 for a patient currently experiencing Moderate Crohn’s Disease and taking a Thiopurine (Thio) medication. This is saved as the Annalisa screen to be opened at the appointment, when clinician and patient discuss the opinion it has produced (Figure 24). The patient can then vary their criterion weights, and ratings on treatment burden and relationship impact, to see the effect on the Scores. Likewise the clinician can modify the ratings for any of the remaining criteria if they seem inappropriate for this particular patient. All such changes become part of the record when saved and can be analysed.

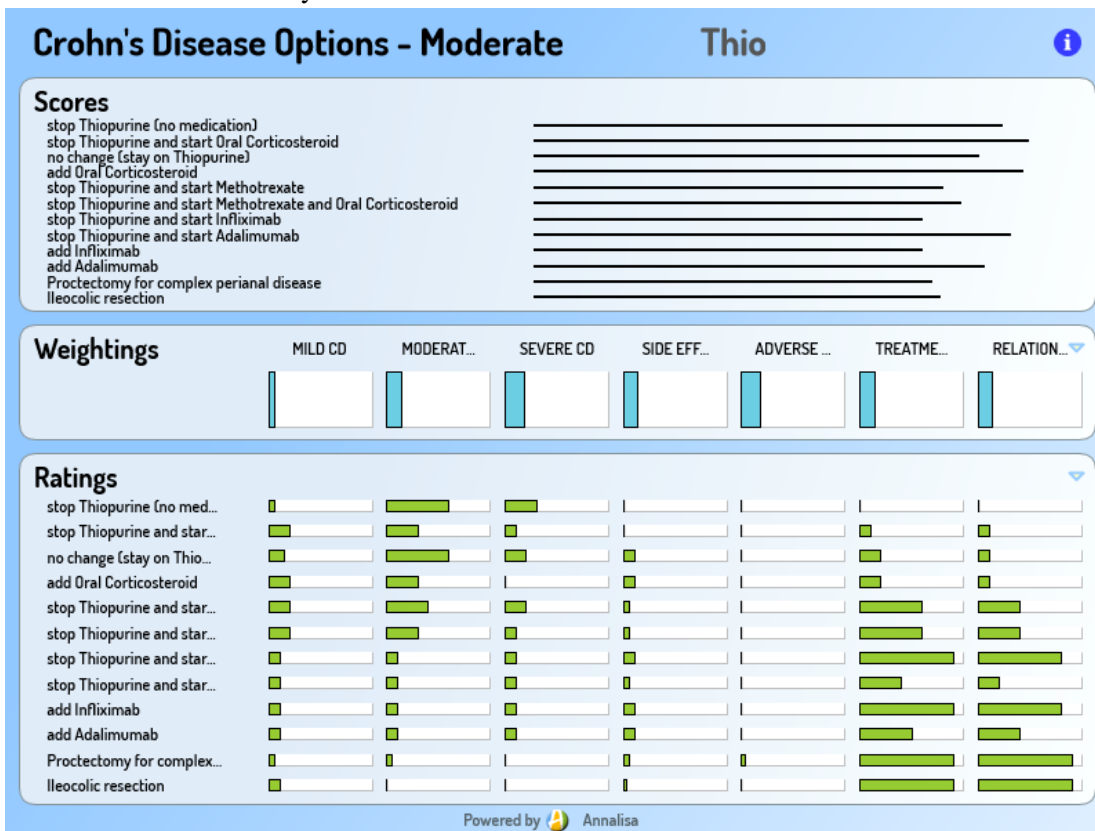


Figure 23: Annalisa screen capture for patient experiencing Moderate Crohn’s Disease and taking Thiopurine



Figure 24: Photo of Sydney clinician discussing the Annalisa opinion produced by the aid (hypothetical patient)

4.5.4 Recruitment

Very early on it became clear that recruitment through the St Marks IBD specialist nurse Advice line was simply not happening. Inadequate time had been available for the training which had been agreed was necessary for the nurses to have sufficient familiarity with the aid to be able to answer basic questions about it and become confident in introducing it. Attempts approved by the PI to move to written invitations were not successful for a variety of reasons. The growing logistical difficulties, compounded by firewall issues and room availability, meant that my project supervisor, London co-supervisor, and I agreed that the research was clearly too disruptive of the clinical arrangements at St Mark's, which were under increasing resource pressure and that, mistakes on our side acknowledged, the obstacles to pursuing the research further were too great to justify further effort. The relative importance of resource pressures on the clinicians and growing concern with the disruptive potential of the aid remain unknown. All of us felt that the initially proposed post-intervention interviews would produce useful insights on this central issue for future publications within the tradition of action research (Wagner 2005).

As in St Marks, the recruitment of patients in Sydney was much lower than expected, for a number of reasons.

The one common to both settings, which led to the initiation of the revised 'MDQ-only' route, was the fact that IBD patients were mostly attending either for a routine regular check-up, with no expectation of a major change in disease management. Or were coming as an emergency as the result of a flare, which needed to be dealt with immediately, discussion about any possible change in disease management being postponed for later. This meant that the majority of patients were either in Remission or the Mild Disease State, for which the aid did not contain ratings, since it had been agreed it was then clinically unlikely that a major change in management would be considered. On the other hand, for patients coming as the result of a flare, there was insufficient time to go through the standard ethics-required procedures of issuing an invitation, receiving back acceptance, e-mailing an ID and password to access the aid - and engage with it before the appointment. While the Sydney PI eventually developed a 'fast track' route to overcome some of these difficulties, it did not succeed, in my absence, in addressing critical obstacles. However the MDQ-only route did provide substantive proof of program functionality and method, as well as leading to some rewarding interviews. Saturation was not achieved by these interviews in Sydney and London, and their small number meant that anonymity could not be guaranteed, so further interviews are sought. They might be conducted within the 'person-as-researcher' concept, see 4.6.

4.5.5 Adaptation: the MDQ route

Patients with an upcoming appointment who were currently in the Mild Disease state or Remission found themselves directed down a MDQ-only route in the aid, as opposed to being asked to exit the program. They would experience MDQ as a generic decision aid rather than as an outcome measure and be asked for their reactions to it in this role. In London the interim ethics report introduced the possibility of all patients going down the MDQ route regardless of their self-rated disease state.

While no patient went through the full IBD aid as part of clinical practice in London, and only 3 in Sydney, the technical functionality of the MDS program was established by the several patients who went through it either down the MDQ-only route or as ones invited outside the clinical context to provide feedback. Despite the revision, the numbers going down this route were too small - 20, with less completing fully - to claim more here than that the functionality of the program at proof of method level was established. The data from this phase will be written up in a subsequent paper.

4.5.6 Priorities and concordance

The Sydney research was able to take advantage of the software enhancements which were occurring throughout the thesis period, notably the increased math functionality which enabled more efficient feedback of the potential source of increased decision quality in future consultations. Moreover, if the consultant was willing to enter his perception of the patient's weights and his own ratings into a parallel version of the instrument, we have the basis for a decomposable measure of concordance. This would indicate how future decision quality could be improved, by providing an element-by-element break down for clinician and patient separately.

It will be recalled that MDQ provides patients with help in prioritisation for future decision making by calculating, for each criterion, the Incremental Value of Perfect Rating, i.e. the increase in their decision quality score that would result if their performance rating on the criterion were 100%, weighting unchanged.

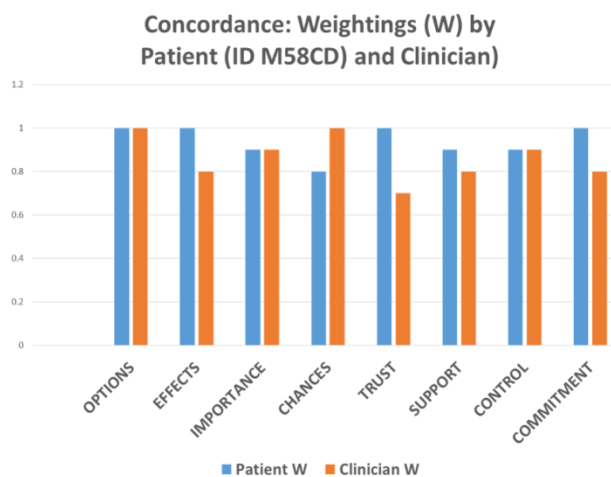


Figure 25: Weightings (W) data for one dyad involving a patient with Crohn's (CD) using MyDecisionQuality

The potential to implement these priorities clearly depends on many factors in the particular clinical setting and dyadic relationship, but also on the concordance on the weightings and ratings. The Sydney gastroenterologist

was willing to provide (the clinician version of MDQ), his perceptions of the patient’s weightings (without access to those previously seen) and his own ratings for the quality of the decision taken. One of these Weightings comparisons appears in Figure 25.

In illustrative results for two dyads (Figure 26), one displayed perfect concordance on both Weightings (W) and Ratings (R) for options and control, but otherwise a different W distribution. The other dyad showed more discordance. The Mean Squared Differences of Weightings and Ratings were .0275 and .0175 for the former patient and .0150 and .0025 for the latter. The Mean Absolute Differences (ignoring signs) of W and R were .1250 and .1000 for the former and .1000 and .0250 for the latter.

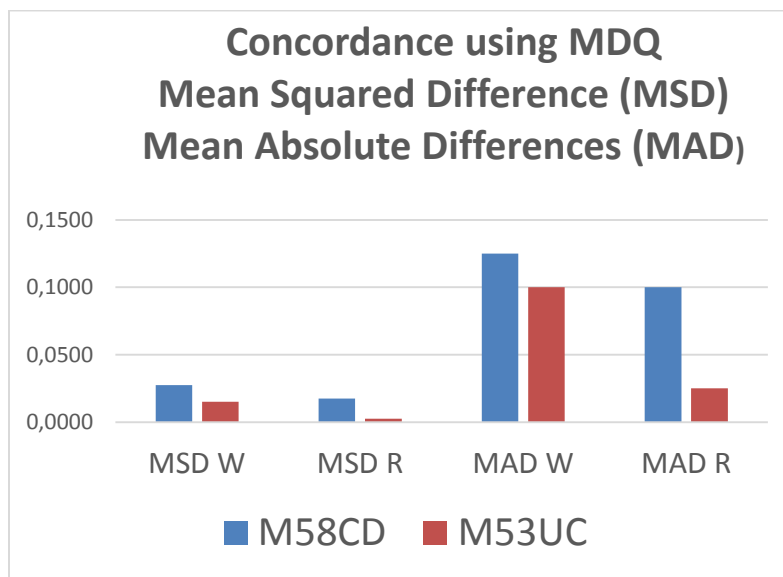


Figure 26: MyDecisionQuality Weightings and Ratings concordance for two patient and clinician dyads [male aged 58 with Crohn’s Disease (CD) and a male aged 53 old with Ulcerative Colitis (UC)]

The documentation, including a graphic picture of the decision quality assessment, can be saved and printed for communication and consent.

We decided not to return to seek Sydney ethics approval to communicate the concordance results to the other party, including each other’s ratings of the consultation. This would be essential if it were to provide the basis for dyadic discussion and change in the content of future consultations.

We were satisfied to be able to establish the feasibility of dual elicitation and generate measures of the overall extent of concordance, defined as the mean squared and absolute differences for ratings and weightings (Figure 25 and 26), as well as the underlying detailed breakdowns criterion by criterion (data not shown).

4.5.7 Patient interviews and written weblog comments

Several patients with IBD agreed to go through the aid outside the context of an upcoming consultation. These intensive interviews constitute a rich resource from the point of both existing decision making processes in IBD

and the potential of an MCDA-based aid to influence that process in a desirable direction from the patient perspective.

The patients who consented to interviews at both settings shared many challenges and constructive ideas to improve their care and symptom control treatment, preventive pathways, and health promotion. The richness and relevance is conveyed here by two short excerpts from the written comments provided by two women in their weblog. Their selection for use here is purposeful, chosen to show the importance of shared decision making in a health team and the potential for supplementing quantitative and qualitative approaches in relation to MDQ.

The consultant may at times overestimate my capacity to understand the technical aspects of my situation, for example, by using names of drugs with which I don't have great familiarity and which I need to clarify with him. Additionally in my case the opinion of another consultant (my surgeon) would also help in the decision making process as the consultant and I had a different recollection of why previous actions had been taken (year ago), particularly by the surgeon. A higher level of discussion between the relevant consultants would be useful, instead of them tending to work entirely within their own spheres. This was something I also noted when I was actually in hospital having surgery and treatment [Woman with CD, about 60 years old, MDQ route]

I am extremely pleased with the quality of care I receive from both my surgeon and Gastroenterologist. I believe they always provide me with all possible options available to me without pressuring for or against, allowing me to come to my own decisions at my own time. I trust their knowledge and judgement. Therefore, this survey to me personally has not really effected my decision making process, it may have made me think a little more in depth about how I honestly have come to make the many decisions I have made now and over the years in regard to treatment with the consultants I see, and I believe the selected criteria are well chosen. Although this survey may not change my personal decision, I do believe it is a great tool for those patients who are having difficulty making these huge life changing decisions, allowing them to think more clearly about the support, care and knowledge they need with the help of this break down [Woman with CD about 30 years old, MDQ route]

Made me think about asking if there were alternate medicines that could be used, and what would be the pros and cons of doing so. [Written comments from the man with CD shown in Figures 25 and 26 as having a MDQ score 0.953 and SWD score of 29/30 (i.e. 0.967. MDQ route)]

Each person provided rich data for future qualitative analysis and all found possible future benefit of some sort from being asked to reflect on the qualities of a good decision. The Sydney PI reported that a patient with aphasia took part as she was able to communicate via computer, whereas during 'normal care' she was not able to take active part herself. Another example is provided by a couple interviewed who were presently expecting a child and facing the uncertainty and different trade-offs involved (Habal & Huang 2012). The transcribed data will be used in a qualitative paper (Dibley et al. 2010; Dibley et al. 2014) which may well highlight the difficulties of nutrition and coming out as in IBD sufferers. The experiences shared by these patients helped inspire the wider perspectives of 'persons-as-researchers' reconceptualisation reported later. These experiences need supplementation to ensure anonymity of the participants and their trust in health care and research. A fresh press release introduces the concept of a meta-consent (The Danish Council of Ethics/Det Ethiske Råd 2015).

4.5.8 Conclusion

Owing to unforeseen NHS cost cutting, severe time constraints, and competing priorities, the proposed recruitment of London patients by the specialist IBD nurses on their Advice line was not possible. Overall, time and resource constraints had different impacts in the two settings but shared problems in pursuing the original objective and recruitment targets in the form of identifying qualifying patients in time for them to access the support tool before their consultation.

One of the reasons advanced for the difficulty in implementation of the aid was that I, as researcher, was not physically on the spot, as opposed to being available by any other means of communication. While this was undoubtedly true given the practice resource pressures being experienced in the research setting, such continuous presence would quickly have become delivery by researcher and thereby invalidated the research. Delivery by researchers is not delivery of the aid in anything approaching normal conditions. Specifically it would not be the professionals undertaking those aspects of the delivery process outlined in the study design and agreed at the outset.

The dominant theme throughout the development and attempted delivery of the IBD aid was the emerging and increasing inability of the clinical partners to participate in the manner, and to the degree, they offered at the initial planning meetings. This was much more the case in London than in Sydney where a solo consultant practice gave the clinician greater control in respect of patient load. In London this inability seems to have resulted largely from the time and resource constraints, which were substantial at the outset and increased objectively during the research period as a result of institutional cutbacks. There may also have been some increasing doubts about the value of the aid as a source of improved care, but it has not proved possible to separate these from the major logistical issues which arose in recruitment and delivery.

Asked about implications by the decision resource developer to reflect on the overall potential of the decision aid, the Sydney clinician suggested it would likely be more helpful for patients than him personally (because of his 30 plus years of experience) but 'ask a young gastroenterologist' who might well benefit considerably. It was clear that while he saw the advantages of an MCDA-based approach in allowing the patient to articulate what mattered to them more explicitly and precisely there was no easy way to merge that with his traditional clinical reasoning. Our conclusion is that it is necessary to emphasise that these are two distinct approaches to decision making and that it is better not to try to merge them, but to consider each as producing an independent opinion. How any dissonance between the opinions is dealt with cannot be settled outside the specific clinical relationship or specific clinical dyad.

Confronted by the fact that very few of their patients had a chance to benefit from its use, the Sydney consultants have agreed to make the aid using their ratings available on open access. This would enable IBD patients across Australia to explore a variety of scenarios, though only on a hypothetical basis, not dependent on their current disease or health status. This is now a part of a wider initiative <http://www.healthdecisions.org.au/> website at the Sydney School of Public Health. The next planned phase includes the IBD patient organisations providing a link and issuing invitations. As a result we will obtain more experience and dually-personalised data to further develop the tools for open access deployment to help meet the challenges that persist for all concerned about IBD and wider health decision literacy.

The difficulties experienced in implementing the IBD aid, even in the less complex Sydney setting, led to some fundamental thinking about whether the pursuit of increased decision quality within the existing structural arrangements was the most effective route. The following subchapters and final included Papers IV and V report some of the results from that rethinking. First, the reconceptualisation of the patient as a ‘person-as-researcher’.

4.6 MCDA-based decision resources for ‘person-as-researcher’

IV: Increasing user involvement in health care and health research simultaneously: A proto-protocol for “Person-as-Researcher” and online decision support tools.

The disappointing aspects of our experiences in the empirical research on aid implementation, recounted in 4.5 were to have positive consequences. The fact that many of these experiences were in line with those reported by others (Elwyn, G, et al. 2013; Wyatt et al. 2014; Elwyn et al. 2012) encouraged us to rethink some of our basic assumptions about the best way to pursue the overall aim of improving decision quality in health, healthcare, and health research. This rethinking took us more deeply into the field of ‘user involvement’ than had previously been the case, as well as to revisiting the translation literature which had been one key background to our research and development efforts. It also involved raising questions about whether existing approaches to health literacy and decision support were failing to capitalise on existing competencies in the community and whether they were focusing excessive attention on information relevant within existing medical arrangements, rather than within a wider approach to health as part of personal life and decision making.

Ultimately what seems a significant reconceptualisation emerged and this became the basis of an umbrella protocol for future research, beyond the current thesis, but utilising the IBD program successfully developed and functionally tested during it (4.5), as well as others of the same sort developed for other conditions for the Sydney website <http://www.healthdecisions.org.au/>

4.6.1 User involvement

An overview of recent calls for increased user involvement in health care systems quickly revealed a complex mix of motivations and interpretations (Shippee et al. 2013; Mavis et al. 2014). These were reflected in the diversity of terms and interpretations for both user (client, customer, patient, person) and involvement (participation, engagement, activation, emancipation) (Corrigan & Tutton 2006; McLaughlin 2009). It was not surprising, then, that many and varied approaches to increasing user involvement have been canvassed, and implemented in some cases, without serious, comparative empirical evaluation.

One striking feature of both the literature on (Lee & Nørgaard 2014) and practice of, user involvement is the fact that involvement in research (column 2-4 of Figure 27 below) is seen as completely differentiated and distinct from involvement in health care (column 1 dark blue). This applies whether the focus is on individual or community. The growing interest in research about user involvement in care at both levels requires us to add extra column 3 and research about such research extra column 4. (We have added column 1 to the (Lee & Nørgaard 2014) classification).

Another feature of the literature was that the involvement in research and community level care was to be undertaken almost exclusively through a representational approach, where selected users were given 'a seat at the table' where decisions on research issues (e.g. study design, dissemination strategies) or community policy (e.g., reimbursement decisions) were taken. At these tables the decision making process would be a combination of deliberation and intuition, with no formal MCDA, and draw heavily on expertise that the user representatives do not possess.

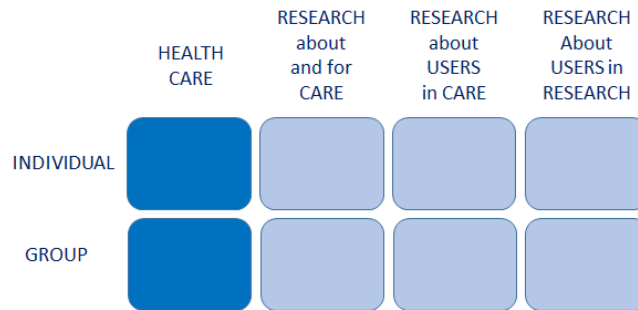


Figure 27: Taxonomy of user involvement in healthcare (dark blue) and healthcare research (light blue) adapted from (Lee & Nørsgaard 2014, p.14)

Within the status quo, three types of reason are usually given for involving patients in their care: improving patients’ rights, improving their health, and contributing to organizational learning (Groene 2011). And a matching set of three are typically given for involving users in healthcare *research*

Public involvement in health research is underpinned by epistemological, moralistic and consequentialist arguments. The epistemological argument states that health research can benefit from the experiential knowledge and personal insights of patients, carers and service users. The moralistic argument states that the public have a right to be involved in any publicly funded research that may impact on their health status or the services that they receive. Finally, the consequentialist argument states that public involvement helps to improve the quality, relevance and impact of health (Boote, Wong, et al. 2012, p.2)

The complete separation of care and research is clear in these statements and in the growing body of research on user involvement (Barber 2014; Barber et al. 2012; Boote et al. 2011; Boote, Baird, et al. 2012) including that on more emancipatory approaches in the tradition of Paulo Freire (Schneider 2012; Beresford & Croft 2012). That clear separation was to come into question in our rethinking. The resulting project introduced here involves a fundamental reconceptualisation of the user and of the border between healthcare and healthcare research.

4.6.2 The reconceptualisations

The difficulties of introducing MCDA-based decision support within existing clinical arrangements, with patients being given access through the provider, led us to ask whether such resources could be provided on wider access in the community. The user as person as well as patient could access them and use as they decided, including bringing them to the clinical setting.

Following this line of thought, but also reflecting on the patient interviews in 4.5, we were led to conceptualize the person as a researcher who is engaged in a continual, living, informal “n-of-1”-type study (Lillie et al. 2012; Duan et al. 2013) of the effects of different actions and interventions on their own health, including those that involve contact with health care services as well as personal and online resources. Secondly, while their research might be primarily carried out in order to make better decisions for themselves, if they engage with decision support resources on open access, they could offer to contribute the results to the wider population, either because it could eventually lead to better, or better-evaluated, interventions for themselves (through policy

changes) or because it could contribute to some wider public health goal. If they did so, they would become part of the research team not subjects of the research.

The explicit aim of the person-as-n-of-1 researcher approach is therefore to increase the individual's involvement in healthcare practice and health care research *simultaneously*. The basis of the approach, through online interactive decision tools available as open access resources, differs significantly from most others on offer, and these differences extend to the theoretical and empirical bases of the aids.

Our online decision support tools, delivered directly to the person in the community and openly accessible, were now to be regarded as “research resources”. The tools take the form of interactive decision aids for a variety of specific health conditions based on the template introduced in 4.2, as well as a generic one that aims to support all health and health care decisions through its focus on key aspects of decision quality, introduced in 4.3.

In the rethinking and reflection on empirical experience it became clear that MDQ, which had initially been conceptualised only as an outcome measure, was actually functioning also as a generic decision aid, one that could facilitate fuller informed consent when the weightings part was positioned at an early point in the decision making process.

As outlined in 4.2 and 4.3 the tools focus directly on the person-as-researcher's fundamental question, ‘What should I do?’ This requires answers to the two subordinate questions: ‘What should I believe?’ and ‘What do I prefer?’ They generate an *opinion* that integrates a set of beliefs, in the form of the Best Estimates Available Now (BEANs) for the performance of the relevant options on criteria that matter to the person, with their preferences, expressed as relative importance weights for those criteria. The integration, by a simple and transparent expected value calculation, produces a set of scores for each option that constitute the opinion produced by the process - nothing more and nothing less.

For some criteria, the person is themselves the expert source of the BEANs, since they measure the impact of options on their personal life. The difficulty, burden, or bother associated with administration routes for medications or journeys to provider facilities are good illustrations of where different individuals may make very different BEAN assessments. All persons-as-researchers contribute their individual preferences to the opinion as criterion importance weights.

Many who consult the tools in the course of their research will be satisfied that they have received a personalized opinion for their own private use. But they can offer to contribute the results of their n-of-1 research to an n-of-n database, by registering with the site by named email and declaring any conflict of interest. Their name will appear in any publication based on the aggregation of the individual results, though personal results will never be displayed. They receive feedback *as part of the research team*.

Most of the key requirements for accessibility, usability, and functionality of patient-centered decision support, whether they come in the form of computer-based decision aids or traditional professional interaction, apply equally to the design of aids to be presented as research resources (Lyden et al. 2013; Lorig 2012; Lown et al. 2011). Nevertheless, the re-conceptualization from patient to person-as-researcher does have major implications in the tone of address and register adopted. Most importantly, our decision support tools should not be seen in any way as providing care, or as a way of delivering better care. They are offered as an optional resource available for accessing in the person's own pursuit of the sources of better care. However, they also provide a

way that users can add the results of their engagement to those of others - if they choose to provide a general (meta) consent (The Danish Council of Ethics/Det Ethiske Råd 2015).

4.6.3 Health decision literacy

Within the conceptualization of person-as-researcher, those who lack the capability to function as effective researchers should be supported in their efforts to achieve that capability (Entwistle & Watt 2013) through measures to increase health decision literacy and numeracy, especially in disadvantaged populations. But it is important to be wary of confining concepts of health literacy to functional forms, such as ability to read drug labels. This can amount to what Bourdieu has called 'symbolic violence' (Adkins & Corus 2009).

'Symbolic violence' is committed, however well-intentionally, by the imposition of particular conceptualizations of what information, in what form and quality, is needed in order to make an 'informed choice' and hence - by segue - a high quality decision. The social and cultural forms of capital possessed by those who fail, because of their low general literacy, to pass professionally-set knowledge tests of functional health literacy, are ignored. But failing to recognise and exploit a particular form of functional decision literacy, also leads to the symbolic violence experienced by individuals at any and all levels of general literacy. It leads many of high general literacy to adopt the same range of avoidant and other apparently undesirable strategies such as non-adherence observed in those of low basic literacy (Laba et al. 2012).

The alternative response we propose exploits the alternative generic *decision literacy* which comes in the form of the ability to access and use the decision-relevant resources provided for many consumer services and products on comparison websites and magazines. The methodology is the simple form of multi-criteria analysis in which the products 'ratings on multiple criteria are combined with criterion weights (supplied by the site) to produce scores and 'best buys' and 'good value for money' verdicts. As established in earlier chapters, our approach extends this approach to healthcare options and permits the incorporation of the individual's criterion importance weights in furtherance of person-centred care. (For the reconceptualisation in relation to information provision which draws on the same argument, see subchapter 4.7. and related paper F.)

4.6.4 The hypothesis and protocol

Our underlying hypothesis concerns the person-as-researcher who is equipped with a prescriptive, transparent, expected value-based opinion that combines their criterion importance weights with the Best Estimates Available Now (BEANs) for how well each of the available options performs on each of those outcomes. The hypothesis is that this person-as-researcher is more likely to be able to position themselves as an active participant in a clinical encounter, if they wish, than someone who has engaged with a descriptive decision aid that attempts to work with their existing cognitive processes and stresses the importance of information. Research that opens the 'black box' of the clinical encounter (Wyatt et al. 2014; Joseph-Williams et al. 2014) is revealing less and less impact from the latter approach to decision support. We feel this is most likely attributable to their failure to provide the person with powerful enough ammunition to move clinicians away from their preferred consultation structure and preferred course of action, reflecting tradition, training, time and regulatory constraints. Training and increased decision literacy is needed (Gigerenzer & Gray 2011; Zeuner et al. 2014; Barry 2012). This is particularly likely to happen in the situation where the evidence is low (Politi et al. 2013).

Our decision resources (MCDA condition-specific aid and MDS generic) are designed explicitly for those who wish to be able to involve themselves in clinical decision making as persons who are empowered (emancipated, enabled, and armed) by their prior research. They are also intended for those who wish to keep open such positioning as an option, even if it may not eventually be exercised.

Researching one of our relevant tools will yield an opinion, based on principles that they have accepted (for their research purposes) and inputs they have supplied. We assume that the person opts into obtaining the opinion as part of the research basis for their decision involvement and emphasize that they are free to reject its content or use it in any way they wish in any subsequent decision communication with a clinician.

A bonus resulting from the use of both condition decision-specific and generic aids comes in the form of the enhanced and automatic documentation of the process. The outputs can be saved by the person-as-researcher and incorporated into their provider's and own health record/s, if desired and subject to interoperability being established.

We have developed an umbrella protocol for the condition-specific studies that will implement our approach and facilitate testing of the hypothesis. It is organized using the Populations, Interventions, Comparators, Outcomes, Timings, and Settings (PICOTS) framework (Thompson et al. 2012). Full details are available in Paper IV.

The comparator is particularly crucial. In our opinion, all user involvement interventions should be evaluated with a comparative methodology using the same empirical comparator, for example an instrument, and not a normative checklist. In other words, evaluation should be based on the same principles applied to drugs and devices. The relevant comparator will necessarily be a 'usual practice' arm, and we welcome the opportunity to engage in an empirical comparison with all other proposed interventions on a 'level playing field'.

4.6.5 Translation

Clinical decision making occurs as the final 'bedside' stage of most translation models of the research-into-practice process. In many ways, it is the most complex stage to understand, to assess, and to intervene. In an increasingly multi-cultural environment a more team-oriented health care practice is required, one which accepts the need for transdisciplinary competencies (Satterfield et al. 2009; Bellamy et al. 2013; Papadopoulos 2006).

We believe the inclusive Callard et al. model is the most appropriate one for a person-centered health care system (Callard et al. 2012). The user, now person-as-researcher, is separately placed in the middle of the model, rather than at the end of a translation pathway, or at one point in a cyclical translational system. Consequently they have direct impact on, and input into, all stages on the forward translation continuum from 'bench to bedside'.

In a small but significant modification to the Callard model, we see the person-as-researcher at the center is equipped with a decision support tool based on person-important criteria. The BEANs in their personalized resource represent the product of all necessary and practical forward translations needed at the point of decision, while the assessed quality of the BEAN for each cell constitutes the basis for backward translation to research priorities. In contrast (but not opposition) to the James Lind Alliance approach, which focuses on developing specific questions for researchers (Lophatananon et al. 2011), priorities are indicated by the potential score gains for options from higher quality criterion ratings, given the criterion weights.

The Callard model of translation from the Introduction is modified to place the user at the centre of the model as a person able to access web-based decision resources in the form of the MCDA-based decision support tools.

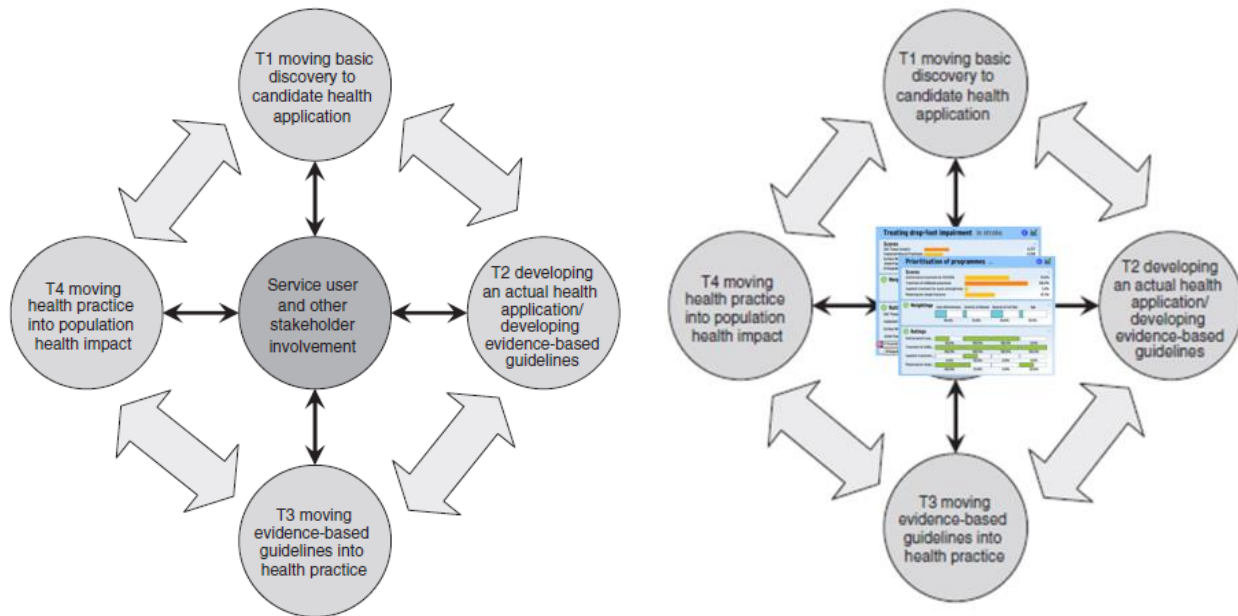


Figure 28: Original Callard et al model and model with Annalisa-equipped user

4.6.6 Conclusion

Web-based decision resources can provide fast and efficient access to the results of slower thinking and encourage individuals to take a more involved role in their health production by viewing themselves as researchers involved in ongoing n-of-1 type studies. Some basic distinctions, such as those between science and non-science, research and practice, community and individual, and lay and professional become somewhat blurred and will need to be rethought in the light of this approach. The future research we contemplate within this model will be taking place in the context of continuing and new experiments in user involvement. The challenge will be to ensure that experiments which question key assumptions of the status quo are considered for support.

4.7 Information provision as a preference-sensitive decision in person-centred care

V: Who should decide how much and what information is important in person-centred care?

In the preceding subchapter we noted how reconceptualising the person as a researcher had implications for the way in which our web-based aids were to be interpreted and used. They would become decision research resources on open access to the community rather than patient decision aids *per se*. A second consequence of the rethinking was an examination of the role played by information possession in the provision of decision support and the assessment of decision quality.

It seems taken-for-granted by most of those interested in a patient's healthcare decision making, and in providing decision support for it, that only an 'informed' decision can be a good decision, let alone the best possible decision. Being informed is seen as a necessary, almost sufficient, condition of decision quality, even when there is little agreement about what the necessary information is and no guarantee that the information, if possessed, can be understood and translated into a form directly relevant to the immediate decision. In the context of our development work and reconceptualisations it appeared time to further question the orthodoxy, as has already been done in an implicit and limited way in subchapter 4.3.

Against the background of the vast literature on normative, prescriptive and descriptive approaches to decision making (Lipshitz & Cohen 2005) we do not have the absurd aim of defining a good decision. We merely make a narrow point concerning the place currently assigned to 'being informed' in assessing the quality of a clinical decision. From the perspective of person-centred health care, the assumption that 'being informed' can, and should, be defined external to the individual at the point of decision, needed to be challenged. This included questioning the closely-related assumption that the relative importance to be attached to information criteria in evaluations of clinical decision quality and decision support tools can be defined without reference to the preferences of the specific individual in the specific clinical setting, or indeed any decisional context.

Currently, decision quality is being assessed formally or informally by methods that are dominated by the *externally-defined and assessed* information state of the patient. As a result, he or she is denied the right to decide the attributes of a good decision and assign their own personal importance weights to those considerations, including how much and what information is important. This led to our formulating the central question as 'Who should determine what and how much information is important in person-centred healthcare?'

We can make the key point in a concrete way by referring to the evaluation of the decision aids being produced by Karen Sepucha and colleagues (Lee et al., 2014; Sepucha, Feibelman, Cosenza, Levin, & Pignone, 2014; Sepucha et al. 2011; Sepucha, Belkora, et al. 2012). While these decision quality instruments contain both knowledge and goals/values components, only the knowledge score is available at an individual level. The values component of quality is processed only at a group level in terms of the statistical relationship between goals and eventual actions. Their recent herniated disk decision aid study provides a good example of what is advanced as a decision quality instrument, but at the individual level reduces to a measure of the knowledge possessed by the patient after administration of the aid (Sepucha, Feibelman, et al. 2012). This is, not unexpectedly, the knowledge that was provided in the aid, on the basis of what was regarded necessary for the choice to be regarded as 'informed'. 'The mean knowledge score from the patient sample who viewed the decision aid can be used to set a threshold for informed patients of 55%'. The setting of an arbitrary 'pass' mark

is symptomatic of the group-level approach and the choice of 55% lacks any justification apart from being the mean for the group. We find the argument to be essentially circular, but the issue is not only whether a patient's knowledge of the information deemed necessary is incorrect, while being perceived to be correct. This may be important, but the more important issue is whether showing that it is incorrect and attempting to correct the misperception, by providing the correct information, will lead to a *better* decision, as opposed to possibly an 'informed decision' according to the orthodox metric. And whether with the best of intentions the attempt may constitute 'symbolic violence'.

As pointed out in the preceding chapter, 'symbolic violence' is committed, however well-intentionally, by the imposition of particular conceptualizations of what information, in what form and quality, is needed in order to make an 'informed choice' and hence - by segue - a high quality decision (Adkins & Corus 2009). The social and cultural forms of capital possessed by those who fail, because of their low general literacy, to pass professionally-set knowledge tests of functional health literacy, are being ignored. But failing to recognise and exploit a particular form of functional decision literacy, also leads to symbolic violence, experienced by individuals at any and all levels of general literacy. It leads many to adopt the same range of avoidant and other undesirable strategies within healthcare situations observed in those of low basic literacy. (See related paper G)

The alternative response we propose exploits that alternative generic decision literacy which comes in the form of the ability to access and use the decision-relevant resources provided for many consumer services and products on comparison websites and magazines. The methodology is the simple form of multi-criteria analysis in which the products' ratings on multiple criteria are combined with criterion weights (supplied by the site) to produce scores and 'best buys' and 'good value for money' verdicts. Our alternative approach extends this approach to healthcare options and permits the incorporation of the individual's criterion weights in furtherance of person-centred care. It provides decision support that does not imply that only an 'informed choice' can be a good decision, with the qualification for 'being informed' imposed from above, including in guidelines produced, with the best of intentions, by international collaborations (Joseph-Williams et al. 2013).

The reconceptualisation can be best introduced through the homely analogy of purchasing a home appliance like a refrigerator. With products and services of most sorts, many people now regard good practice decision making as consulting trustworthy comparison websites and magazines, ones that go beyond expressing opinions, or recording 'likes', to numerically rate the alternative products on a set of attributes or criteria. (Comparison websites have become a major feature of rapidly expanding e-commerce. In the UK, the commercial Comparethemarket.com was receiving more than 2 million hits per month in 2010. And the U.S. non-profit monthly Consumer Reports, which publishes reviews and comparisons of consumer products, has approximately 7.3 million subscribers (<http://wikipedia.org>). They go to these sites to find ratings that can be trusted because they are produced free of any conflict of interest or other biases. (As stated, we refer to these performance ratings as the BEANs – Best Estimates Available Now.) The consumer does not know, and does not want to know, why this refrigerator is given a 4*/80% rating on 'reliability', and a 3*/60% rating on 'environmental impact', and another brand has the opposite ratings. Feeling justified in assuming a common sense, lay understanding of the terms 'reliability' and 'environmental impact', they do not have either the time or motivation to find out more about what these concepts mean, in terms of the mechanical functioning of the refrigerator, the quality of its

components, the emissions it produces or whatever else contributes to these ratings made by the expert assessors. They do not want to know more about how a refrigerator works.

Some may wish to establish whether consumers buying a refrigerator have made ‘an informed decision’ by seeing how well they score on a test of refrigerator knowledge. Giving considerable and fixed weight to knowledge in their measures of decision quality, consumers’ decisions might be regarded as poor quality, because their knowledge score is low. They need to be better informed to make a high quality decision. In contrast, the consumers may regard themselves as having made good decisions, indeed the best possible decisions they could make, given the time and cognitive effort they are willing to devote to research in their decision making process.

The other major problem with any imposed information requirement is that it condemns many on the continuum of health literacy, and especially health numeracy, to receiving little or no help. We fully support attempts to reduce health illiteracy and innumeracy, especially their decision-focused forms. However, it is too much to expect of a decision support tool – or a clinician – to overcome the limitations of previous education and socialization in these respects. Moreover, it is important to accept that even if aid users are able to register and report the relative numbers of sad and smiley faces in frequency diagrams, or repeat back ‘1 in x’ statements – about which there is considerable doubt (Stovring et al. 2008; Sorensen et al. 2008; Dolan et al. 2012; Harmsen et al. 2014) this does not in any way ensure that they can meaningfully incorporate the numerical probabilities they have correctly registered (say 10% and .05%, or 1 in 10 and 1 in 2000), into their decisions. This is not to say that a decision aid should not contain help in this respect, including guidance on how the person can best avail themselves of what it offers, and information on the bases of that offering. It is to suggest that much of this should be provided on an opt-in basis.

Normative checklists for decision support tools, such as those constructed in accordance with the guidelines of the IPDASi collaboration (Elwyn et al. 2009) are clearly intended to promote person-as-patient empowerment. But most decision aids that comply with these guidelines are designed for use only within the context of shared decision making, in which the person is assigned the status of patient. In many cases, the support can be accessed only within the clinical encounter, or with provider permission. They all perpetuate the idea that only a decision informed in a particular way and to a particular extent can be a good decision. We do not need the concept of an ‘informed decision’, only that of a good, better or best possible decision. For none of last three will there be a definition that is not multi-criterial and therefore preference-sensitive. The question is to whose preferences (criteria and importance weights, including those relating to information) should the definition be sensitive? There can only be one answer: the person’s, whether or not they are a patient.

Subject to the rights of other persons, that is. Nothing in what we have said is intended to imply that the community is not entitled to apply community-level criteria and weights to what it provides, or allows to be provided, to whom, under what conditions, and at what cost, in the pursuit of goals such as efficiency, equity and justice. Formal laws and regulations (including those on informed consent and clinician liability) and resource allocation policies (including reimbursement decisions) will make up the context in which the individual decision are made, and they will frequently be in conflict with what the individual sees as best for him/herself, given their personal criteria and weights. External consequences for others may trump an individual’s preferences, as in the case of infectious diseases, and legal standards may or may not be compatible with person-centred care. But that is life as lived by person-as-citizen in society.

5.0 Discussion

The period since the outset of the research, has shown increasing interest in all the themes identified in the Background. Looking back at its stated overall aim - to explore the potential of web-based decision support based on MCDA to increase decision quality at the individual level - there have been few major changes from our perspective, despite a vast increase in the quantity of projects and studies in the field.

5.1 Multi-Criteria Decision Analysis (MCDA) and person-centred care

One clear trend has been the increased prominence of the MCDA technique in healthcare discussions (Diaby et al. 2013; Tony et al. 2011; Goetghebeur et al. 2008; Thokala & Duenas 2012; Claxton et al. 2015). However, this has only been in relation to policy level decisions and associated exercises as health technology assessments. With rare exceptions and then only in a poster (Tony et al. 2012), MCDA has been considered for use exclusively in the policy context. Battles over resource allocation have led the existing Cost-Effectiveness QALY-based analyses being questioned and wider multi-criteria approaches canvassed as alternatives. Even the main champion of MCDA-based clinical decision support seems to have moved towards pure information support, albeit using an updated 'dashboard' approach (Dolan, Veazie, et al. 2013).

Given its prescriptive basis MCDA is a paradigmatically different approach to decision making and support than that deeply embedded in current healthcare. The conclusion to be drawn about the future of MCDA depends on one's attitude to, and definition of, person-centred care. If it is defined as we have done in earlier chapters and papers, there seems to us no other route than an MCDA-based one to ensure transparency. It is the only one which empowers the person by having their preferences as importance weights over the criteria explicitly elicited and entered transparently into the decision process.

Clinicians and providers will have to learn the decision matrix language familiar to many coming to appointments with them as a result of contact with product and service comparison websites. They will have to focus their expertise on producing the personalised cell-specific ratings rather than relying on population-level evidence on options, such as found in guidelines, inevitably based on average preferences. It is obvious that, for both cognitive and resource reasons, effective and efficient MCDA-based decision support tools for this new 'clinical judgement' are the most likely solution, while being far from a panacea.

Patient/person-centred care remains controversial once it attempts to move from talk to walk. Blumenthal-Barby et al (Blumenthal-Barby et al. 2013) exemplify one common concern in arguing for 'nudging' as often being an ethical and professional obligation. However, their definition of nudging - always a contestable concept (Hansen & Jespersen 2013; Langrial et al. 2013) - often comes very close to persuasion, if not manipulation or deception. They fail to accept that they are simply rejecting the autonomy of the person. Assuming that they do not simply want to say the person has the 'wrong' preferences, they are on the slippery slope to believing that the person would have a different preferred option if only they had more and better information, or a better grasp of it. What we do not find in the whole descriptive MCDDeliberation literature is the situation where the person's outcome and process criteria have been *explicitly* elicited and discussed, along with the Best Estimates Available for the performance of each option on them, in order to arrive at an opinion on the best option minimally influenced by any prior, or clinician-provided, option preference. The possibility of nudging always exists, but is at or near the maximum level of exposure, in a MCDAnalysis-based approach.

It is important to clarify that Motivational Interviewing (MI) has no place at the point of decision, since it assumes that an optimal decision has already been made and that the task is to motivate the individual to implement that decision (Rubak et al. 2005; Elwyn et al. 2014).

5.2 Shared decision making, user involvement, and decision support

A bibliometric analysis, conducted within a scoping review, has documented the exponential growth in Shared Decision Making (SDM) publications in the period 1996-2011 (Blanc et al. 2014).

The background literature was dominated by the metaphors of ‘barriers’ and ‘blockages’. This was true of the translation literature, concerned with failures or weaknesses in the movement of evidence from ‘bench to bedside’. But it was also true of the research focusing on the ways patients could be more involved in decision making at the bedside, usually within a SDM approach and involving some sort of patient decision aid. The barriers were relatively easy to list (da Silva, 2012; Légaré et al., 2010, 2008) which remain unchanged three years on: time and resource constraints; clinician commitment to the existing way of doing things as best practice within the specific disciplinary or practice setting; clinician belief that while of general merit the approach and/or aid did not match this particular patient population’s needs, lack of awareness of, or interest, in alternative ways that would be disruptive and call for changes in attitudes and competencies not included in existing professional capital.

The lack of incentives within the existing organisational arrangements and reward systems underpinned all of these. Some remain optimistic despite the magnitude of the obstacles (Agoritsas et al., 2015; Ahmad, Ellins, Krelle, & Lawrie, 2014; da Silva, 2012, 2014; Glyn Elwyn, Scholl, et al., 2013). However, there seems to be a tendency to accept that existing approaches to SDM and decision support are not proving as successful as was hoped, and that this approach is currently almost stalled and may need serious rethinking if progress in respect of ‘the many miles to go’ is to be made (Elwyn et al. 2013; Joseph-Williams et al. 2014; Elwyn et al. 2012).

Another and maybe underestimated reason for the lack of progress is that different disciplines or trained experts in a specific field tend to trust their own over others’ BEANs for example as pointed out in 1988

... considerable variation was found among experts in their decision on the basis of X-ray and endoscopy in patients with suspected duodenal ulcer disease. Gastroenterologists generally rely more on endoscopic than on radiographic findings. (Gjørup & Hartling 1988, p.583)

The history of reference values provides a fascinating insight into the nature and magnitude of the problem (Siest et al. 2013).

Our own empirical experience with MCDA-based support, given that our research study and approach represents a much more disruptive innovation than the conventional aids, confirms the difficulty of introducing innovations in complex systems. Rethinking seemed called for.

The rethinking by others, while in the same direction, has not so far extended outside the traditional box, though Légaré et al. see it may possibly be necessary to take the initiative away from providers because their

... results suggest that health professionals might be screening a priori which patients will prefer or benefit from shared decision-making. This is of some concern because physicians may misjudge

patients' desire for active involvement in decision-making. Therefore... future interventions will need to target the public and patients directly and not depend solely on health professionals' evaluation of the patient desire for active participation in decisions. In other words, patient-mediated interventions will need to be considered in order to foster the implementation of shared decision-making in clinical practice. (Légaré et al. 2008, p.533)

Grande et al (Grande et al. 2013) now seem to contemplate movement in this direction is necessary to make progress in Shared Decision Making (SDM)

... [there is a] lack of incentives, either extrinsic (payments or performance reports) or intrinsic (enhanced status or esteem), to support the adoption of these approaches. In fact, undertaking SDM may lengthen clinical encounters, or lead to potential loss of fee-for-service if patients decline procedures, issues that physicians may view as barriers. Patients also report a fear that physicians react negatively to individuals who ask questions or voice personal preferences.... Might a Community-Based Participatory Research approach, fostering a co-developed rather than an imposed solution, overcome perceived barriers to the adoption of SDM? An example of one such co-developed solution could be a decision support tool that serves the needs of the patient and physician by promoting collaboration within the clinical encounter rather than outside it. Two examples of these types of tools are Option Grids and Issue Cards... (Grande et al. 2013, pp.1–2)

However this type of approach, endorsed by others including (Légaré & Witteman 2013), involves intensifying the efforts to achieve change *within* the clinical setting. This, despite its limited success, essentially because the barriers seem much deeper than can be addressed by more collaboration.

These suggestions come closer to the approach we are exploring, even if they are still far from the open access to individuals in the community which we have concluded could be a more effective way to address the undesirable barriers and blockages to patient empowerment - as strong in 2015 as they were in 2012. Our 'person-as-researcher' approach might also be labelled as a community-based participatory research one, but it is based on a much wider concept of community than that proposed by Grande et al., as well as envisaging a very different shared clinical encounter.

Web-based social media are widely recognized as major part of future health and healthcare and we see our MCDA-equipped 'person-as-researcher' as part of this wider movement e.g. <http://www.webicina.com/> and <http://quantifiedself.com/>

5.3 Evaluating decision aids

It might be asked whether our IBD aid would meet the International Patient Decision Aids Standards Instrument (IPDASi) guidelines, widely accepted in the decision aid community which produced them (Elwyn et al. 2009; Joseph-Williams et al. 2013; Elwyn, Kreuwel, et al. 2011; Volk et al. 2013). Our questioning of the guidelines follows that of McDonald et al and echoes some of the concerns of Bekker about their prematurity (Bekker 2010). They point out that while it is stated that

the overarching goal of Decision Aids is to improve the quality of decisions and defines decision quality as the extent to which patients choose and/or receive health care interventions that are congruent with

their informed and considered values... key concepts underlying this goal such as informed and considered values are not, raising concerns about how one would know whether these goals have been achieved (McDonald et al. 2014, p.236)

And that

There are many theories of how people make decisions under conditions of uncertainty and we do not know which, if any, of these theories provided the underlying framework for the development of the quality criteria produced by the IPDASi Collaboration (McDonald et al. 2014, p.236)

Of particular interest from the perspective of our own research they note that

Patient recall of probabilities and patient understanding (e.g. interpretation of what the probabilities mean for them) are two different concepts, hence, the empirical evidence summarised in the Cochrane review [on the former] may not offer support that presenting probabilities facilitates patient understanding (McDonald et al. 2014, p.238)

These concerns about the IPDASi criteria are admitted to be 'counsels of perfection'. However, they are not our prime reason for rejecting those criteria. Our aids would indeed meet many of them and also respond to the concerns of McDonald et al. in relation to probability. We do not accept the checklist because it effectively condemns any aid based on prescriptive decision analysis. Implicitly, the IPDASi group seems to regard aids based on any version of decision theory, such as MCDA, as inappropriate, to the point of unacceptability.

5.4 Decision quality and concordance

In relation to MDQ we note the concerns of Sepucha 2014 (Sepucha, Matlock, et al. 2014) that the bases of instruments purporting to measure decision quality are not being adequately reported and that simple validity criteria are relevant, but not sufficient. The point remains that we still lack any suggestion as how to 'validate' a dually-personalised instrument such as MDQ, except at the population level, which would be inconsistent with its personal basis. Population level studies are poorly equipped to deal with preference-sensitive decisions in general and MDQ is based on the proposition that decision quality is preference-sensitive, with the preferences being those of an individual. As in the case of Sepucha's own Decision Quality Instruments (DQI), the focus of existing instruments is mostly on the evaluation of decision aids in *research* studies. This is very much at odds with our development of MDQ as a measure to be used in healthcare *practice* in the individual decision context, at or near the point of decision. See Figure 27.

The reduction of the DQIs to an information recall test, in which the 'informed' pass mark is set at the average for the respondents, cannot be regarded as an advance in the measurement of decision quality (McDonald et al. 2014). To our knowledge MDQ is the first ever dual-personalised measure of decision quality. Being generic it can be used for the evaluation of all decision technologies, especially those concerned with concordance. For example, in cases where parents are giving informed consent in relation to the treatment of their child/children (Bridges et al. 2001) or in the standard situation of inter-professional discordance (Bridges et al. 2013; Bajramovic et al. 2004).

The key issue is the wider one of whether it is a condition-specific or generic instrument that is 'fit for purpose', the purpose being determined by the decision taken (Dowie 2002). For most decisions we argue a generic

decision quality instrument is needed, one which the person/policy-maker can apply across all healthcare decisions.

5.5 The analytical-intuitive balance

There is little innate enthusiasm either among patients or providers for moving northwards towards the equator in Judemakia. We note that (De Vries et al. 2013) do not even include MCDA as an alternative to intuition and deliberation. There continues to be an almost exclusive investment in deliberative approaches (Elwyn et al. 2010). The 2000+ references in (da Silva 2014) are equally devoid of non-deliberative approaches.

Some (Nease et al. 2013) are skeptical about increasing patient engagement precisely because they doubt the willingness as well as ability of human beings to move from intuitive/fast/system 1 to the analytical/slower/system 2 mode of thinking called for in moving from Tiabimia to Analsysia in Judemakia (See 1.0 Introduction). But we have argued, hopefully convincingly, that it is unlikely that the talked objectives of patient and person-centred care can be walked without such a move. And that the move should take advantage of existing decision literacy, rather than requiring the acquisition of new forms, at the risk of committing symbolic violence.

The skepticism regarding promoting greater patient engagement also arises from what are seen as undesirable consequences from a provider/public health perspective. There are worries that progress towards public health goals will be jeopardised, though there are countervailing concerns that these can constitute ‘healthism’ (Skrabanek 1994; Hartling 2010). We argue that the inherent tension between the two should be addressed openly and MCDA is well situated to achieve this. This can make a major contribution to the health literacy initiatives by making the health decision the center of attention, for example in the EU (Sorensen et al. 2015), and help address the Aarhus Convention on Public Participation in Decision Making in Environmental Matters (Aarhus Convention (UNECE) 1998).

5.6 Costs

The evidence regarding the cost implications of SDM and decision support remains inconclusive (Stacey et al. 2014; Trenaman et al. 2014) despite the results of (Veroff et al. 2013) and (Arterburn et al. 2012) who found savings resulting from the reduction in invasive procedures in patients who had decision support for surgery decisions.

Walsh et al. performed a detailed systematic review (Walsh et al. 2014) to assess the potential of patient decision support interventions to generate savings, concerned that premature or unrealistic expectations could jeopardize wider implementation and lead to the loss of the already proved benefits. Their review yielded seven studies, four of which predicted system-wide savings, though two analyses were from the same study. The predicted savings ranged from \$8 (£5, €6) to \$3068 (£1868, €2243) per patient. As was predictable, larger savings accompanied reductions in treatment utilization rates. The authors concluded that while there is evidence to show that patients choose more conservative approaches when they become better informed, there is insufficient evidence, as yet, to be confident that the implementation of patient decision support interventions leads to system-wide savings.

The evidence that these tools act to inform and enable patients to determine the likelihood of benefit versus harm is clear and well proved... We acknowledge that the absence of evidence for savings does not mean we have evidence of an absence of savings, nor do our findings argue against the usefulness of

these tools – we believe that there is a strong ethical imperative to share decisions with patients whenever possible (Walsh et al. 2014, p.2,4)

At the personal level costs are incurred by the person using an aid and this is an important potential determinant of their effectiveness and acceptability. Joseph-Williams recommends, on the basis of the average time 83 participants spent on an online aid, that developers have roughly 20 minutes to provide useful information that will support informed decision making (Joseph-Williams et al. 2010).

5.7 Translation

Almost completely absent from the translation literature and from the suggestions of how the barriers and blockages might be reduced or eliminated, in the interest of enhanced care or improved decision making, was the use of an MCDA-based approach.

Translation models continue to seek to capture the complexity of the processes involved. However, as the one recently used in a presentation of a new ‘Health for All’ strategy, it fails to identify and make explicit the preference-based nature of the decisions that must occur in and between all the nodes in the pathways (media, culture, public opinion in the public realm embedding policy and health policy) (Faculty of Health Services & University of Southern Denmark 2014) - (Ogilvie et al. 2009) (Figure 29). This model therefore misses the opportunity, indeed necessity, to provoke discussion on whose and what preferences should apply at any and every juncture, and fails to provide any way of explicitly entering alternative sets of preferences to see the effect. Only a multi-criterial approach to these decisions, with user involvement based on an MCDA-based enhancement of the Callard et al model, seem likely to move things towards more transparent person- and citizen-centred care.

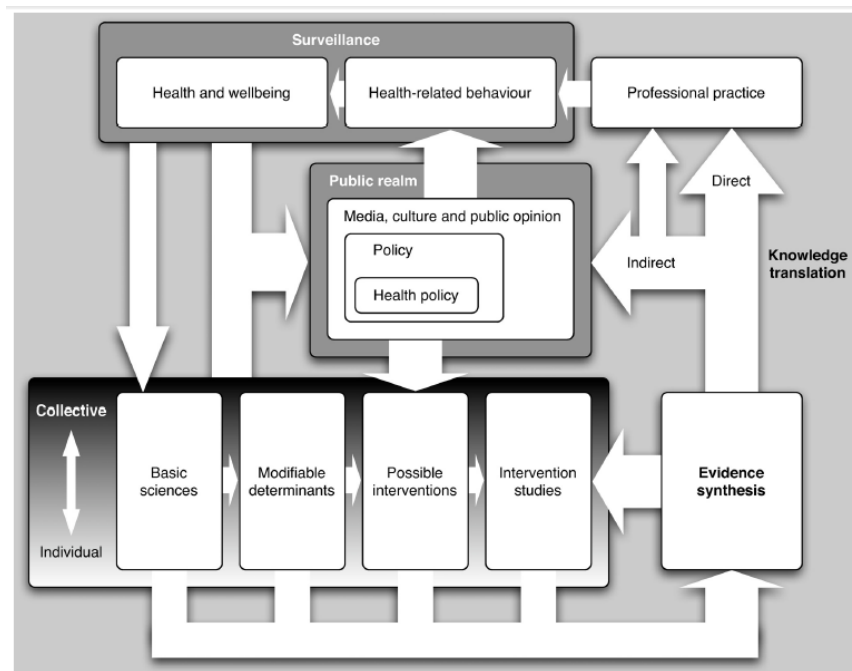


Figure 2
Translational framework for public health research.

Figure 29: Translational framework for public health research, Figure 2 in (Ogilvie et al. 2009, p.5)

The table following the above figure makes no mention of values and preferences:

Key differences between the translational framework for public health research and the linear translational medicine pathway

- Redefines the endpoint from that of institutionalising effective interventions to that of improving population health
- Incorporates the epidemiological traditions of population health surveillance and the identification of modifiable risk factors
- Reflects a spectrum of determinants of health from the individual to the collective level and a corresponding spectrum of levels of intervention
- Embraces a wide range of biomedical, social and environmental 'basic sciences' that have roles throughout the framework, not merely in supplying knowledge to be implemented
- Identifies a pivotal role for thoughtful and inclusive evidence synthesis
- Describes the iterative and bidirectional processes by which public health research and public health action may influence each other
- Recognises the non-linear and intersectoral interfaces with the public realm where decisions that influence population health are made

5.8 The underlying philosophy

It will be evident from what has been written earlier in my thesis and in the included papers that its philosophical basis is pluralist. The approach has elements of positivism, insofar as we assume the existence of a reality independent of the observer, but accept that this reality must be socially constructed. In the building of an Annalisa decision tool the criteria and options must have a communicable meaning. On the other hand, it is not possible to tackle the task of improving decision quality with decision aids solely within the critical realist position advocated by Greenhalgh and others (Greenhalgh & Russell 2010). These can throw light on the reasons, such as power relationships, why interventions such as ours might 'fail'. But Greenhalgh et al. have already indicated that a truly radical route is not within their conception of best evidence-based practice (Greenhalgh et al. 2014). The latter prompted a published response from us which draws attention to the incompatibility of conventional evidence-based practice with person-centred care. See related paper A

5.9 Limitations

The present research was massively under resourced by conventional standards given its aim. The balancing of resourcing and ambition is clearly a preference-sensitive decision, and we see a strong case for assessing the limitations of any research in the light of its costs and resource-effectiveness (Every-Palmer & Howick 2014; Elkins 2015).

This does not excuse what can be seen as failures on my part although it has proved extraordinarily difficult, both at the time and in retrospect, to attribute the breakdowns in either procedures or relationships to particular causes. Suffice to say that most, but far from all, could have been avoided in the case of St Mark's, but only by my carrying out all the practice activities myself as a full time employee, thereby undermining the fundamental design of the research. Similarly in the private consultant setting in Sydney, by being a constant presence in the

clinical setting. This can be regarded either as an inbuilt limitation of the study, or a necessary feature of study design that ultimately produced the limited proofs of method that were achieved, but no more.

In relation to the empirical work, many of the limitations which would have applied did not manifest themselves due to the limited uptake and the specific settings. Many of them can be addressed in the resumed research but it is inevitable that any study will infringe some ideals, particular those involving subsections of the population.

As made clear in the introduction I personally see the restriction of the options to medical and surgical ones as a limitation to the specific decision aid for IBD (Barello et al. 2014; Barello et al. 2013; Woodward et al. 2014; Czuber-Dochan et al. 2014; Dibley et al. 2014; O'Connor et al. 2013; Nathan et al. 2013). It is acknowledged that what was achieved must be seen through the lens of 'pragmatic realism' (Matlock & Spatz 2014).

The rich interview material contributed to the reconceptualisations towards the 'person-as-researcher' proto-protocol envisaged in Paper IV.

In spite of the fact that relevant background literature has expanded enormously in quantity terms, there is as yet no indication that MCDA-based decision aids for persons are on the radar of those interested in the task, let alone ones to be delivered on open access without provider involvement or use in Shared Decision Making.

On the brink of submission of this thesis the annual report of the Danish patients' ombudsman (Patientombud) showed complaints are increasing (Hansen 2014) as an indication of acceptance of patient demands for involvement in their health and care. And the Danish Ministry of Health announced a new era of patient and public involvement (Ministeriet for Sundhed og Forebyggelse 2015b). It included the following section:

Behandling med patienten i centrum – inddragelse og sammenhæng: Patienten skal være omdrejningspunktet for den inddragende og sammenhængende behandling. En styrkelse af personalets kompetencer og mere systematisk brug af redskaber, der understøtter fælles beslutningstagning, skal være med til at sikre, at patienter og pårørende i højere grad bliver hørt og inddraget i deres egen behandling (Ministeriet for Sundhed og Forebyggelse 2015b, p.4).

Treatment with the patient in the centre – involvement and coordination/coherence: The patient shall be the fulcrum for the involving and coordinated/coherent treatment. A strengthening of the staff's competences and a more systematic use of tools, which support shared decision making, shall contribute to ensuring, that patients and relatives to a higher degree will be heard and involved in their own treatment. (own translation)

We wait to see whether MCDA-based approaches will be involved in the walking following the talking.

6.0 Conclusions and Implications for Future Research

The title of my thesis - 'Towards improved decision quality in person-centred healthcare: exploring the implications of decision support via Multi-Criteria Decision Analysis' – indicated a specific purpose, despite the apparent scope and complexity of its setting. That aim was to explore one particular (web- and MCDA-) based approach to decision aiding. The aim was not to critique the numerous other existing approaches, most of which attempt to help individuals overcome their cognitive or social limitations through an improved deliberative process, based on some description-based principles. Our task was to assess the case for adding an approach based on prescriptive principles to the available portfolio of decision support tools.

One main conclusion is that the barriers identified by many others in relation to the introduction of decision aids into clinical decision making are confirmed. We find they are not confined to those well-established and - as reported - encountered in our own research. They need to be extended to include ones resulting from those pursuing the same overall aim, but refusing to admit prescriptive decision aids into their discourse.

As the bases for genuinely shared decision making, online MCDA-based decision support tools can only succeed with complete buy-in by clinicians logistically as well as philosophically. Substantial resourcing is needed to ensure willing clinicians can engage fully in the relevant training, without threat to the delivery of best practice care to all their present patients. Assuming that such resourcing is most unlikely to happen, we have developed protocols involving the reconceptualisation of the support task and assumptions concerning the facilitation of person-centred care.

Given the logistical difficulties as well as paradigmatic differences involved in attempting to deliver MCDA-based decision support in the provider context, we now see the future as one of 'flipping healthcare', at least in relation to substantial and growing sections of the populations. Our support tools are to be seen as resources for persons to consult as researchers into a condition for themselves or others. We envisage the decision resources will be delivered on open access for persons in the community to access them when they wish, as opposed to their becoming available only in the context of a planned - or ongoing - clinical consultation.

Sydney patients supported our ideas for future use of the IBD aid bypassing the inevitable restrictions and handicaps of research context, into wider access provision via patient organisations. This would for example include the one for IBD in collaboration with the University of Sydney as part of a wider web-based project for disseminating health-e-decisions to the community. Social media are envisaged as playing a key role in this wider dissemination process.

This open access reflects a wider ambition to increase generic health decision literacy through contact with condition-specific MCDA-based resources. This dual goal is also reflected in our conclusion that provider feedback surveys and PROMs should not only be extended to give greater prominence to decision making, but also be used to enhance health decision literacy by the inclusion of a generic decision resource as MDQ. While the research into this objective is currently stalled, we look forward to bringing our perspective to bear in national quality initiatives, embedding the results from both condition-specific aids, such as that for IBD, and generic decision quality measures, such as MDQ, in personalised electronic health records. In the Danish context, the WestChronic initiative in the Central Region (Region Midt) is showing a viable way forward by incorporating the Patient-Reported Outcome Measures into the electronic health journal. Meanwhile, the Region

of Southern Denmark has established the IT infrastructure which can handle the ‘Big Data’ needs of ‘flipped healthcare’ in the future ([http://www.deic.dk /](http://www.deic.dk/)) (OUH Operational Excellence and IT 2013).

We therefore envisage an expanded participation route to complement the current emphasis of representational approaches to ‘walking the talk’ of user involvement. Web-based delivery using a simple common language and template is crucial for communication in social networks by ‘persons-as-researchers’. MCDA provides a transparent technique that can ensure that the ubiquitous need to trade-off normative rigour and operational practicality is explicitly confronted in the delivery of decision support and decision resources. It also ensures that the inevitable framing of a decision will take place in full view.

We also conclude that the provision of information, and its possession, is over-emphasised relative to both the clarification of the values/preferences and the integration of evidence and preferences into a decision. This over-emphasis is partly the result of a desire to be ‘scientific’. Whether or not a patient recalls a fact, they have been told is ‘hard’ data, their values and preferences are notoriously ‘soft’ from the point of the scientific researcher.

In relation to integrating evidences and preferences, the case for making available the results from using a transparent algorithm, such as expected value, is clear. The lack of willingness to supply any alternative algorithm is testimony to their reluctance to respect the right of an autonomous person to access an opinion based on their preferences, the best estimates available at the point of decision, and the expected value principle. An invitation to ‘make up their mind’ in the basis of a large and complex body of information, not specifically decision-focused, is of questionable value and may even constitute symbolic violence.

The desire to fulfill the demands of science leads inevitably to population-level studies and analyses where the use of group value judgements is necessary to enable conclusions to be assessed for statistical significance. The methodological difficulties posed by recognising and accepting heterogeneity in preferences within any population, are nowhere better illustrated than in the difficulty of validating a ‘dually-personalised’, practice-focused instrument such as the Patient-Reported Outcome Measure, we have named MyDecisionQuality (MDQ). We conclude that N-of-1 methods may offer a valid approach, and maybe the only one.

In sum, this thesis has introduced, in the multi-disciplinary contexts of clinical decision making, a theory-based decision-analytic framework for the transparent forward translation of research into practice, simultaneously identifying and communicating the need for backward translation from practice to research.

Tools developed within the MCDA-based template move decision making a little closer to the analytical pole of the cognitive continuum. This is a movement which the research group of which I am a member sees as essential to provide the explicitness and transparency desirable in person-centred healthcare decision making and citizen-focused public health policy in a democratic society. This applies to research for and about healthcare, as well as about healthcare itself, so our future research will be focused on how this movement towards ‘Health for All’ can be accelerated at all points in the translation pathways.

The paradigmatic change involved in ‘flipping healthcare’, and providing decision resources on an open access to ‘persons-as-researchers’, should not be underestimated, but is seen as essential if genuinely person-focused care is to be walked and not just talked.

7.0 Summary

This PhD thesis is the story, in overlapping phases, of my pursuit of increased decision quality in healthcare via decision support software based on Multi-Criteria Decision Analysis (MCDA) in the spirit of action research.

A simple implementation of the MCDA technique is used. It requires an estimate in the 0-100% range for the performance ratings of each option on each criterion ('What we believe') and similar estimates for the relative importance of each criterion ('What we prefer'). The expected value (weighted sum) principle is used to integrate the two sets of estimates and calculate the option scores, which represent the *opinion* of the aid ('What we should do').

The phases are successively developmental, empirical, and conceptual in nature as indicated by the **titles** of the five peer-reviewed publications included. During its course, my thesis shows how the underlying technique of MCDA can help address some prominent questions in the academic and policy debate about public health and healthcare in Denmark, and internationally:

- The translation question: How can research evidence be translated into improved healthcare and public health?
- The involvement question: How can users of health services be better involved in decision making relevant to their health and healthcare?
- The feedback question: How can providers (professionals and organisations) know whether they are contributing to better healthcare?

Phase 1 introduces a metaphorical map of the judgment and decision making world, on which are located the MCDA-based decision supports that were developed. The article **Nursing Informatics and Nursing Ethics: addressing their disconnect through an enhanced TIGER vision** employs a sandwich-as-decision metaphor to introduce the template and instrument and present them to a specific health professional audience.

The most important feature of MCDA is its basis in prescriptive decision theory, rather than in descriptive theories of how humans make decisions. A key principle is the complete separation of the 'scientific' estimation of the performance ratings on the criteria from the making of value judgments about their importance weighting. The numerical MCDA approach to decision making and decision support is contrasted with more deliberative approaches using words. In verbal argumentation, the separation of ratings from weightings is less clear and their integrations into a decision less transparent, due to the lack of numbers.

The development and implementation of a generic MCDA-based decision support template in the Annalisa© software is recounted in **Towards generic online multicriteria decision support in patient-centred health care**. This is followed by an account of the development of a 'dually-personalised' instrument for measuring decision quality MyDecisionQuality (MDQ) in **Assessing decision quality in patient-centred care requires a preference-sensitive measure**. The dually personalised decision quality score arises because the person supplies the weightings for the quality assessment as well as the ratings. MDQ is envisaged as a possible Patient-Reported Outcome Measure (PROM). It can provide a decomposable measure of concordance (agreement), supporting communication for treatment adherence as well as documenting an enhanced informed consent.

Phase 2 involves the empirical research in an outpatient setting on the application of the aid and instrument in the context of Inflammatory Bowel Disease (IBD) in London and Sydney, and the pre-piloting of MDQ as a possible web-based enhancement of the national patient experience survey in Denmark (LUP). IBD was chosen as the case study because of its great and growing public health impact and its complexity in relation to decision-making, health, and healthcare.

Despite numerous adaptations, in the spirit of action research, this phase is less about empirical success in implementation than achieving a proof of concept and method in relation to concordance measurement and correlation between the Satisfaction With Decision and MDQ instruments. Moreover, substantial developmental and methodological progress was made, insofar as technically well-functioning online MCDA-based aids for Crohn's Disease and Ulcerative Colitis are ready for deployment, taking advantage of e- and m-technologies and social media. A protocol is developed for using MDQ as a generic decision aid to enhance health decision literacy for all, in order that a Danish LUP survey can benefit the respondent personally and simultaneously contribute to the healthcare provider feedback process. This dual strategy is designed to minimise cost and enhance respondent motivation so as to maximise the return to both healthcare providers and the responding person in terms of decision making quality.

A rich body of material from patients with IBD in London and Sydney exists to be exploited, but requires supplementation to ensure anonymity for those who contributed their experiences via weblog and interviews, thus far.

The lessons learned in regard to implementation prompted fundamental rethinking about the way the overall aim - increased decision quality in health and healthcare - might be alternatively, and perhaps better, achieved. This rethinking led to the final two included papers: **Increasing user involvement in health care and health research simultaneously: A proto-protocol for "Person-as-Researcher" and online decision support tools** and **Who should decide how much and what information is important in person-centred care?**

My thesis is seen as confirming the importance of remaining open to conceptual innovation within action research, especially in complex settings that are experiencing rapid change of all sorts under severe resource pressures. Future efforts using the protocol and tools developed will build on the reconceptualisations and include translation into the Danish context. MCDA-based support can help move both clinical and community decision making a little closer to the analytical pole of the analytical-intuitive cognitive continuum, as portrayed on the metaphorical map.

This is a movement which the research group of which I am a member, sees as essential to provide the explicitness and transparency desirable in a democratic society. This applies to research for and about healthcare, as well as about health itself, so our future activities targeted at 'Health for All' will focus on how this shift can be accelerated everywhere in the translation process. The paradigmatic change involved in 'flipping healthcare', and providing multi-criterial decision resources on an open access to 'persons-as-researchers', should not be underestimated. But it can be seen as essential if genuinely person-focused healthcare is to be walked and not just talked.

8.0 Danish Summary (Dansk resume)

Denne PhD-afhandling er en historie, i overlappende faser, om min søgen efter øget beslutningskvalitet i sundhed og sundhedsvæsen via online beslutningsstøtte baseret på Multi-Kriterie beslutningsanalyse (MCDA) i ånden af aktionsforskning. En simpel form af MCDA teknikken er anvendt. Den kræver et estimat (0-100%) for henholdsvis graden af opfyldelse (vurdering) af hver valgmulighed for hvert kriterium ('Hvad tror vi') og for væsentlighed (vægtning) ('Hvad er vores præference'). Softwaren integrerer 'Hvad tror vi' og 'Hvad er vores præference' ud fra princippet om forventet nytte (vægtet sum) til at beregne scores, som repræsenterer beslutningsstøttens mening (*opinion*) ('Hvad skal vi gøre').

Faserne er af fortløbende udviklingsmæssig, empirisk og begrebsmæssig art, som antydtes af **titlerne** på de fem fagfællebedømte publikationer, der indgår i afhandlingen. Igennem forløbet viser min afhandling, hvordan den underliggende MCDA teknik kan bidrage til at løse nogle fremtrædende spørgsmål i den akademiske og politiske debat om folkesundhed og sundhedsvæsen i Danmark, såvel som internationalt:

- Spørgsmålet om translation (oversættelse): Hvordan kan forskningsresultater omsættes til et bedre sundhedsvæsen og folkesundhed?
- Spørgsmålet om involvering (inddragelse): Hvordan kan brugere af sundhedsydelser blive bedre inddraget i beslutningsprocessen relevant for deres sundhed og sundhedsvæsen?
- Spørgsmålet om feedback (tilbagemelding): Hvordan kan udbydere (fagfolk og organisationer) vide, om de bidrager til et bedre sundhedsvæsen?

Fase 1 introducerer et metaforisk kort over bedømmelse og beslutningstagning verdenen, hvorpå den udviklede MCDA-baserede beslutningsstøtte er placeret. Artiklen **Nursing Informatics and Nursing Ethics: addressing their disconnect through an enhanced TIGER vision** anvender en sandwich-som-beslutning metafor til at introducere skabelonen for MCDA-baseret beslutningsstøtte og instrumentet for beslutningskvalitet, og til at præsentere dem for et specifikt sundhedsfagligt publikum.

Det vigtigste kendetegn for MCDA er dets afsæt i forskriftsmæssig beslutningsteori, snarere end i beskrivende teorier om hvordan mennesker træffer beslutninger. Et centralt princip er den totale adskillelse mellem de 'videnskabelige' estimater (vurdering) for opfyldelse af kriterierne fra betydningen af deres indbyrdes væsentlighed (vægtning). Den numeriske MCDA tilgang til beslutningstagning og beslutningsstøtte står i kontrast til de mere deliberative, der bruger ord. I verbal argumentation er sondringen mellem vurderinger og vægtning mindre tydelig, og deres integrationen i en beslutning mindre gennemsigtig på grund af fraværet af tal.

Udviklingen og applikationen af en generisk MCDA-baseret skabelon for beslutningsstøtte i Annalisa© softwaren beskrives i **Towards generic online multicriteria decision support in patient-centred health care**. Dette efterfølges af en redegørelse for udviklingen af et 'dobbelt-personaliseret' instrument til måling af beslutningskvalitet, MinBeslutningsKvalitet (MDQ), i **Assessing decision quality in patient-centred care requires a preference-sensitive measure**. Den dobbelt-personaliserede beslutningskvalitet score opstår, fordi personen angiver både vurderinger og vægt. MDQ kan ses som patientrapporterede oplysninger (PRO). Det kan udgøre et mål for concordance (overensstemmelse), støtte kommunikation for adherence (overholdelse af behandling) og dokumentere et informeret samtykke.

Fase 2 omhandler den empiriske forskning i ambulant regi om gennemførelsen (implementering) af beslutningsstøtten og instrumentet i forbindelse med inflammatorisk tarmsygdom (IBD) i London og Sydney, og en præ-pilot af MDQ som et mulig webbaseret bidrag til den Landsækkende Undersøgelse af Patientoplevelser (LUP). IBD blev valgt som casestudie på grund af sin store og voksende betydning for folkesundheden og kompleksitet i forhold til beslutningstagen, sundhed og sundhedsvæsen.

Trods talrige tilpasninger i aktionsforskningens ånd, handler denne fase i mindre grad om empirisk succes i forhold til gennemførelse (implementation) end om at opnå bevis for koncept og metode i relation til et mål for concordance og korrelation mellem instrumenterne Tilfredshed Med Beslutning og MDQ. Det handler således også om væsentlig metodeudvikling og fremskridt, i det omfang teknisk velfungerende online og MCDA-baseret beslutningsstøtte for Crohn's sygdom og colitis ulcerosa er klar til brug, og kan drage fordel af e- og m-teknologier og sociale medier.

En protokol er udviklet til at bruge MDQ som generisk beslutningsstøtte til fremme af health decision literacy (sundhedsmæssige beslutningsfærdigheder) for alle, så den danske LUP kan bistå respondenten personligt og samtidigt bidrage med tilbagemelding til sundhedsvæsenet. Denne dobbelte strategi er designet for at minimere omkostninger og øge deltagermotivation og udbyttet for sundhedsvæsenet og svarpersonen i forhold til kvalitet af beslutningstagning. Et rigt materiale fra patienter med IBD i London og Sydney findes til fremtidig udforskning men kræver supplerende for at sikre anonymitet for dem, som har bidraget med deres erfaringer via weblog og interviews.

De indhøstede erfaringer i forhold til implementering førte til fundamental nytænkning om den måde, det overordnede mål - øget beslutningskvalitet i sundhed og sundhedsvæsen - alternativt og måske bedre kan opnås. Denne nytænkning førte til de sidste to inkluderede artikler: **Increasing user involvement in health care and health research simultaneously: A proto-protocol for 'Person-as-Researcher' and online decision support tools** og **Who should decide how much and what information is important in person-centred care?**

Min afhandling ses at bekræfte betydningen af at forblive åben overfor konceptuel (begrebsmæssig) innovation i aktionsforskning, særligt i komplekse miljøer som oplever hurtige forandringer af alle slags, ofte under svært pressede ressourcemæssige forhold. Det videre forløb med brug af protokollen og de udviklede værktøjer vil bygge på disse re-konceptualiseringer og omfatter oversættelse til en dansk kontekst. MCDA-baseret støtte kan bidrage til at bevæge både klinisk- og samfundsmæssig beslutningstagning lidt tættere på den analytiske pol af det analytisk-intuitive kognitive kontinuum, som afbilledet på det metaforiske verdenskort.

Dette er en bevægelse som forskningsgruppen jeg er en del af, ser som afgørende for at bibringe den tydelighed og gennemsigtighed, som er ønskværdig i et demokratisk samfund. Det gælder forskning for og om sundhedsvæsenet, såvel som for sundhedsvæsenet i sig selv, så vores fremtidige tiltag rettet mod 'Sundhed for Alle' vil fokusere på hvordan denne bevægelse kan fremskyndes overalt i processen af oversættelse/translation. Paradigmeændringen involveret i 'sundhedsvæsenet vendt på hovedet', og at tilbyde multi-kriterielle beslutningsressourcer, frit tilgængelige på internettet, for 'personer-som-forsker' bør ikke undervurderes. Men den forekommer afgørende, hvis et genuint person-fokuseret sundhedsvæsen skal omsættes til at være af gavn og ikke bare af navn.

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Included publications

Nursing Informatics AND Nursing Ethics: Addressing Their Disconnect Through an Enhanced TIGER-vision

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Abstract

All healthcare visions, including that of The TIGER (Technology-Informatics-Guiding-Educational-Reform) Initiative envisage a crucial role for nursing. However, its 7 descriptive pillars do not address the disconnect between Nursing Informatics and Nursing Ethics and their distinct communities in the clinical-disciplinary landscape. Each sees itself as providing decision support by way of information inputs and ethical insights, respectively. Both have reasons – ideological, professional, institutional - for their task construction, but this simultaneously disables each from engaging fully in the point-of-care-decision. Increased pressure for translating 'evidence-based' research findings into 'ethically-sound', 'value-based' and 'patient-centered' practice requires rethinking the model implicit in conventional knowledge translation and informatics practice in all disciplines, including nursing. The aim is to aid 'how nurses and other health care scientists more clearly identify clinical and other relevant data that can be captured to inform future comparative effectiveness research.' A prescriptive, theory-based discipline of '(Nursing) Decisionics' expands the Grid for Volunteer Development of TIGER's newly launched virtual learning environment (VLE). This provides an enhanced TIGER-vision for educational reform to deliver ethically coherent, person-centered care transparently.

Keywords:

Nursing Informatics; Nursing Ethics; Clinical Decision Making; Decision Support; Cognitive Continuum; Multi-Criteria Decision Analysis.

Introduction

The TIGER (Technology-Informatics-Guiding-Educational-Reform) summit website states, 'Our vision is to enable nurses to use informatics tools, principles, theories, and practices to make health care safer, more effective, efficient, patient-centered, timely, and equitable by interweaving enabling technologies transparently into nursing practice and education, making information technology the stethoscope for the 21st century'[1]. The 7 key pillars of The TIGER Initiative in the outlined action plan are Management and Leadership; Education; Communication and Collaboration; Informatics Design; Information Technology; Policy; and Culture. Clinical decision support is one of 8 categories of Development in the Grid for Volunteer Development of TIGER's recently launched Virtual Learning Environment [2]. A matrix maps these, as vertical columns, with 7 horizontal Categories of Development (Web-Resource, Case Studies, Decision Tree, Develop Modules, Competency Matching, Simulation-Based, and Second Life). The TIGER Phase III goal is to Educate Nurses and Interdisciplinary Providers about Evidence-Based Practice

Benefits of Health IT Adoption. 'Nurses, along with physicians and other interdisciplinary providers need to: Understand more about Comparative Effectiveness Research (CER); How Electronic Health Record (EHR) data can be used for research purposes; How EHR data in the future can inform practice through CER; and become aware of, and where relevant, develop expertise in; Research Methodologies used in CER, Privacy Requirements related to use of clinical data; Possibilities of changes in Evidence-Based Practice with increase of CER; and more clearly identify clinical and other relevant data that should be captured to inform future CER research' [2].

What seems to be lacking explicit attention in TIGER pillars and VLE matrix is the current disconnect between Nursing Informatics and Nursing Ethics. This is a common feature of other recent summary statements from Nursing groups e.g. the AMIA Nursing Informatics Working Group [3]. A search on Medline and Cinahl (from 2000) returned hundreds of hits for 'Nursing Informatics' and 'Nursing Ethics' individually, but combining the searches with 'AND' returned no results. Some of the papers with 'nursing ethics' as title/abstract keyword address 'informatics issues' from the ethical perspective and some with 'nursing informatics' address 'ethical issues' from the informatics perspective. But few, if any, focus on the decision itself, since both fields see themselves as primarily providing what they see as decision support, by way of information inputs and ethical insights respectively. Each of the distinct communities has reasons – ideological, professional, institutional - for maintaining this supportive construction of their function, but it is a significant source of the disconnect since both hold back from fully engaging in the point-of-care-decision.

Increased pressure for the translation of 'evidence-based' research findings into 'ethically-sound', 'values-based' and 'patient-centered' practice requires rethinking of the model implicit in conventional knowledge translation and informatics practice in all disciplines, including nursing [4].

Translation requires more than mastering one language. The ethical implications of enabling those in nursing care are most exposed in multi-disciplinary settings where decisions involve multiple parties – such as in the real case story of an 88-year-old woman in intensive care. The case exposes the implicit choices made in such contexts and acts as an exemplar of the challenge to make decisions that are coherent with respect to a variety of ethical principles, as well as transparent in regard to diagnostic and prognostic evidence [5].

While the (decision) point is being made here in relation to Nursing Informatics and Nursing Ethics, it also applies to Medical, Clinical and Health Informatics and Ethics which display similar disconnects. The focus on nursing should therefore not be misinterpreted as suggesting the situation is exclusive to nursing, but there are features of nursing that

make it of particular interest and concern. The lack of transparent decision making structure e.g. in intensive care settings as shown in the case [5], compromises what nursing can contribute at the individual, as well as at the policy level.

The argument can be made in only truncated form here. For the historical background and definitions of the field of (nursing) informatics see ‘Health and medical informatics education: perspectives for the next decade exemplified by case stories and a specific address to health service managers [6,7]; following ‘What Every Nurse Should Know About Computers’ published in 1984, the year of WHO’s launching ‘Health for All 2000’¹ [8,9]. For the 21st century of globalization, an editor’s ‘column serves as a clarion call to the discipline of nursing for value-specific, theory-guided knowledge [...] that highlights the discipline of nursing as accountable to society for the quality of nursing services. [...] May we begin the journey afresh and anew. Nurses must understand and face possible challenges and opportunities, and examine the efficacy and worth of their practices in light of the values and beliefs set forth in nursing’s theories’ [10].

The aim of this paper is to take up that call and provide food for thought and further debate by proposing a prescriptive theory-based addition to the TIGER VLE Grid. This incorporates Cognitive Continuum Theory applied to nursing [11] with prescriptive weight elicitation in Multi-Criteria Decision Analysis [12] toward a new discipline of ‘(nursing) decision-ics’. In the spirit of ‘perspectives for the next decade,’ an example from the multicultural clinical landscape of health visiting and critical care is used to explore the value of applying a particular form of analysis at the health care team’s point of care for that particular decision. This is done at a given point of time and is always situation-, condition-, position-, and resource-specific in terms of age, sex, literacy, numeracy, knowledge, language, power, and culture.

Methods

Decision making

Whether by individual practitioner or practice team and whether shared or not, decision making in patient-centered healthcare - as opposed to following a rule or algorithm - is a matter of integration. It involves integrating evidence and expert judgments concerning the outcomes and other considerations relevant to the patient (typically characterised by significant uncertainties), with the relative importance of those considerations to that patient (typically characterised by internal conflicts, for instance professional-patient disagreements).

The synthesis and integration of the evidence/judgments and the patient’s values/preferences can be carried out in three main ways, as well as in various combinations of the three. One is clinical or professional judgment. The second, currently the dominant form, is some type of verbal argumentation or deliberative discourse that processes the benefits and harms (informally, the pros and cons) to arrive at a conclusion, often in a social or interpersonal setting. It is useful to characterise this way of making decisions as ‘verbal multi criteria decision deliberation’, since then it can be clearly differentiated from the third method, multi-criteria decision analysis, which arrives at a conclusion through numerical calculation, albeit a calculation based on extensive deliberation about the inputs.

In the following diagram (Figure 1) we use the sandwich as a metaphor for an evidence-informed and value-based decision. By combining the bread (the evidence) with the filling (the preferences) one produces the sandwich, or decision. The clear implication from this construction is the need for a prime focus on the sandwich-making/decision-making process with the supportive/input supplying activities operating in a way that is decision driven, (what should we do?), not only evidence-driven (what do we know?) or value-driven (what do we prefer?). It follows that we need a *decisionics* discipline to complement the *informatics* discipline and a transformation (or expansion) of the ethics discipline into a ‘*valuematics*’ one, in order to ensure that the resulting decision is of high quality. A high quality decision would be coherent, transparent, and necessarily prescriptive [11,12,13].

Transparency is a necessary condition for effective communication between nurse and patient at the clinical level, and between nurses and other stakeholders at the policy level. This is especially true when facing increasingly scarce resources in the context of new drugs being marketed within a fixed or reduced health budgets and competing guidelines for evidence-based practice [14].

However, there is a missing piece in this argument. To supply it we will refer to a metaphorical map of the world of judgment and decision-making (Figure 2) [15]. *Judemakia* enables us to better comprehend and acknowledge the nature of the task of making patient-centered care decisions, and to both identify and meet the challenges of connecting ethics and informatics in a transparent and coherent way via what may be named ‘*decisionics*’ in order to distinguish it from informatics.

Judemakia has two bases, one longitudinal and one latitudinal.

The longitudinal base is the assumption that decisions (which are always taken in the central Decision-land) require inputs from the two distinct flanking and supporting provinces of Belief-land (where we address the question the likelihood of something, such as an adverse event) and inputs from Preference-land (where we address the question the undesirability of something, such as an adverse event).

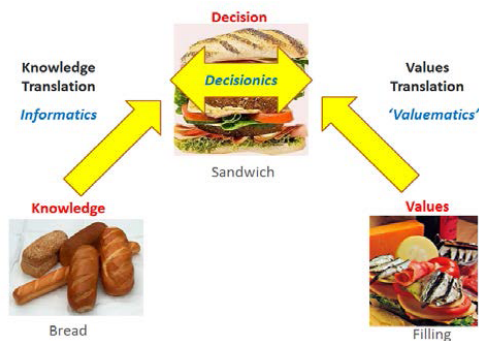


Figure 1 – Decision as sandwich

The orientation of the map has no significance, north (i.e. a higher analysis to intuition ratio) is not better than south, *per se*. Quality is a third, altitudinal dimension.

¹ Translated by The Danish Nurses Association in 1987 [9]

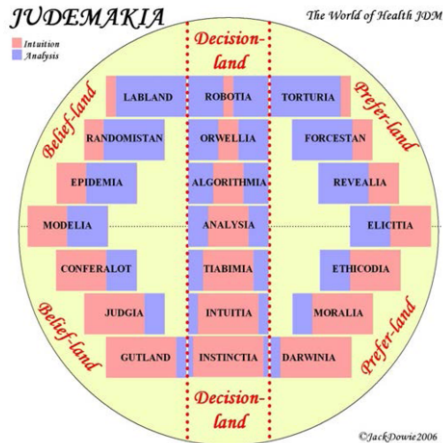


Figure 2 – Judemakia

Judemakia's latitudinal base is derived from the Cognitive Continuum framework of Hammond [16]. Based on empirical evidence, knowledge of the Cognitive Continuum Theory has been found highly relevant to understanding the decision-making tasks and processes of nurses in the clinical environment [11,17]. Cognitive Continuum Theory suggests that a variety of possible balances between intuition/fast thinking and analysis/slow thinking exist in relation to any judgment and decision-making task. Applying that idea in all three 'lands' creates a set of regions within each to locate various activities and methodologies on the basis of their analysis-to-intuition ratio. For example, ranging from Gutland to Labland in Belief-land. The map is the result of a prolonged search for a way of communicating the intrinsic complexities of decision-making at different levels, and depicting the multiple locations relevant to an increasingly multi-cultural clinical landscape. (Dowie, personal communication).

Implications for decision-making (nursing) practice

Benner, Schön and others have extolled the virtues of intuitive expertise in nursing [17,18,19]. In Intuitia the separation of the three lands is minimal, perhaps non-existent, in practice. Nursing clinical judgment almost instantly supplies both the evidence and values and integrates them. However, beyond the practitioner deciding and acting alone, most nursing decision-making takes place in Tiabimia (derived from Taking-Into-Account-and- Bearing-In-Mind), what others would call verbal argumentation or deliberative discourse. Evidence-based nursing says TIABIM *should* rely on 'scientific' evidence coming via informatics processes from the 'north' of Belief-land, with its higher analysis-to-intuition ratio. This would be supplemented by clinical expertise from its 'south' and then integrated with preferences coming largely from the 'south' of Prefer-land.

We can now see that the problem of connecting Nursing Informatics and Nursing Ethics requires two things: (i) focusing on the decision in Decision-land and (ii) ensuring that the essential informatics inputs from Belief-land and ethical insights from Prefer-land enter Decision-land in a way that enables them to be synthesised transparently and coherently. At the moment, that is being done in the 'taking into account and bearing in mind' decision technology of Tiabimia. Whatever its advantages, this location perpetuates the disconnect since the informatics inputs are coming from different and (at least normatively) much higher analysis-to-intuition ratios than the ethical ones.

A partial remedy (not a panacea) involves bringing the connection nearer to the equator with the decision also being made at that level, or at least having the decision analysed and supported at that level. It may, however be essential for legal or socio-psychological reasons to move to deliberative discourse in Tiabimia to finalise the decision [20].

The patient and the placing of the apostrophe

The final link in the argument involves introducing the patient, who is the pre-eminent concern of the nurse, and thus of nursing ethics as a scholarly and scientific discipline. The ultimate purpose of both Nursing Informatics and Nursing Ethics is to help improve the patient's care, which inherently involves making the best possible decisions. If we also accept that we are delivering patient-centered care, this means that those decisions must be heavily influenced, if not determined entirely, by the patient's preferences. The placing of the apostrophe in patients –'s or s' - is crucial in these discussions.

The treatment of patient's/s' preferences in preference-sensitive decisions in nursing contexts is analytically weak and non-transparent, especially in relation to the multiple and conflicting concerns and trade-offs frequently present. While lists of nursing informatics competencies usually mention the use of decision support, they rarely refer to the *systematic elicitation* of patient's preferences or values. This is in marked contrast to the situation in nursing ethics where this becomes almost the sole object of concern. This gap needs to be addressed via a revised framework for complementing nursing informatics teaching and practice with formal attention to values and preferences and their elicitation, accompanied by explicit focus on their integration into decisions. Attempts to tackle these tasks exclusively in Tiabimia (i.e. by Taking-Into-Account-and-Bearing-In-Mind) seem unlikely to achieve the necessary transparency. Thus the nurse's portfolio is here suggested to be extended 'north' to include a technique like Multi-Criteria Decision Analysis (MCDA), and, necessarily, an implementation of it which makes it clinically practical at the point of decision care.

The Nurse's Dilemma: an example

With roots in multi-cultural health visiting and intensive care, the chosen example presents a dilemma familiar to nurses in these contexts: responding to questions of parents or other caregivers concerning the prognosis for a child or increasingly ill and demented relative, which is known to the nurse to be very poor; often in the literal sense of the word as well. The specific details of the case will vary enormously. Its framing will always be influential, but a number of ethical principles are always in play - beneficence, non-maleficence, justice, autonomy, veracity, and confidentiality, to name the six used in Wilson and Dalglish [21]. To keep the example simple, the options are limited to two: disclose the prognosis fully, or in some way deny possessing significant information about it. There will be many variations on each in practice, but including them would add nothing to the point being made here.

Results and Discussion

The different options within a given decision context will impact in different ways on how the ethical principles translates into a real time scenario. As neither action is best or equally best on all, the principles will have to be weighted. Some deontologists will argue for 100% weight to one of them, but most ethicists will argue that several, if not all, should be 'taken into account'. The power of Multi-Criteria-Decision-Analysis lies in the way nurses, either individually or as part of a care team, can make their assessments of the impact of

the options on the principles (their ratings) separately from their views on the relative importance of the principles (their weightings), and then explore the effect of both - and variations in them - on the case for each option. Using purely hypothetical ratings and weightings, some combinations may favour 'denial' (Figure 3), some 'disclosure' (Figure 4). (The figures are screen captures from the Annalisa© implementation of MCDA).

Without suggesting this approach is appropriate in all cases, its transparent structure could help focus deliberation in many. If each patient, and their designated significant others, is given a chance to express individually what matters to him or her in obtaining a quality decision, then under- as well as over-informing the involved parties can be reduced. A shared 'decisionics' language with common grammar and vocabulary can provide the required novel structure for the future multi-disciplinary teams in which each individual participant – regardless of which side of the table they are on – can make an optimal input to, and impact on, the decision, including transparent 'voice' for the usually speechless part. Being web-based, this can include those who cannot attend due to distance by providing access in their own home setting. For those who can express themselves only via trained computers e.g. if they have speech difficulties such as aphasia, this offers an excellent solution. The 'medical home' provides an ideal setting [22].

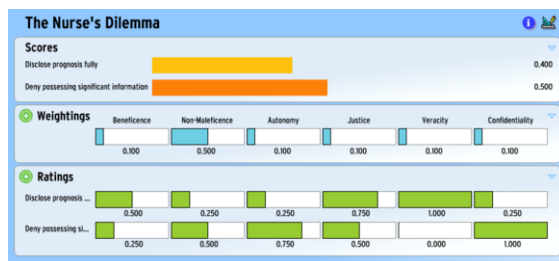


Figure 3 – 'Denial' favoured

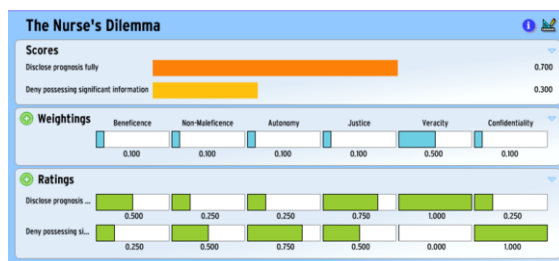


Figure 4 – 'Disclosure' favoured

Care-ful decision making: a new discipline

There is opportunity and need to develop Nursing Decisionics as a discipline, complementary to Nursing Informatics and Nursing Ethics. Nursing Decisionics focuses specifically on the Point of Decision rather than on the knowledge translation (synthesising, exchanging, disseminating) mechanisms on the one hand and ethical discourses on the other, each of which acts to support the decision process. The practical curriculum for Nursing Decisionics will introduce the three main 'decision technologies' – (clinical) judgment, multi-criteria deci-

sion deliberation, and multi-criteria decision analysis – as essential components of the nursing professional's competency portfolio. They will be presented at different levels depending on the nurse's roles and responsibilities. As we have seen, all three vary in their intuition-analysis balance and all three should be available for deployment, depending on the decision setting and task structure. This is equally true whether the context is community, primary, secondary, or tertiary care, and whether the focus is on the individual patient or on patient populations. The specific and transparent use of the simple weighted-sum approach of Multi-Criteria Decision Analysis (MCDA) is proposed as an additional row and column in the TIGER VLE matrix, and also as a possible overarching framework for integration.

It is important to see MCDA as a useful technique for approaching clinical decision making, and not simply as a clinical decision support tool, though it is also, and very importantly, the basis for such tools. It may act as a catalyst for the translation of The TIGER Phase III goal into prescriptive practice: 'To Educate Nurses and Interdisciplinary Providers about Evidence-Based Practice Benefits of Health IT Adoption' [1,2]; by acknowledging the human factors [13].

It is, of course, not sufficient to simply throw a Multi-Criteria Decision Analysis-based aid into an existing decision process. A framework for evaluating and documenting the decision process, as well as aiding it, is needed and this is the aim of the MyDecisionSuite template (Figure 5). It comprises a set of elements that provide navigation and preparation segments (the latter providing the opportunity for a variety of multimedia links) before the aid, and decision quality assessment and follow-up elements after it. While it cannot be expounded on this occasion, the framework is adaptable to any specific set of organisational circumstances, nursing arrangements, and patient's preferences regarding decision style.

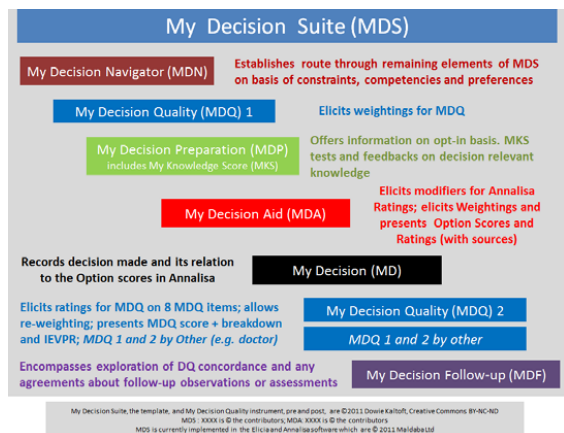


Figure 5 – MyDecisionSuite structure

Conclusion

The lack of literature addressing Nursing Informatics AND Nursing Ethics since the 'expiry' of Health for All 2000 vision is a symptom of their persistent disconnect within the clinical-disciplinary landscape of 21st century health care despite the emergence of new concepts like 'translation'. Multi-Criteria Decision Analysis has been applied to a case to show how it can help acknowledge and better comprehend the nature of the task of making person-centered care decisions as well as meeting the challenges of connecting ethics and informatics in a

transparent and coherent way within a theory-based discipline of '(Nursing) Decisionics'. This has been proposed as an expansion of the Grid for Volunteer Development of TIGER's virtual learning environment (VLE), as well as an enhanced vision for educational reform that can help deliver ethically coherent, evidentially-transparent person-centered care for, if not all, then more, by 20??!

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Towards generic online multicriteria decision support in patient-centred health care

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Abstract

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Objective To introduce a new online generic decision support system based on multicriteria decision analysis (MCDA), implemented in practical and user-friendly software (Annalisa©).

Background All parties in health care lack a simple and generic way to picture and process the decisions to be made in pursuit of improved decision making and more informed choice within an overall philosophy of person- and patient-centred care.

Methods The MCDA-based system generates patient-specific clinical guidance in the form of an *opinion* as to the merits of the alternative options in a decision, which are all scored and ranked. The scores for each option combine, in a simple expected value calculation, the best estimates available now for the performance of those options on patient-determined criteria, with the individual patient's preferences, expressed as importance weightings for those criteria. The survey software within which the Annalisa file is embedded (Elicia©) customizes and personalizes the presentation and inputs. Principles relevant to the development of such decision-specific MCDA-based aids are noted and comparisons with alternative implementations presented. The necessity to trade-off practicality (including resource constraints) with normative rigour and empirical complexity, in both their development and delivery, is emphasized.

Conclusion The MCDA-/Annalisa-based decision support system represents a prescriptive addition to the portfolio of decision-aiding tools available online to individuals and clinicians interested in pursuing shared decision making and informed choice within a commitment to transparency in relation to both the evidence and preference bases of decisions. Some empirical data establishing its usability are provided.

Introduction: multicriteria decision making

Asked how they make a decision, health professionals, either individually or as part of a multidisciplinary medical team, will often say something like

Together with the patient we look at the available options to see how well each performs on the main effect benefit, then take into account the side effect and adverse event harms, the burdens of the treatment and so on, finally weighing the benefits and harms and any other considerations to arrive at a conclusion as to the best option. We naturally bear in mind what the most recent relevant high quality guidelines have to say.

A patient responding to the same question will probably come up with something similar, albeit expressed in different words such as ‘taking the ‘pros and cons’ into account’ and ‘giving all the considerations due weight’.

Clearly, these are not accurate characterizations of all clinical decision-making processes, but would seem to be reasonably *descriptive* of many. More importantly, they would certainly be common responses when the *prescriptive* question is asked: ‘How *should* a clinical decision be made?’

These sorts of statements indicate that we operate in a health-care system where *some* form of shared decision making is accepted as the aim. The majority of health professionals routinely ‘talk the talk’ of informed choice and patient-centred care, increasingly emphasizing ‘patient-important outcomes’ as promoted by the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) collaboration¹ and the newly established Patient-Centered Outcomes Research Institute (PCORI) (<http://www.pcori.org>) among many other individuals and groups. They do so with genuine conviction and intent, but find it more difficult to ‘walk the walk’^{2,3} and even to agree on what the key steps should be in terms of pace, direction and support.

The presence of cultural and socio-economic variations, together with great individual heterogeneity *within* cultures and classes, is at the

heart of the challenge posed in pursuing shared decision making (and informed choice) within an overall philosophy of person- and patient-centred care. The challenge to the professionals is mirrored by that of the individuals with whom they engage. All parties lack a *simple* and *generic* way to picture and communicate about the decisions that need to be made in health care. We seek to address this major handicap to progress towards all three goals. For convenience, the discussion is focused on the encounter between individual clinician and patient, but we regard our proposal as applying beyond the microclinical setting, to the meso- and macrolevels of health-care decision and policymaking.

Two broad types of decision technology are compatible with shared decision making. The first is that captured in the opening quotes. As it takes some form of argumentation conducted in words, even if it refers to numbers as inputs, we feel an appropriate shorthand term for it is *verbal multicriteria decision deliberation (MCDD)*. It embraces all forms of decision making that occur through deliberative processes, including those which are based on decision aids and support grounded in *descriptive* theories of human decision behaviour, usually involving descriptive theories of expert decision making.⁴ It dominates recent work in relation to shared decision making and patient-centred decision support.^{5–7} MCDD is a useful term because it highlights the key similarities and differences with the alternative decision (and decision support) technology that we argue should be included in the portfolio of clinical decision-making competencies of both health professionals and patients. This alternative is based on the well-established, theoretically grounded, *prescriptive* technique of multicriteria decision analysis (MCDA).⁸ To make the comparison with *verbal* MCDD even clearer, we can imagine the adjective *numerical* preceding it.

In short, we are suggesting, along with Dolan,⁹ van Hummel and Ijzerman¹⁰ and Liberatore and Nydick¹¹ that numerical MCDA (hereafter simply MCDA) be added to the

competency portfolio of all those involved in clinical decision making. We regard their studies as establishing that MCDA-based clinical decision support systems can be successfully developed and deployed. However, despite the high quality of the efforts of these researchers, the implementation of MCDA-based decision support in health care has been fairly limited – not that the success of MCDD-based aids in routine practice has been spectacular to date.^{12,13} The reasons for this undoubtedly include the usability and communicability of the current software implementations of MCDA technique, computerization being a necessary condition for its application, in contrast to MCDD. In this respect, we believe it reasonable to infer that an implementation which is superior in these respects will be more successful and can be regarded *a priori* as a workable clinical decision support system. But the reasons also trace back to the fundamentally different theoretical paradigm from which MCDA itself emanates, compared with that underlying current clinical practice and the majority of decision aids built for use within it (a comprehensive inventory of patient decision aids is available at <http://decisionaid.ohri.ca/index.html>). It is vital to keep this in mind in any attempted evaluation.

MCDD and MCDA: similarities and differences

There are two key *similarities* between the two broad modes of multicriteria decision making, the umbrella term. First, both imply that in every clinical decision, two sorts of judgement are needed: (i) on the *performance* of each of the available options on each of the multiple relevant considerations and (ii) on the *relative importance* of those multiple considerations. Second, that these conceptually different types of input must be integrated/synthesized/combined in some way to arrive at a decision.

The key *differences* are reflected in the final words of the labels – deliberation and analysis – and in the preceding, implied adjectives – verbal and numerical. (In this paper, we

include a graphical representation of data within the scope of the latter term.)

It might be asked why we characterize the distinction as a ‘verbal/numerical’ contrast, rather than a ‘qualitative/quantitative’ one. We do so because it is crucial to accept that MCDD is replete with the *quantification of magnitudes*. This quantification is simply done in predominantly verbal ways during the decision-making parts of the discourse. This applies in relation to the performance magnitude judgements, for example, of different medications reducing the chance of Pain, where terms such as ‘low probability’, ‘good chance’ and ‘very likely’ are used to characterize the chances of the criterion being met for *this* patient. It also applies to the relative importance judgements, for example, of the importance of pain reduction relative to medication side effects, where again a variety of terms such as ‘paramount’, ‘trivial’ and ‘major’ – or simply ‘very important’ and ‘not very important’ – are deployed.

The word *Analysis* is used because the explicit aim in MCDA (and in fact of any version of decision analysis, including its cost-effectiveness and cost-utility forms) is to arrive at a result – an *opinion* is our preferred term – by a process of *analytical calculation* on the basis of numerical judgments. Of course, the process of arriving at those numerical judgements almost certainly involves extensive verbal, non-numerical elements and hence deliberation, in the same way that the deliberative discourse of MCDD may contain many judgments of magnitudes, including some expressed numerically. *Deliberation* on the other hand is an interpersonal process where the provenance of the emerging conclusion inheres in the social process adopted and the participants involved in it. Unless the deliberation is structured as an MCDA,¹⁴ the conclusion cannot be detached from them in the form of a graphic summary, or equation, or set of numerical option scores.

A process that would benefit from the perceived strengths of each approach is an attractive prospect, and such a hybrid form has been implemented by Proctor and Drechsler in the

context of environmental policy formation.¹⁴ A ‘stakeholder jury’ was used to structure an MCDA through a deliberative process and populate it with the help of experts. MCDD then followed as the final stage. The extensive time and resources involved, as well as the environmental policy context, make the empirical conclusions of limited relevance, but the hybrid case is well made in general. However, such a hybrid involves compromise from both sides, and this is not easy once it becomes clear that paradigmatic principles are involved, not merely syntactic or semantic differences that can be addressed by ‘translation’, for example, of verbal magnitude quantifiers into numerical ones. These paradigmatic differences need to be articulated before proceeding.

The objective of decision support is to improve decisions. This means establishing whether improvements can be made, identifying where improvements could be made and providing support that will lead to improvements. The concept of improvement means one cannot avoid being *prescriptive*. Purely *descriptive* approaches, which focus on describing how decisions *are* made – by individuals or by organizations, communities and other groups – provide no basis for change as they have no basis for identifying what would be an improvement.¹⁵ Purely *normative* approaches, which focus on establishing, without reference to how decisions are made, the fundamental principles and processes that an ideal decision maker would implement, are simply impractical.

On what basis can such desirable, potentially decision-improving prescriptions for decision-making processes be identified? There are two main possible bases.

One basis is the normative principles of decision theory and decision analysis. Decision analysis is essentially the ideal processes of decision theory converted into processes that are practical, given the time, resource and cognitive constraints of the real world. Lipshitz and Cohen⁴ call prescription arrived at on this basis *analysis-based prescription*, and this is exactly what we mean when we say MCDA-

based decision aids are *‘prescriptive’*. They produce an opinion which reflects, as closely as practicable – for many reasons this may not be *very* close at all – the logical processes of an idealized decision maker. Interestingly these principles and processes have been endorsed by many people if they are asked how a decision *should* be made, even when they do not follow the principles and processes themselves.⁴

The other possible basis of prescriptions for improvement in decision making is *description* of the decision processes of expert decision makers, on the one hand, in contrast to non-expert decision makers on the other. The former are defined as those whose decisions generally produce good results and outcomes. Identifying the differences between them – what makes the experts expert – can lead to what Lipshitz and Cohen call *expertise-based prescription*. Despite the accuracy of this term, in the world of decision support the term ‘prescriptive’ is almost exclusively associated with the analysis-based approach. Those who favour the expertise-based approach prefer to characterize themselves as operating within an *descriptive* approach, which in many ways is true, even though, by definition, prescription is necessary to distinguish experts from non-experts and good from not-good results.¹⁶

Expertise-based description/prescription has been virtually the only route to improvement in decisions considered professionally acceptable in clinical medicine, and this is reflected in the curricula of medical schools and in clinical practice. Decision analysis is rare to non-existent in both the curricula of medical schools and in clinical practice. It is also the basis for the regular attacks on the ‘expected utility/value’ principle which underlies analysis-based prescription. These critiques, most recently that of Russell and Schwartz,¹⁷ are always derived from the *descriptive* inadequacies of the expected value principle. But such inadequacies are ultimately irrelevant within a *prescriptive* paradigm because it is not derived from actual behaviour. As it is hard to conceive of unbiased cross-paradigm evaluation, it is not surprising that this is never proposed in such

critiques, which ultimately reflect the intuitive appeal of descriptive approaches that seek to 'take into account' the complex characteristics, history and contexts of the individual. The issue is not whether these inadequacies and complexities exist – are descriptively true – but whether a user would *prefer* to be supported by analysis-based prescription or expertise-based description. The ethical responsibility is to make clear the paradigmatic origins of the type of support offered.

The analysis-based prescriptive approach has one compelling advantage in the provision of patient/person-centred care and genuinely shared decision making. In its multicriteria form, decision analysis provides a generic approach to all decisions, that is, it is not condition specific and does not mandate the reasoning expertise and knowledge acquisition in the particular area (e.g. a disease) required to follow and share expertise-based prescriptions. As long as expertise-based prescription is the sole basis of the clinical encounter, patient empowerment will be a very difficult and demanding task. An MCDA-based prescriptive approach allows the person/patient to input their preferences as importance weights for criteria in a straightforward manner and to have them transparently combined with the published evidence and the clinician's expertise.

Developing an MCDA-based decision support system

This paper focuses on MCDA as an appropriate technique for facilitating person-centred health care in relation to the *adoption decision* – deciding what to do given the available options. It is important to distinguish this decision from two other decisions where we also regard MCDA as an appropriate support technique. One is the *quality decision* – deciding how good the decision just taken was, given the decision technology used. An MCDA-based instrument for measuring decision quality has been developed and is presented in J. Dowie, M. Kjer Kaltoft, G. Salkeld and M. Cunich (submitted). The other is the *decision*

decision – deciding how to decide, given the available decision technologies. In our case, the decision decision is whether the adoption decision is to be made by the exercise of the health professional's 'clinical judgment', by some form of MCDD-based decision making, or in conjunction with some type of MCDA-based decision support? We return to this central, 'meta' question later.

A great number of software implementations of MCDA exist, reflecting both widely varying versions of the technique and particular judgments about the extent and type of complexity to be catered for and the time and cognitive resources required.^{18,19} These range from implementations of a SMART (Simple Multi Attribute Rating System) in a simple spreadsheet, implementations using the analytic hierarchy process (AHP) as executed either in a spreadsheet template or a dedicated software package, notably Expert Choice, <http://expertchoice.com/products-services/expert-choice-desktop/>, to specific MCDA implementations such as V.I.S.A <http://www.visadecisions.com>, HiView <http://www.catalyze.co.uk/index.php/software/hiview3/>, Web-Hipre <http://hipre.aalto.fi/> and Logical Decisions <http://www.logicaldecisions.com/>. The latter two packages also contain an AHP option. The prime motivation for developing an MCDA decision support system in the form of Annalisa was that none of the existing implementations of MCDA had, despite proving themselves as clinical decision support systems, made significant progress in health care. That was the situation when Annalisa was first conceived and we feel it remains true now, despite the growing research in this area (see Dolan,⁹ Maarten Ijzerman and colleagues,²⁰ and other examples cited in the Liberatore review).¹¹ Most of the increasing use of MCDA in health care is at the policy and health technology assessment level, with the recent developments within the EVIDEM framework and software in the forefront^{21,22} confined to this setting.

In deliberately implementing the simplest, compensatory 'weighted-sum' version of the MCDA technique we make no claim of it

being innovatory as a decision model. It is, in essential respects, an enhanced interface for any SMART-type matrix. These can easily be developed in a spreadsheet. However, Annalisa seeks to provide enhanced interactive online usability by way of the numerous customizing and personalizing functionalities provided in the survey program Elicia, into which the Annalisa file is normally embedded. For example, Annalisa enables personalization of the performance ratings of options on criteria on the basis of patient characteristics and personalization of the weightings of the criteria by the patient at the point of decision.

Thus, the focus of this paper is not to re-introduce MCDA or confirm its value as the basis for clinical decision support systems, but to introduce a particular software template, Annalisa, as a practical and person-centred implementation for use at the individual level, not only in shared decision making, but also in the community, especially in relation to cancer and other disease screening decisions and policies.

The AHP has been the MCDA implementation used most widely in the clinical health-care context and warrants special mention. In an extensive series of papers, James Dolan has expounded and investigated the ways it can contribute to both shared decision making and the wider issues involved in clinical decision support.^{8,9,23} However, in its standard form, AHP involves a level of complexity that imposes high demands on both the developers and implementers/users of AHP-based support systems. Primarily responsible for this increased complexity is the hierarchical attribute structure which AHP permits and indeed encourages (hence its name) and the unique pairwise comparison method used to establish criteria importance weights and performance ratings, devised by its founder, Thomas Saaty.²⁴ While this increased complexity can be seen as leading to a high level of performance by some standards of normative rigour and comprehensiveness,²⁵ it creates the difficulties in the development and delivery of AHP-based decision support²⁶ that have hindered its wider dissemination.

French and Rios Insua²⁷ propose 5 key characteristics that any 'good' implementation of decision analysis, single or multi criteria, should possess. We use them, as summarized by Riabacke *et al.*,²⁸ to highlight the basis of the claims of Annalisa in each respect.

1. *Axiomatic basis.* The axiomatic bases underlying Annalisa are those of decision theory. All the implementations of MCDA mentioned in this paper embody some version of the weighted-sum principle which is at the centre of decision theory. Annalisa implements this basic principle in a very simple way while still retaining its key principles.
2. *Feasibility.* Feasibility has been the main driving force in the development of Annalisa. The template was explicitly designed to reduce the complexity – and resulting cognitive demands – that is possible and tends to be facilitated by increasingly sophisticated implementations within the other available packages.
3. *Robustness.* No provision for sensitivity analysis is built into Annalisa, but both the weightings and ratings can be directly varied and the effect on scores instantly observed.
4. *Transparency to users.* In best practice implementation, the weighted-sum principle is not only explained and illustrated prior to the user's interaction with Annalisa, but also during interaction where appropriate, for example when and whether the individual panels (Weightings, Ratings, Scores) are opened or closed at different stages during engagement. Application of the weighted-sum principle is manifestly transparent on any populated Annalisa screen.
5. *Compatibility with a wider philosophy.* This criterion relates to the model developed in the software rather than to its basic functionalities. It is up to the user of Annalisa to develop a model relevant to their context and setting. The embedding of Annalisa in the online survey program Elicia makes interactivity and cyclical iteration simple and efficient and leaves the amount of each entirely in the user's control.

The final point requires further development in the light of the increasing interest in the comparison and evaluation of decision aids on the basis of multiple criteria relating to development, performance, accessibility and impact.

Within its essential prioritization of simplicity over complexity, the functionalities provided by the Annalisa-in-Elicia software create the possibility of building decision aids that should perform well on most criteria of adaptability and personalization. According to the Eiring *et al.* coding scheme for the personalization of decision aids,²⁹ the basic components of personalization are media content, user features, user model construction and representation and adaptive system behaviour. User features can broadly be classified into the user's knowledge level, interests, preferences, goals/tasks, background, individual traits and context. Adaptive system behaviours include adaptive navigation support, adaptive selection, organisation and presentation of content, adaptive search, adaptive collaboration and personalized recommendations. Used in conjunction with Elicia, any implementation of Annalisa should provide a medium to high degree of personalization in all these respects and hence compare favourably with the 10 of the initial 259 decision aids that were subject to detailed classification in the Eiring-led study.

It is up to the developer of a decision support tool within this software to determine what degree and type of adaptational flexibility and personalization – to individuals or groups – is to be offered in terms of attributes (such as content, language, connectivity and presentation). It is also up to the developer to determine whether these are to be provided on an opt-in or opt-out basis. While compared with some *ideal* decision aid there are limitations in all these respects, a tool built in the Annalisa software is capable of technically matching, or possibly surpassing, any of the *actual* decision aids subjected to intensive analysis in the Eiring-led project. Most differences that arise will not be for reasons of functionality, but be traceable to their MCDA basis, because this is what influences *what* is offered and required –

and *how* it is offered and required – by way of adaptation and personalization.

This point is worth emphasizing because it is important that a *particular* decision aid is assessed as an implementation of the underlying technique and philosophy within which it is built. A tool using Annalisa is based on the paradigm of analysis-based prescription, as opposed to that of expertise-based description within which all the other aids examined by Eiring *et al.* have been constructed. What is paramount in the development and use of a particular decision support tool or system is to make the potential user very clear about its underlying paradigm, so that questions concerning lower levels of functionality are relevant to it. The appropriate evaluation of Annalisa-based aids is therefore in comparison with other MCDA-based ones and such a comparison, involving Annalisa and AHP (using Expert Choice), carried out within Hi-View, is that has been undertaken by Pozo-Martin (personal communication).

This makes the 2005 French and Xu³⁰ survey of the five MCDA packages cited earlier – Hi-View, V.I.S.A, Web-Hipre, Expert Choice and Logical Decisions – the most relevant available published comparison at a functional level. A survey of current decision analysis software, including full technical and operational details, is provided biennially by INFORMS. The 2012 survey results are available at <http://www.orms-today.org/surveys/das/das.html>. Fifteen packages offer some form of multicriteria DA, but this is a purely descriptive listing of information provided by 24 vendors, with no comments or assessments added. Of the five MCDA packages in the French and Xu comparison, V.I.S.A. does not appear.

French and Xu compared the five programs in terms of the aspects in which they differed, notably (using Annalisa terminology) decision structuring, weighting elicitation, rating elicitation, data presentation and sensitivity analysis.

When Annalisa, in conjunction with Elicia, is added to the comparison, two things stand out. First, the package fails to provide the vast majority of the functionalities and features that

these five offer, considerably augmented in the 8 years since the survey. These functionalities and features are entirely appropriate where complex analysis is of benefit, such as in major projects with numerous stakeholders involved and large amounts of resources used, but even in such contexts the limited use of these packages either in practice or as the basis of decision support templates is noteworthy. And even where used, the complexity of the analysis is rarely matched in, or warranted by, the extensive deliberation that follows, as exemplified in a Swedish exercise in participatory democracy.³¹ Somewhat paradoxically it is the failure of Annalisa to provide alternative and/or more sophisticated and complex methods for key tasks (including determining the criteria and eliciting weights) that we regard as its positive virtue, because it will provide the potential for much wider use. The growth of product comparison websites and recommender systems within e-commerce^{32–35} is a clear sign that multicriteria analysis is eminently accessible to large sections of the population, *but only at an appropriate level of complexity*. William Buxton has pointed out that the speed of technological progress captured in Moore's Law (a technology generation is 18 months and decreasing) is in complete contrast to his 'God's law', which states that 'the capacity of human beings is limited and does not increase over time – our neurons do not fire any faster, our memory doesn't increase in capacity, and we do not learn or think faster as time progresses'.³⁶ The problem this creates for the evaluation of innovative and disruptive systems of all kinds is succinctly captured in Martin Buxton's law 'It is always too early [for rigorous evaluation], until suddenly it's too late'.³⁷

The second difference is closely associated with the pace of change in both the hardware and connectivity within which any MCDA software will operate. Both French and Xu and an earlier study by Belton and Hodgkin in 1999³⁸ saw three main settings for use of an MCDA package: Do-It-Yourself use by a single individual, an analyst-facilitated group meeting, and 'off-line' analysis by a consultant sandwiched

between face-to-face meetings with decision makers. Subsequent developments in communication technology and connectivity means that there are now many more possibilities, including one in which a pre-structured (options, criteria) and evidence-populated MCDA-based decision aid is made available online. Decision makers then need only to have their preferences (utilities, importance weights) elicited to obtain an opinion on the merits of the alternative options. In terms of data presentation and display, as well as interactivity, Annalisa benefits from being developed specifically for online use within the latest technology. Now written in html5, with tablet use prominently in mind, it has mobile presence on touch-operated devices using iOS, Android and other operating systems. Such interactive mobile accessibility is likely to trump most other functional considerations in the coming years, making a level of complexity compatible with such operation a paramount consideration.

Annalisa was designed to embody the following practical principles:

1. It should be possible to undertake an analysis within a very short time, such as the 5–10 min often available in time/resource pressured situations, to ensure that the possible benefits of even a modicum of 'slow thinking' should not be lost.³⁹ This was in no way, of course, intended to prevent weeks or months being devoted to generating the detailed structure and inputs – if the time and other resources are available.
2. Irrespective of the time available at the point of decision (and therefore including 5–10 min), the decision owner should not be asked to make the necessary trade-offs among more than 7 ± 2 criteria.^{40,41} (Annalisa actually has a maximum of 10.)
3. All the elements of the decision (preferences and evidence) and the outcome (best option) should be simultaneously visible on the screen, providing a complete picture of all elements of the decision and with the effects of changing any weighting or rating dynamically visible in real time.

4. Pop-ups on the screen should provide access to additional information, especially the provenance of the option performance ratings (including external links where appropriate).

Giving higher weight to practical considerations, Annalisa adopts the simplest and most colloquially familiar form of MCDA. In the decision matrix ‘weighted-sum’ approach, all attributes exist at the same level (there is no hierarchy of criteria and sub-criteria); the performance of each option is *directly* rated on each attribute; the importance of each attribute is *directly* weighted in relation to that of all the other attributes; and the option Scores are *calculated* by summing an option’s ratings on the attributes multiplied by the attribute weightings.

An illustrative example of a completed Annalisa screen is provided in Figures 1 and 2. These might be seen as either those for two different patients or those of the same patient

at two points of time (where Fig. 1 is produced at Time 0 and Fig. 2 is produced at the next encounter i.e. Time 1). In the ratings panel of both instances, we can see that new treatment is better at maximizing the main effect benefit than current treatment (0.70 vs. 0.50), is better at minimizing the treatment burden than the current treatment (0.80 vs. 0.70), but is worse at minimizing side effects (0.20 vs. 0.50). (Longer bars mean the particular option does better.) The two are equally good in relation to minimizing adverse events (both 0.90).

Given the relative weightings of the four attributes in Fig. 1, new treatment emerges with the highest score in a simple expected value calculation.

$$\begin{aligned}
 \text{Score for CURRENT treatment} &= (0.50 \times 0.50) + (0.50 \times 0.30) \\
 &\quad + (0.90 \times 0.10) + (0.70 \times 0.10) \\
 &= 0.56
 \end{aligned}$$

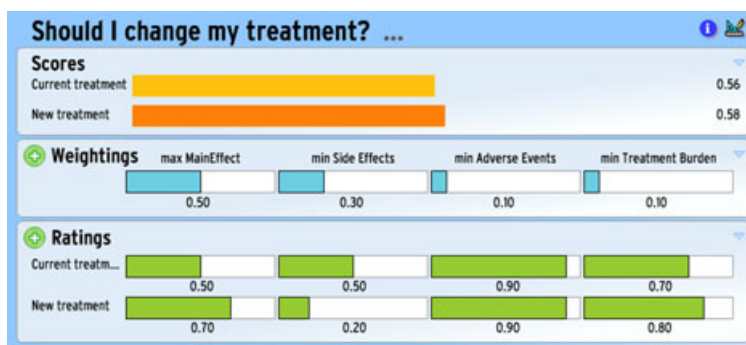


Figure 1 Example of Annalisa for hypothetical Patient 1 at Time 0.

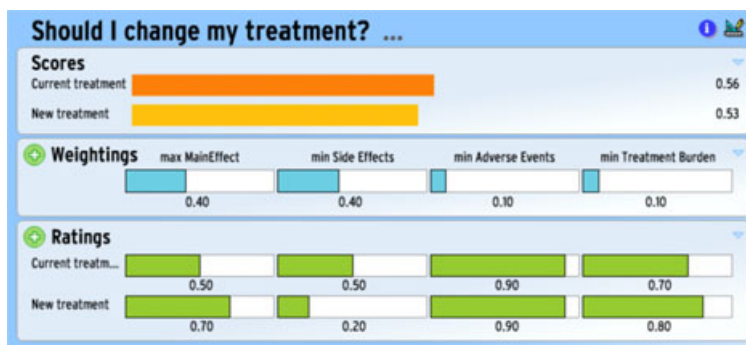


Figure 2 Example of Annalisa for hypothetical Patient 1 at Time 1.

$$\begin{aligned}
 &\text{Score for NEW treatment} \\
 &= (0.70 \times 0.50) + (0.20 \times 0.30) \\
 &\quad + (0.90 \times 0.10) + (0.80 \times 0.10) \\
 &= 0.58
 \end{aligned}$$

Figure 2 presents the scores when the weight assigned to minimizing side effects harm is increased, with correspondingly reduced weight to maximizing main effect benefit. (The weightings for the set of attributes must sum to 1). Current treatment now has the highest score, which means we interpret this option as the *opinion* emerging from the Annalisa.

From wherever and however they are derived, both the ratings and the weightings entered into Annalisa are treated as measures on a *ratio* scale running from a (true) zero to 1 or 100%. Zero on the ratings scale means either zero probability (literally, and in many cases logically, no chance) or zero fulfilment of the attribute concerned; 1 means 100% probability or complete fulfilment. Similarly, zero on the weightings scale means of no importance whatsoever, and 1 means all important to the exclusion of all other attributes.

The choice of the simple weighted-sum approach, among many other decisions in the design and development of the Annalisa template, was made in the light of our value judgments as to the weight to be assigned to particular considerations. Pre-eminently, we have assigned high weights to relevant practical considerations in both development and delivery, in full recognition and awareness that these may lead to poorer ratings on other criteria, pre-eminently ones concerned with normative rigour. We do not see rigour/relevance and practicality/normativity as dichotomies, where one must make binary choices, but as matters of *weighting* and hence preference sensitive. Annalisa, as with any implementation of MCDM including *MCDD*, embodies a particular view as to the criteria and weights to be used in ‘deciding how to decide’. This point continues to apply even when choosing among the candidates within the field of *MCDA*.

Deciding how to decide: the decision decision

Given that a patient faces multiple options and regards multiple criteria as relevant to choosing among them, should they stick with *MCDD*, the currently dominant decision technology, or move to *MCDA*, at least as a decision support technology?

As discussed earlier, the two basic forms of MCDM and their many internal variations differ in important ways, as well as having key similarities. But from the clinical decision-making standpoint, we should not be thinking of making a choice between them at some general and abstract level. It hardly makes any sense to ask whether *MCDD* or *MCDA* is better *in general* as a technique. Neither is it particularly useful to ask whether AHP/Expert Choice or weighted-sum/Annalisa is a ‘better’ template implementation of *MCDA*. We need rather to focus on particular instantiations of each technique template in a tool for a particular clinical decision setting, where ‘setting’ embraces such things as the organization, the professional, the patient and the condition involved.

This implies we need to establish the decisional criteria relevant to a setting. These criteria will probably include such higher-level considerations as evidential strength and coverage, theoretical grounding, explicitness, precision, transparency, communicability and potential for social or institutional biasing. But given that this is clinical decision support, they should also include the basic resource requirements, such as the time and cognitive effort and commitment required from all parties, as well as any financial implications for them.

It can be taken for granted that the performance of particular implementations of *MCDD* and *MCDA* will vary on these criteria, not least because of conscious value judgement-based trade-offs regarding the selection and weighting of the criteria made by individual parties in the case of *MCDD* and by the developers and implementers in the case of *MCDA*-based decision support. For example, an *MCDA*-based aid – or *MCDD*-based appointment – designed

to take no more than 20 min will (should) perform less well on a criterion such as 'coverage of the evidence' than one assumed to have 40 min at its disposal. The various interactive decision support systems we are developing all allow customization of the support process to the time and other resources available, as well as personalization of the weightings by, and ratings for, the specific patient on the selected criteria. They explicitly assume, indeed emphasize, that such customization choices will impact on which aspects of the decision support will be accessed and that the personalization of weightings will affect the outcome (opinion) emerging from the analysis.

Thus, given that the decision on what decision procedure or decision support system to adopt involves multiple criteria and is therefore preference sensitive, it does not make sense to ask whether Annalisa has, or ever can be, shown to work in some overall or average

sense as the basis of a clinical decision support system. The answer will vary as a function of the particular decision maker's preferences in the particular context as well as the quality of the instantiation. Empirically, we can note that in a study with a small number of Australian GPs, 80% agreed that the demonstrated Annalisa-based tool for prostate cancer screening would be useful in discussions with their patients and half thought it would be useful and could be recommended for use in decisions on any health matter.⁴² Pozo-Martin has recently established the preference sensitivity of decision support evaluation in a comparison of Annalisa and the Analytic Hierarchy Process for developing and delivering decision support for patients with advanced lung cancer in some Spanish hospitals.⁴³ Finally, while it is not appropriate to report the full set of results of a RCT involving Annalisa-based decision aids for PSA testing here, Table 1 provides

Table 1 Age of participants and individual ratings on criteria relating to usability of Annalisa decision aids for PSA testing

	All, <i>n</i> = 1447		Annalisa for PSA Testing with a Fixed Set of Attributes Chosen by Researchers, <i>n</i> = 727 (50.2%)		Annalisa for PSA Testing with Attributes Chosen by Study Participants, <i>n</i> = 720 (49.8%)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Age						
40–49 years	591	40.8	282	38.8	309	42.9
50–59 years	487	33.7	248	34.1	239	33.2
60–69 years	369	25.5	197	27.1	172	23.9
Difficulty deciding on the Weights for Criteria						
Very difficult	93	6.4	52	7.2	41	5.7
Fairly difficult	282	19.5	140	19.3	142	19.7
Neither difficult nor easy	466	32.2	235	32.3	231	32.1
Fairly easy	433	29.9	209	28.8	224	31.1
Very easy	173	12.0	91	12.5	82	11.4
Difficulty entering the Weights for Criteria						
Very difficult	100	6.9	55	7.6	45	6.3
Fairly difficult	323	22.3	159	21.9	164	22.8
Neither difficult nor easy	467	32.3	242	33.3	225	31.3
Fairly easy	392	27.1	184	25.3	208	28.9
Very easy	165	11.4	87	12.0	78	10.8
Contents of Evidence panel met needs for information						
Very well	362	25.0	163	22.4	199	27.6
Well	847	58.5	433	59.6	414	57.5
Not very well	238	16.5	131	18.0	107	14.9

information on the age of participants and their ratings on various criteria, such as difficulty in responding to the key items on criteria weighting, that confirm its accessibility.

Given the resource requirements of decision making and decision supporting – and hence their opportunity costs – we suggest there is a strong case for ‘deciding how to decide’ being approached analytically as an exercise in ‘decision resource–decision effectiveness analysis’. This simply parallels in relation to the *decision decision* (should we adopt this or that way of deciding whether, for example, to adopt this new drug or device technology?) the use of conventional cost-effectiveness analysis in relation to the *adoption decision* (should we, for example, adopt this new drug or device technology or not?). As implied above, both numerator and denominator in decision resource–decision effectiveness analysis are appropriately conceptualized as multicriterial indexes. It follows that MCDA is the appropriate analytical technique for decision resource–decision effectiveness analysis.

Conclusion

A template designed to facilitate generic online multicriteria decision support in person-centred health care is presented in this paper as a valid addition to the portfolio of decision support systems available to clinicians and their patients.

It is essential that any comparative evaluation of decision support systems makes the theoretical basis of each aid and process very clear to all respondents and decision stakeholders. In the context of person-centred care, this comparison will involve multiple criteria, of which the paradigmatic basis of the aid or process is a crucial one. The choice will be preference sensitive, with the weighting sometimes leading to an instantiation of multicriteria decision deliberation emerging as the best way of deciding and at other times to an implementation of multicriteria decision analysis. Ultimately whether Annalisa and similar templates have a role to play in person-centred care is

not a question with a binary answer. The empirical question, which will need to be iteratively asked and re-asked as technology and attitudes change, concerns the precise roles it can play in the increasingly complex world of translational health. This is what we are researching.

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Conflict of Interest

Jack Dowie has a financial interest in the Annalisa software, but Annalisa and Elicia are ©Maldaba Ltd. (<http://maldaba.co.uk/products/annalisa>)

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Assessing decision quality in patient-centred care requires a preference-sensitive measure

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Abstract

A theory-based instrument for measuring the quality of decisions made using any form of decision technology, including both decision-aided and unaided clinical consultations is required to enable person- and patient-centred care and to respond positively to individual heterogeneity in the value aspects of decision making. Current instruments using the term 'decision quality' have adopted a decision- and thus condition-specific approach. We argue that patient-centred care requires decision quality to be regarded as both *preference-sensitive* across multiple relevant criteria and *generic* across all conditions and decisions. MyDecisionQuality is grounded in prescriptive multi criteria decision analysis and employs a simple expected value algorithm to calculate a score for the quality of a decision that combines, in the clinical case, the patient's individual preferences for eight quality criteria (expressed as importance weights) and their ratings of the decision just taken on each of these criteria (expressed as performance rates). It thus provides an index of decision quality that encompasses both these aspects. It also provides patients with help in prioritizing quality criteria for future decision making by calculating, for each criterion, the Incremental Value of Perfect Rating, that is, the increase in their decision quality score that would result if their performance rating on the criterion had been 100%, weightings unchanged. MyDecisionQuality, which is a web-based generic and preference-sensitive instrument, can constitute a key patient-reported measure of the quality of the decision-making process. It can provide the basis for future decision improvement, especially when the clinician (or other stakeholders) completes the equivalent instrument and the extent and nature of concordance and discordance can be established. Apart from its role in decision preparation and evaluation, it can also provide real time and relevant documentation for the patient's record.

Keywords

decision aids, decision quality, patient-centred care, patient-reported outcome measure

Background

The increase in the range of options available for health and disease management, coupled with the shift towards greater patient involvement in recent years, has led to a profusion of decision aids and related support systems aimed at patient, clinician and medical team.^{1–3} This has been followed by the development of instruments and checklists to assess the quality of such aids. Most have focused on the internal quality of the particular decision aid as appraised by a set of normative criteria, with the International Patient Decision Aid Standards instrument (IPDASi)⁴ emerging as the most prominent of such checklists. Where empirical evaluation has been undertaken or is proposed, most attention has been on *particular process*

and outcome aspects (e.g. acceptability, involvement, conflict, knowledge), rather than on the comparative performance of aided and unaided decision making in relation to *overall decision quality*. (A list of evaluation

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measures is available on the Ottawa Patient Decision Aids website, <http://decisionaid.ohri.ca/eval.html>)

None of the clinical trials included in the Cochrane systematic review of decision aids has evaluated the quality of the decisions derived from different decision technologies (including decision aids) using a single index measure of *overall* decision quality. There is therefore a need for evaluation measures that address the overall quality of decisions, as distinct from measures that address particular aspects of decision making.

Adopting the Berwick⁵ philosophy of patient-centred care implies that *all* decisions should be regarded as preference-sensitive, with the relative importance a patient attaches to various outcomes and processes having a large influence on, if not determining, what is decided. This philosophy also necessitates that *decision quality* be regarded as preference-sensitive and that the relevant preferences are those of the patient facing the decision, as opposed to the average preferences of a group of patients with the same condition or those of the health professional(s) involved in the decision.

In the case of drugs or medical devices the main purpose of the intervention is to achieve a health benefit. It follows that the primary outcome of intervention research is to determine its effectiveness in accomplishing that task. We suggest that, in the case of decision aids, the main purpose should be to enhance the overall quality ('goodness') of the aided decision relative to that which can be achieved without it – by some other 'decision technology' – and that this should be assessed at the time of decision making and not in terms of any subsequent change or outcome.⁶ Hence, decision quality should become the primary outcome of studies comparing decision-aided and unaided practices. This essay therefore argues for the use of decision quality as a directly measurable patient-reported measure for all health conditions. It could be regarded as a Patient-reported outcome measure if the decision is regarded as an outcome of the decision-making process⁷ or, alternatively and more conventionally, as a patient-reported experience measure.⁸ While policy makers and researchers may benefit from a generic measure, the fundamental reason for it is so that the individual is able to assess the quality of the various health-care decisions they face in, and through, their life, using the same instrument, whatever the context, condition, timing in life or role occupied. We describe and illustrate the application of the MyDecisionQuality (MDQ) instrument to this task.

The development of MDQ followed an assessment of the available instruments for evaluating decision aids – mainly on the Ottawa website – which was designed to establish whether any of these instruments generated a generic and preference-based index of *overall* decision

quality; as opposed to ones that were: (i) condition-, setting- or decision-specific; or (ii) measured one or more *possible* aspects of decision making such as preferred involvement in decision,⁹ satisfaction with the decision¹⁰ or decision conflict experienced,¹¹ rather than overall decision quality or (iii) did not weight their components to produce an index measure (i.e. were profile instruments) or, if they did enable weighting, did not elicit weights from the specific patient on the specific decision occasion.

None of the instruments identified in the search constituted such a personalized preference-based measure of decision quality. The only instruments uncovered that used the label 'decision quality' *per se* were those developed by Sepucha and colleagues.¹² Their condition- and decision-specific decision quality instruments (DQIs) include items that assess: (i) knowledge – the extent to which the patient was 'well informed', (ii) concordance – the level of agreement between the patient's goals and concerns and their treatment and (iii) involvement – the extent to which the patient was involved in decisions about their care. In addition to the fact that they are not generic, these DQIs are not preference-based. The scores that are produced relate to particular segments of the DQI and are not aggregated, by weighting, into a single overall index measure of decision quality for the individual patient. Moreover, the score for the concordance component is calculated only for patient populations, not for any specific patient.

We do not regard the Decisional Conflict Scale¹¹ and its 4-item form SURE¹³ as measures possessing construct validity in relation to decision quality because they penalize decision processes and support systems that leave the decision maker in a state of warranted equipoise.

Decision *satisfaction* is not an appropriate measure for assessing the *quality* of a decision aiding or making process, and will often reward suppression of uncertainties rather than their expression.¹⁴ For example, item two of the widely used Satisfaction with Decision instrument ('The decision I made was the best possible choice for me') makes it unsuitable in the evaluation of decision quality because it denies the possibility that there may be two or more best possible choices.¹⁰ We regard patient empowerment as incompatible with the notion that the role of the physician is to provide a confident and single recommendation.

Defining decision quality

We take the view that both the definition and measurement of decision quality should be treated as preference-sensitive. Accordingly, in principle the measurement of decision quality will require the decision owner to

choose which criteria to include in the instrument. A DQI based on a set of consensus-led items and weights (including the equal weights implied in most checklists) seems incompatible with truly personalized patient-centred care. While Edwards and Elwyn¹⁵ raise a number of legitimate issues concerning the operationalization of decision quality, many of these stem from their view that a ‘good decision’ exists, but is yet to be defined. In contrast, we take the view that decision quality – defined tautologically as the goodness of a decision – does not *exist* and should not be defined in a positivistic way. ‘Decision quality’ is a multicriterial *construct* and all we can do, given the necessity to assess it, is to propose a set of items that appeal to our – and others’ – *value* judgements as to what should be included. (In this respect it parallels constructs like ‘health-related quality of life’ that instruments such as EQ-5D simultaneously define and measure.) Beyond this immediate challenge, the next task that any one constructing a DQI faces is operationalizing the measurement and synthesizing its components. We interpret Edwards and Elwyn as agreeing with us that abdicating from this task because of the substantial operational challenges it poses is not an option, and we regard ‘subjective’ numerical calculation as a vital complement to their ‘subjective’ verbal deliberation approach in responding to these challenges.

Developing a personalized and generic decision quality measure

MDQ is a web-based generic instrument for the individual-specific measurement of decision quality based on Multi-Criteria Decision Analysis (MCDA).

Dolan recently explored the potential of MCDA as the basis for decision support systems in health care, including Shared Decision Making (SDM).^{16,17} He outlined the current portfolio of multicriteria methods and commented on their respective merits and problems. His assessment led him to favour the Analytic Hierarchy Process (AHP) because it offered greater flexibility, ease of use and strength of measurement compared with the other methods. However, he acknowledged that one of the main problems with using the AHP in clinical decision support is that its pairwise comparison elicitation processes, the main source of its strength in measurement, is both time consuming and cognitively demanding.

In conjunction with the online survey program called Elicia© in which it is embedded, Annalisa© forms an interactive, online decision support template that was explicitly designed to make MCDA-based decision support less temporally and cognitively demanding.¹⁸ It was not developed solely with applications in the

health-care setting in mind, but it was designed to be the basis for tools which were practical in both time and resource-pressured situations – as well as relaxed ones. Annalisa meets one of Bates et al.’s¹⁹ commandments for the satisfactory delivery of a decision aid in stressing visualization and presenting all aspects of the decision (preferences, evidence and options) on a single screen. Annalisa-based decision aids provide a structured analytical framework for decision deliberation and hence for the balancing of the two main contributors to decision making – analytical modelling and intuitive judgement.²⁰ Above all, Annalisa tools seek the requisite balancing of normative rigour and operational practicality.^{21,22} A study involving an Annalisa tool for prostate cancer screening has confirmed its ease of use.²³

MDQ is a dually personalized DQI based on MCDA and currently implemented in Annalisa©, though in principle it could be implemented in any form of online spreadsheet. (By saying MDQ is *based* on MCDA we mean that there is always an implicit alternative decision process (option) with which the MDQ result for the currently implemented option should be compared.) The assessor (e.g. patient) is responsible not only for (i) weighting the criteria of decision quality in terms of their relative importance but also (ii) rating the quality of a decision just made on the criteria. MDQ is generic in the sense that the criteria are phrased without reference to any particular decision or context. Information relating to the specific decision (such as one in a particular health-care setting and population) is to be provided outside the MDQ instrument, but in the larger decision support system in which MDQ will often be situated.¹⁸

As with all implementations of the simple ‘weighted-sum’ version of MCDA, MDQ combines a set of importance weights for multiple criteria with performance ratings for each option on these criteria and calculates the overall score as the expected value of these components. The patient’s weightings for the eight criteria of decision quality are elicited as early as possible in the decision-making process and their ratings on how well the decision made performed on these criteria as soon as possible after it was made. The MDQ Score, unique to the patient and to the particular occasion, is automatically calculated as the summed multiplication of criterion weightings and ratings. A worked example is provided in Figure 1.

Both MDQ and the decision aids developed in Annalisa are accessible via the internet from any operating system, browser and on mobile tablets (iPad, Android). The resulting summary picture of the decision quality assessment (showing Weightings, Ratings and MDQ Score) can be printed and/or downloaded as an image for later use, including sharing and formal clinical documentation.

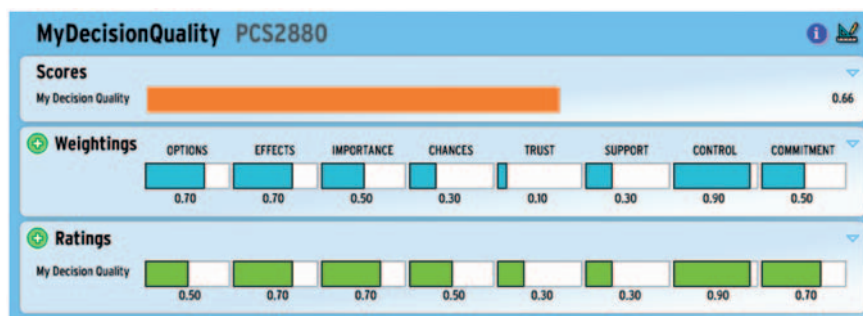


Figure 1. Screen capture of Annalisa presentation of MDQ for patient PCS2880.

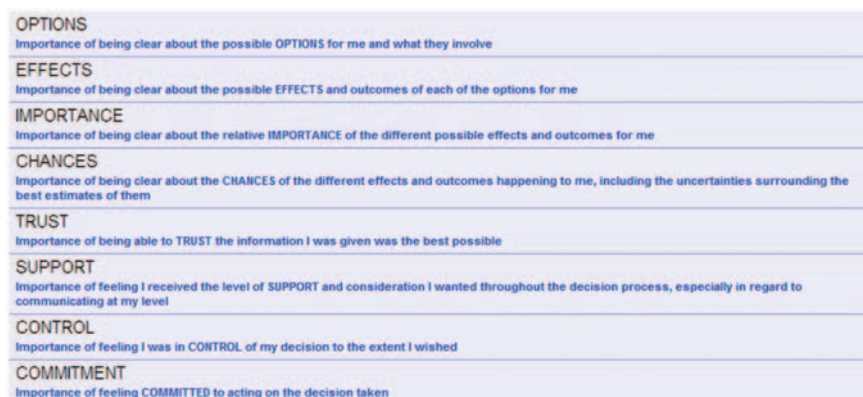


Figure 2. Screen capture of MyDecisionQuality weightings items (Ratings items are rephrased in past tense). Scale: 0 = Not at all important, 5 = moderately important and 10 = extremely important.

The desire to make MDQ practical in pressured situations such as a health-care clinic determined the number of criteria included. The number that an individual could realistically be asked to weight and rate at the time of decision making was initially set at 10. The review of the most commonly used instruments in relation to patient involvement and participation in health decision making helped us to generate a list of candidate criteria. This list was reduced to 10 on the basis of either conceptual redundancy or inappropriateness for inclusion in a universal (i.e. not specifically health) decision quality measure. These 10 included six items which remained when it was later decided that eight was the maximum practical number for a user to weight and rate at the time of decision making and hence the maximum number of items to include in a decision quality measure. This number is within Miller's magical number seven plus or minus two and is endorsed in the Cochrane Handbook.²⁴ The shorthand labels for these six criteria are: 'Options', 'Effects', 'Importance', 'Trust', 'Control' and 'Commitment'. Of the remaining four items in the original 10, an Uncertainty criterion was subsumed in a 'Chances' criterion and an

Emotional Support item in a general 'Support' criterion.

Of the eight criteria in the current version of MDQ (Figure 2), the first four match the structural requirements for *any* MCDA implementation in any context (Options, Criteria, Weightings and Ratings). These criteria also appear, in one form or another, in all checklists for developing decision aids for health decisions, including IPDASi. The last four criteria relate to other aspects of the decision process and are also explicitly or implicitly included in most checklists for decision aids. The 'Commitment' criterion creates for investigating concordance at the point of decision and correspondence with future actions and outcomes.²⁵

As with all the existing instruments referred to earlier there is no intention in MDQ to capture or assess the subjective experience of the patient (fear, anxiety, etc.). The patient expresses their views as to the support they received in relation to their feelings and emotions – and all other aspects of the decision experience – by their weighting and rating on the Support criterion.

After discussions of the provisional eight items with immediate colleagues, we uploaded an online survey

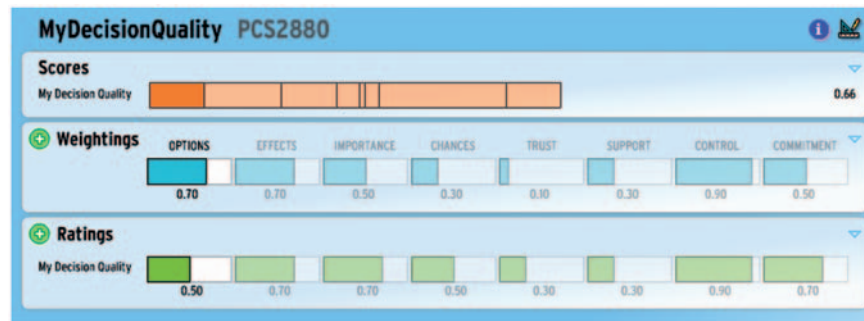


Figure 3. Screen capture of Annalisa presentation of MDQ for patient PCS2880 showing MDQ Score breakdown and highlighting of part-worth, weighting and rating for Options.

incorporating the initial MDQ on the Facebook page of the SDM Group, and emailed an invitation to comment to those on the lists of the Society for Medical Decision Making (SMDM) and Society of Judgment and Decision Making in mid-December 2011. Allowing for crossover, we estimated that this provided us with a few hundred potential respondents. Twenty individuals completed the questionnaire (latest in mid-January 2011) and nine also provided comments on the MDQ screen. Their feedback was incorporated in the re-development of the MDQ, when it was compatible with the underlying framework and construct.

Figure 1 shows the *Weightings* component of MDQ as now adopted. The equivalent *Ratings* component of MDQ is not presented here, but it is identical to the *Weightings* except that the descriptions are phrased in the past tense (e.g. ‘I was clear about the Options available to me and the processes they involve’).

While it is possible to have Users enter their weightings and ratings directly into Annalisa, early testing of MDQ using a convenience sample of academics showed that it was easier for their data to be elicited on a 0–10 scale in the survey program (Elicia) within which the Annalisa for MDQ is embedded. The responses were then mapped directly on to a 0–1 scale and ported into Annalisa using the software bridge between the two programs.

There are always tensions between what can be expected from development of a practice-relevant tool and one that is also used for research. Since the first (*Weightings*) part of MDQ is designed to be administered as early as possible in the decision-making process it constitutes an intervention in itself, whether or not any other intervention (e.g. decision aid) is involved before the Rating part is administered. It is not at all clear what should be the primary outcome, in terms of decision quality, of a trial of MDQ-supplemented decision making and standard practice. The challenge of validating a patient-specific, preference-based instrument such as MDQ does not appear to have been

addressed in the literature thus far and we continue to seek assistance in this respect. Given the personalized character of MDQ, we are particularly interested in exploring the use of N-of-1 study designs.²⁶

Illustration of the application of MDQ

Figure 1 presents the MDQ screen of a patient from a randomized controlled trial (RCT) using two Annalisa-based decision aids for prostate cancer screening in Australia.²³ The *Weightings* shown are as they were entered in Elicia in non-normalized format, that is, they do not add to one. They are normalized in Annalisa to add to one as the Score calculation is always using normalized weights.

After seeing the MDQ Score, the patient has the option of viewing its breakdown into the contributions made by each criterion, that is, their ‘part-worths’, to establish whether, and if so how, they might be able to improve their MDQ Score in the future, provided the opportunity exists. In Figure 3, the MDQ Score for the patient is partitioned into eight segments. If a segment is relatively large then the criterion is making a larger contribution to the individual’s MDQ Score. On the other hand, if it is relatively small then it is making a smaller contribution to their MDQ Score. By placing the cursor over any segment of the MDQ score bar, the relevant criterion label and the weightings and ratings for it are highlighted (column 1 in Figure 3; video demonstration at <http://bit.ly/17yKWNm>) If the patient has assigned the criterion a small weighting but also a low rating there is no need for concern. However, if they have assigned the criterion a small rating but a moderate or large weighting, they may want to think about how they might change things for the better, for example, by prioritizing the seeking of more information about the effects, more value clarification about criterion



Figure 4. Incremental (Expected) Value of Perfect Ratings for each criterion for respondent PCS2880, shown as priority distribution. The longest bar indicates biggest gain from perfect rating.

importance, moving towards their preferred level of control or whatever the criterion relates to.

This feedback can be formalized in the form of the Incremental (Expected) Value of Perfect Rating (IVPR) (see Figure 4). The IVPR for a criterion indicates the amount by which the overall MDQ Score could be increased if, given the respondent's weighting of a particular criterion, they achieved a (perfect) rating of one. In the case of this patient, this would suggest priority being given to improving the Rating for Options, followed by Effects and Support.

Discussion

As we move towards patient-centred care it is important that we respond positively and wholly to patient heterogeneity in the value aspects of decision making.²⁷ Developing a portfolio of instruments to evaluate the overall quality of decisions in a transparent and preference-sensitive manner is a growing area of research. MDQ is offered as one that may be able to contribute to this process.

Given its preference-sensitive nature how might MDQ be used to advance patient-centred research? Patients are heterogeneous in both their biophysical profile and their preferences. Because of the preference-sensitive nature of the instrument, the usefulness of average results (Weightings, Ratings and MDQ Scores) from MDQ depends on the purpose of using it in the first place. If a patient uses MDQ to assess the quality of a

decision made after using an online decision aid and prints out the MDQ screen, this may be used during a clinical consultation follow-up to form the basis of a tailored conversation about particular aspects of the decision. In this case, it is only the individual patient's Weightings, Ratings and Score that matter. On the other hand, for an RCT involving simple and complex versions of a decision aid, average MDQ scores may be used to compare decision quality across the two arms of the trial. However, these results still need to be carefully interpreted in light of the personalized criterion weightings they embody. In principle, the average results matter most where health-care resources are being consumed or a relevant group- or population-level policy decision is to be taken.²² In this respect, cluster and latent class analysis²⁸ may be used to establish meaningful patterns of preferences in the community,²⁹ leading to an 'epidemiology of preferences'.

In relation to the Annalisa-based decision aids we are developing, we envisage an alternative route where the individual selects the criteria most important to them from a longer list rather than having a set of criteria provided by researchers. We refer to this as a 'Pick Your Own' version of a decision aid. This version formed one of the arms of the clinical trial involving two decision aids for prostate cancer screening.³⁰ A 'Pick Your Own' version of (MDQ) captures the essence of person-centred care but it is essential that any such alternative patient-reported MDQ measure retains its theoretical and prescriptive basis in MCDA.

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Declaration of Conflicting Interests

Annalisa and Elicia are both © Maldaba Ltd (www.elicia.org.uk). JD has a financial interest in the Annalisa software but did not benefit from its use in the study from which the illustrative data are drawn.

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Protocol

Increasing User Involvement in Health Care and Health Research Simultaneously: A Proto-Protocol for "Person-as-Researcher" and Online Decision Support Tools

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Abstract

Background: User involvement is appearing increasingly on policy agendas in many countries, with a variety of proposals for facilitating it. The belief is that it will produce better health for individuals and community, as well as demonstrate greater respect for the basic principles of autonomy and democracy.

Objective: Our Web-based project aims to increase involvement in health care and health research and is presented in the form of an umbrella protocol for a set of project-specific protocols. We conceptualize the person as a researcher engaged in a continual, living, informal "n-of-1"-type study of the effects of different actions and interventions on their health, including those implying contact with health care services. We see their research as primarily carried out in order to make better decisions for themselves, but they can offer to contribute the results to the wider population. We see the efforts of the "person-as-researcher" as contributing to the total amount of research undertaken in the community, with research not being confined to that undertaken by professional researchers and institutions. This view is fundamentally compatible with both the emancipatory and conventional approaches to increased user involvement, though somewhat more aligned with the former.

Methods: Our online decision support tools, delivered directly to the person in the community and openly accessible, are to be seen as research resources. They will take the form of interactive decision aids for a variety of specific health conditions, as well as a generic one that supports all health and health care decisions through its focus on key aspects of decision quality. We present a high-level protocol for the condition-specific studies that will implement our approach, organized within the Populations, Interventions, Comparators, Outcomes, Timings, and Settings (PICOTS) framework.

Results: Our underlying hypothesis concerns the person-as-researcher who is equipped with a prescriptive, transparent, expected value-based opinion—an opinion that combines their criterion importance weights with the Best Estimates Available Now for how well each of the available options performs on each of those outcomes. The hypothesis is that this person-as-researcher is more likely to be able to position themselves as an active participant in a clinical encounter, if they wish, than someone who has engaged with a descriptive decision aid that attempts to work with their existing cognitive processes and stresses the importance of information. The precise way this is hypothesis tested will be setting-specific and condition-specific and will be spelled out in the individual project protocols.

Conclusions: Decision resources that provide fast access to the results of slower thinking can provide the stimulus that many individuals need to take a more involved role in their own health. Our project, advanced simply as one approach to increased user involvement, is designed to make progress in the short term with minimal resources and to do so at the point of decision need, when motivation is highest. Some basic distinctions, such as those between science and non-science, research and practice,

community and individual, and lay and professional become somewhat blurred and may need to be rethought in light of this approach.

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KEYWORDS

user involvement; decision support; patient empowerment; Internet

Introduction

User involvement is appearing increasingly on the policy and action agendas of health care providers and researchers in many countries. Both “user” and “involvement” are terms broad enough to encompass a wide variety of interpretations [1-3] and to evoke a variety of proposals for how involvement can be encouraged, facilitated, and increased, regardless of interpretation. The belief is that user involvement will produce better health consequences for individual and community and will demonstrate greater respect for the basic principles of autonomy and democracy.

In discussing obstacles to such increased user involvement, the need to tackle professional attitudes, institutional barriers, and silo borders must also be emphasized [4-7]. However, some of the most fundamental barriers and borders remain largely untouched and beyond questioning, except by some at the margins of the discourse.

In our project to increase the involvement of persons in health care and health research, we find four fundamental distinctions that are problematic: (1) science and non-science, (2) research and practice, (3) group and individual, and (4) professional and lay. The four pairs are linked insofar as scientific research occurs overwhelmingly at the public group level, while professional practice, either at the individual or community level, is non-scientific. We use non-scientific in the sense that the actual application of scientifically established evidence can never be validated by the standards of science, let alone the application of beliefs or judgments. The claim that practice is evidence-based or science-based confirms, rather than contradicts, this.

Against the background of the revolution in electronic communications and computer competencies (providing widespread online access) and informatics and information storage (generating large amounts of accessible big data), we see our project, outlined here in the form of an umbrella protocol, as an addition to the variety of technologies available to optimize user involvement. But it represents a challenge to the systemic dichotomies above.

Textbox 1. User controlled research quoted from INVOLVE [9].

-The main aim of such research is seen as liberatory; supporting the empowerment of research participants and the achievement of change in line with service users' rights and self-defined needs and interests. Such user controlled research has generally been based on:

-social rather than medicalized individual approaches and understandings;

-the rejection of positivist claims to “objectivity”;

-and a commitment to personal, social and political change.

The concept of control in research is not a simple one. It may be defined in different ways and open to different interpretations. Service users and their movements, however, have identified user control as the defining characteristic of research which advances user knowledge, rights, and interests.

All four of the above distinctions are implicit in the activities of INVOLVE in the United Kingdom, an excellent example of an attempt to increase user involvement in health and health care *research*, in contrast to parallel attempts to increase user (ie, patient) involvement in health care *practice*. INVOLVE is a national advisory group that supports greater public involvement in the National Health Service (NHS), public health, and social care research. It is funded by and is part of the National Institute of Health Research (NIHR), which is in turn funded by the Department of Health and is tasked with sharing knowledge and learning on public involvement in research.

INVOLVE defines the public as “patients and potential patients; people who use health and social services; informal carers; parents/guardians; disabled people; members of the public who are potential recipients of health promotion programmes, public health programs and social service interventions; and organizations that represent people who use services”. Public involvement in research is conceptualized as “doing research ‘with’ or ‘by’ the public, rather than ‘to’, ‘about’ or ‘for’ the public”. INVOLVE distinguishes between three main levels of public involvement: (1) consultation (where researchers seek the views of the public on key aspects of the research), (2) collaboration (an ongoing partnership between researchers and the public throughout the research process), and (3) “publicly led” (where the public designs and undertakes the research and where researchers are invited to participate only at the invitation of the public) [8].

The split between scientist/researcher, practitioner/professional, and lay/public is clear throughout INVOLVE's descriptions but nowhere more clearly than in the final point. We see it as significant that INVOLVE has chosen to use the collective term “the public”, rather than the individual term “the person”, even though the former is then defined almost exclusively in terms of the latter.

Among the other instantiations of user involvement, “user *controlled* research” is a clear example of a publicly led activity, but it has political ambitions well beyond that envisaged by INVOLVE [9] (see [Textbox 1](#)).

Community-based participatory research is less radical and more in accord with the collaborative category of INVOLVE in that it promotes a specific two-way flow of information within the research group: researchers provide information and tools to enable community members to carry out research and take action, and community members share their expert knowledge and local meanings with researchers to achieve mutual knowledge and solutions to practical problems [10,11].

Within the status quo, three types of reasons are typically given for involving users in research [12]:

Public involvement in health research is underpinned by epistemological, moralistic and consequentialist arguments. The epistemological argument states that health research can benefit from the experiential knowledge and personal insights of patients, carers and service users. The moralistic argument states that the public have a right to be involved in any publicly funded research that may impact on their health status or the services that they receive. Finally, the consequentialist argument states that public involvement helps to improve the quality, relevance and impact of health research.

We suggest that a second consequentialist argument is missing from this list, particularly relevant within the setting of person-centered care [13]. In the Web-based project introduced here, we conceptualize the person as a researcher who is engaged in a continual, living, informal “n-of-1”-type study [14] of the effects of different actions and interventions on their own health, including those that imply contact with health care services. We see their research as primarily carried out in order to make better decisions for themselves, but they may offer to contribute the results to the wider population, either because it could eventually lead to better, or better-evaluated, interventions for themselves or because it could contribute to some wider public health goal or the good of others.

Within the conceptualization of person-as-researcher, those who lack the capability to function as effective researchers should be supported in their efforts to achieve that capability [15] through measures to increase health decision literacy and numeracy, especially in disadvantaged populations [16]. While we agree wholeheartedly with this principle, we note that questions of how far this support should go and at what resource cost must be part of the overall discussion of allocating scarce resources within a community, including those given to formal research. Without this reality check, all recommendations within the “capabilities” discourse remain ethically impressive but practically empty. Our project is designed to make some progress in this direction possible in the short term with minimal resources and to do so at the point of decision need, when motivation is highest.

Methods

Overview

Our online decision support tools, delivered directly to the person in the community and openly accessible, are to be regarded as “research resources”. The tools take the form of

interactive decision aids for a variety of specific health conditions, as well as a generic one that aims to support all health and health care decisions through its focus on key aspects of decision quality.

The tools focus directly on the person-as-researcher’s fundamental question, “What should I do?” This requires answers to the two subordinate questions: “What should I believe?” and “What do I prefer?” They generate an *opinion* that integrates a set of beliefs, in the form of the Best Estimates Available Now (BEANs) for the performance of the relevant options on criteria that matter to the person, with their preferences, expressed as relative importance weights for those criteria. The integration, by a simple and transparent expected value calculation, produces a set of scores for each option that constitute the opinion produced by the process—nothing more and nothing less.

For some criteria, the person is themselves the expert source of the BEANs, since they measure the impact of options on their personal life. The difficulty, burden, or bother associated with administration routes for medications or journeys to provider facilities are good illustrations of where different individuals may make very different BEAN assessments. All persons-as-researchers contribute their individual preferences to the opinion as criterion importance weights.

Many who consult the tools in the course of their research will be satisfied that they have received a personalized opinion for their own private use. But they can offer to contribute the results of their n-of-1 research to an n-of-n database, by registering with the site by named email and declaring any conflict of interest. Their name will appear in any publication based on the aggregation of the individual results, though personal results will never be displayed. They receive feedback as part of the research team.

It is vital to be absolutely clear on one fundamental principle: whether or not the person is assigned, or accords themselves, the status of patient in some other setting, they are involved in our project as a researcher and only as a researcher. And we repeat that this approach is proposed as *one* method to be included in the portfolio of interventions needed to meet the very broad target of increased user involvement in a heterogeneous community.

From this point on the paper takes the form of an umbrella protocol for the condition-specific studies that will implement our approach. It is therefore organized using the Populations, Interventions, Comparators, Outcomes, Timings, and Settings (PICOTS) framework [17].

Populations

Our population consists of individuals researching their personal health using a more or less formal n-of-1 methodology to help decide among different health-related interventions and actions. They regard themselves as interacting with health care professionals and institutions as an individual researcher, even though they are customarily assigned the status of patient. Individuals who wish to see themselves purely as patients are advised that they may find our resources, designed to support the individual’s research for better decision making,

inappropriate or unhelpful. But we hope they will proceed, subject to confirming acknowledgment of being seen in a researcher role. Those who wish to see themselves mainly, or exclusively, as patients will be well catered for by patient-centered shared decision making [18].

The focus is solely on research for better decision making about the individual's care. There is increasing interest in user involvement in relation to community-level activities, such as the development, prioritization, and delivery of health care services; the evaluation of specific interventions in Health Technology Assessments; and the determination of reimbursability for drugs and devices [1]. These are outside the scope of our project, though the approach we suggest is modifiable to this type of policy decision.

Members of the community are entitled to adopt whatever position they wish in relation to their individual interactions with health care professionals and institutions. That includes their interactions involving decision making, subject to any legal requirements, including giving informed consent. Our decision resources are, however, designed explicitly for those who wish to be able to involve themselves in clinical decision making as persons who are empowered (emancipated, enabled, armed) by their prior research. They are also intended for those who wish to keep open such positioning as an option, even if it may not eventually be exercised.

Researching one of our relevant tools will yield an opinion, based on principles that they have accepted (for their research purposes) and inputs they have supplied. We assume that the person opts into obtaining the opinion as part of the research basis for their decision involvement and emphasize that they are free to reject its content or use it in any way they wish in any subsequent decision communication with a clinician. "Clinician" should be interpreted throughout to include nurses, other health professionals, and clinical teams. "Person" should be interpreted to include the person-defined significant others and any legal guardian or proxy.

Interventions

Condition Decision-Specific Aids

Our condition decision-specific aids (eg, Should I have a prostate-specific antigen [PSA] screening test for prostate cancer? What treatment is there for my osteoarthritis?) have several characteristics that distinguish them from most other decision support tools [19,20]. We believe it is these features that carry the potential to increase user involvement, especially for the population defined above and in relation to the specified type of involvement.

While the increased scientific research on values and preferences needed for health decisions [21] proceeds, along with that on information and knowledge, clinical decisions are being made second by second. It would be wrong to say that much of the formal research being undertaken is "fiddling", though increasing concern with waste in research suggests some of it is, and even that many of the results will eventually be proven wrong [22-24]. Metaphorically, Rome is smoldering while academics are learning, and we agree with Wears that "Nothing can be gained by further perseverance in asking why clinicians

fail to adopt research recommendations. Progress may come from asking, instead, why research is failing to provide useful answers to questions important to clinicians" [25]. More importantly, we should be asking questions that are important to persons-as-researchers.

As a result, and as part of our work to improve decision quality in person-centered care, we publicly offer, as research resources, decision support tools that do not require answers to many of the fundamental questions being pursued in scientific research. This is in contrast to most of the decision aids and guidelines produced within both the evidence-based and shared decision-making philosophies, which emphasize current uncertainties, ignorance, and the need for caution. We believe vague urgings to "be cautious" are unproductive, unless accompanied by some operational guidance on *how* to be cautious, given a decision is to be made *now*. We therefore make our offers on the basis that the underlying theory and principles of the aids, as well as the nature and provenance of their empirical inputs, are made clear before any engagement with them (or buy-in) is possible. The user is required to have read and accepted the contents before proceeding. We therefore assume that they are making an informed *meta*-decision about whether to engage with the aid before any further involvement, even as a researcher. An involvement strategy that proceeds without this sort of high-level consent goes beyond "persuasion-as-simply-making-available" into covert nudging at best and coercive manipulation of choice at worst. It is ethically questionable [26-28].

The aids produce an opinion based on a prescriptive model for decision making in the form of Multi-Criteria Decision Analysis (MCDA). The opinion is "dually personalized" as it consists of the scores produced by combining (in an expected value calculation) the person's percentage importance weights for the criteria important to them with the BEANs for the personalized performance of each option on each criterion. The aids make absolutely no claim to be descriptively based in human decision behavior [29]. In fact, in key respects, especially their numerical format and expected value basis, their descriptive inadequacies are a necessary condition of their having something new and important to offer [30]. The aids are presented with as much transparency as possible, in order for the person to be clear about the principles underlying the opinion that emerges. We emphasize that they can reject the opinion of the aid as a contribution to their research, having generated it, but advise that they should consider not even engaging with it if they disagree with the bases spelled out upfront.

While we refer to "preferences", our precise term is "importance weights". As with most other terms in this area, debate surrounds its meaning. We define importance weights simply as the normalized responses of a respondent asked "How important is [each criterion] to you on an 11-point scale ranging from 0='of no importance' to 10='of extreme importance'?". After the responses are transformed into weights adding to 100% by normalization, the respondent has the opportunity to use the cursor or touch to modify the bar-length representations presented on the screen. We regard this elicitation procedure as the only one that is practical, in comparison to the more complex, normatively appealing procedures such as standard

gambles, time trade-offs, and swing weights, which we have tried and found operationally lacking [19]. We do not take any position on whether these importance weights meet anybody's normative requirements for constituting "utilities". The key point is again to make clear to the respondent that it is their importance weights, so defined, that are entered into the personalized opinion that the aid will produce for them as part of their research.

In regard to the performance rates for options on criteria, our tools are *not* designed primarily as information aids. They are therefore clearly different from most other aids that assume a better decision must be an informed decision. We do provide links to high-quality sources of information so that the person-as-researcher can opt in to them if they choose. But it is made clear that our primary aim is to provide information in the form of the BEANs for the performance of each option on each criterion. These are updated within a "living" philosophy [31] and reject any generic value-judgment based threshold (eg, $P < .05$) for what is usable in clinical decision making. In the absence of robust evidence, they may be best elicited by expert-based elicitation. The BEANs entered into the individual's aid are personalized as much as possible on the basis of self-reported characteristics. Opt-in pop-ups provide the provenance of the BEANs, or links to their sources, and the person-as-researcher is free to follow these as further clues to trustworthiness. Why do we not regard these as vital to consult in order to benefit from the aids? Because we are aiming solely to provide an opinion based on an expected value calculation that synthesizes the BEANs with the person's importance weights. Given this purpose, there is no need to communicate about the size or quality of the detailed BEANs in the way typically envisaged by those who see "risk communication" as a central task in informed decision support. Achieving success in this task is difficult [32], perhaps not surprising in the light of the failures of the educational and socialization systems to produce a health literate and numerate population. The only information our person-as-researcher needs to acquire is what the aid will provide and its bases—and what it does *not* offer.

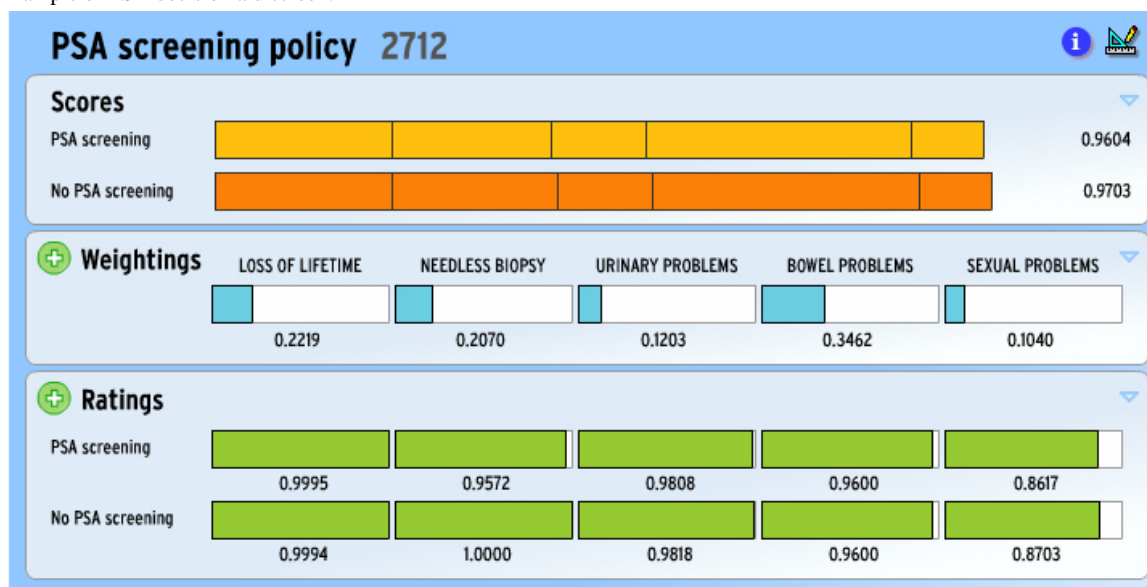
However, there is an important exception. The person-as-researcher does have an important role in supplying, at the point of decision, the BEANs for criteria where they are the expert. This is notably the case regarding the impact of testing and/or treatment on the individual as a person or party to a relationship. The rating of the burden or bother associated with, for example, different modes of treatment delivery (eg, oral, topical, subcutaneous injection, intravenous infusion; home, clinic, hospital) will vary with an individual's workloads and capacities [33]. Personalized elicitation of the BEANs for such criteria is therefore appropriate—not the use of group averages such as those produced by discrete choice experiments. Note that this rating role of the user is conceptually completely different from the role they play in assigning an importance weighting to such criteria, relative to all the others.

Uncertainty is dealt with by offering quality-weighted and unweighted opinions. We make clear that the quality adjustments in the former represent, no more and no less, the judgments of the quality of the BEANs made by the team responsible for their production.

Our aids, such as "Should I have a PSA screening test for prostate cancer?" (Figure 1), are the product of teams of named health professionals, including clinicians. But we stress that the opinion emerging is not offered as, and should not be interpreted as, a medical opinion, legally speaking.

Most of the key requirements for accessibility, usability, and functionality of patient-centered decision support, whether they come in the form of computer-based decision aids or traditional professional interaction, apply equally to the design of aids to be presented as research resources [34-36]. Nevertheless, the re-conceptualization from patient to person-as-researcher does have major implications in the tone of address and register adopted. Most importantly, our decision aids should not be seen in any way as providing care, or as a way of delivering better care. Instead, they are intended simply as an optional resource available in the person's own pursuit of the sources of better care. However, they also provide a way that users can add the results of their engagement to those of others, if they choose.

Figure 1. Example of PSA decision aid screen.



A Generic Decision Aid: MyDecisionQuality

User involvement is for a purpose, and our central aim is to improve decision quality. A measure of effectiveness in this regard is obviously needed.

MyDecisionQuality (MDQ) is a dually personalized decision quality instrument based (as are our condition decision-specific aids) on MCDA [37]. The assessor (eg, the person) is responsible not only for (1) weighting the criteria of decision quality in terms of their relative importance, but also (2) rating the quality of a decision just made on the criteria. MDQ is generic in the sense that the criteria are phrased without reference to any particular decision or context. Information relating to the specific decision condition and setting must be provided (if at all) outside the MDQ instrument, such as in the wider condition-decision support resource where it will often be situated.

As with all implementations of the simple weighted-sum version of MCDA, MDQ combines a set of importance weights for multiple criteria with performance ratings for each option on these criteria and calculates the overall score as the expected value of these components. In the case of MDQ, the person's weightings for the eight criteria of decision quality are elicited as early as possible in the decision-making process, and their ratings on how well the decision made performed on these criteria, as soon as possible after it was made. The MDQ score, unique to the person and to the particular occasion, is shown with the partial contributions of each criterion to it displayed in segments. Its weighting and rating are highlighted when the segment is touched or the cursor is rolled over it. An example is provided in Figure 2 and an illustrative video in Multimedia Appendix 1.

Apart from serving as an outcome measure for evaluating the decision-making process, MDQ represents an aid in itself and, being generic, can be used in conjunction with any of our condition decision-specific aids. Independent of any health care context or setting, MDQ alerts the person-as-researcher to one set of criteria for a good decision and asks them to express their

importance weights for them. Even if these weights are not widely different from each other—not unusual since the criteria have been included because of their importance—the explicit attention given to them has the potential to influence the remainder of their decision-making research. Having rated the decision ex post on the same criteria, the person receives a dually personalized assessment of the quality of their decision. They are also provided with insight into the priorities for future quality improvement by being shown the quality gains possible from improved rating on each criterion, weightings unchanged. For example, in Figure 2 we can inform the person of the effect on their decision quality score of improving their rating on “Importance”, lowly rated at 0.3, given the relatively high weight of 0.188 they have assigned it. Achieving perfect rating on this criterion would increase their score by 0.7×0.188 or 0.132, equivalent to a 20% improvement. Feeding back the result of the same calculation for each of the criteria generates a personalized list of future priorities. Since the criterion “Effects” is already highly rated, it is unlikely to be high on this priority list, even though it has the same weight as Importance.

If an associated clinician completes the parallel MDQ instrument, the bases for a decomposable measure of concordance are established. A prescription for improved shared decision making in future is generated, if desired by both parties. It can help reduce the established differences in a person's preferred and perceived participation in medical decision making [38].

MDQ can also serve as a patient-reported outcome measure (PROM), when the decision is conceptualized as one of the outcomes of a decision-making process. Or alternatively, it can be seen as a patient reported experience measure (PREM), which reflects their decision-making experience [39,40].

A bonus resulting from the use of both condition decision-specific and generic aids comes in the form of the enhanced and automatic documentation of the clinical decision-making process, given that the outputs can be saved by the person-as-researcher and incorporated into their provider's and own health record/s, if desired.

Figure 2. Example of MyDecisionQuality screen.



Comparators

Apart from a few aids also based on an implementation of MCDA (notably the Analytic Hierarchy Process), the vast majority of decision support tools on offer are not designed to produce an opinion in the form of numerical scores. They aim to support the person, normally regarded as a patient, by presenting information and value clarification exercises. They are then encouraged to make up their mind by taking into account and bearing in mind the pros and cons, without being offered explicit synthesizing principle or required to engage in numerical quantification or calculation. We can capture the difference from their aids succinctly by referring to the majority as being grounded in verbal multi-criteria decision deliberation as opposed to ours in numerical MCDA. Note that one of the key contrasts is expressed here as the verbal-numerical, rather than qualitative-quantitative one. All aids of both types are necessarily concerned with quantifying of magnitudes.

Our underlying hypothesis concerns the person-as-researcher who is equipped with a prescriptive, transparent, expected value-based opinion that combines their criterion importance weights with the BEANs for how well each of the available options performs on each of those outcomes. The hypothesis is that this person-as-researcher is more likely to be able to position themselves as an active participant in a clinical encounter, if they wish, than someone who has engaged with a descriptive decision aid that attempts to work with their existing cognitive processes and stresses the importance of information. Research that opens the “black box” of the clinical encounter [41,42] is revealing less and less impact from the latter approach to decision support. Most likely this is attributable to their failure to provide the person with powerful enough ammunition to move clinicians away from their preferred consultation structure and preferred course of action, reflecting tradition, training, and time constraints. This is particularly likely to happen in the situation where the evidence is low [43].

Apart from being provisional, the opinion from our aids will always be questionable by the normative standards built into many checklists for decision support tools [44,45]. We regard the relevant comparator as an empirical one, in the form of today’s clinician, and not abstract normative perfection. Experience so far shows there are many difficulties in carrying out genuinely unbiased empirical evaluations of person-centered

decision aids in the clinical context—some methodological, some professional, and others legal.

Outcomes

The black box metaphor is highly relevant in relation to the question that may be uppermost in some reader’s minds. What and where is the evidence of the impact of resources such as ours on any aspects of clinical decision making, notably user involvement and empowerment? A substantive, not merely rhetorical, response is to ask what and where the evidence is concerning the usual clinical decision-making process. Despite vast efforts to penetrate it, dating back to the pioneering work of Elstein [46], our aids will, by comparison, be shining white boxes.

We note with interest that clinicians and health care institutions are largely free to introduce practice changes as “quality improvements” without citing any robust evidence base or reference to peer-reviewed evaluations. In person-centered care, it is surely appropriate to acknowledge individuals have the same right in regard to their health decisions and behaviors. Using online decision resources of our type, under their explicit ground rules, falls well within our concept of the person’s self-seeking quality improvement in health decision making, whether alone or in collaboration with clinicians.

Nevertheless, in the context of growing funding of research into interventions that (might) increase user involvement, serious evaluation is needed of both effectiveness and cost-effectiveness, with “multi-criteria” preceding “effectiveness” in both cases. Hence this high-level protocol, designed to set out the relevant issues. In our opinion, all user involvement interventions should be evaluated with a comparative methodology using the same empirical comparator, not a normative checklist. In other words, evaluation should be based on the same principles applied to drugs and devices. The relevant comparator will necessarily be a “usual practice” arm, and we welcome the opportunity to engage in an empirical comparison with all other proposed interventions on a “level playing field”. Unfortunately, experience shows the ethical and professional barriers to this may be considerable. Authorities contemplating evaluation and resourcing of alternative user involvement strategies should therefore be aware that the position they take on professional and ethical issues may well bias the result in a particular direction. That direction is more likely to be towards

institutionalized forms of user representation and consultation than towards the more profound involvement envisioned within user controlled research, participant action research, and other emancipatory movements.

Timing

Decision time is always *now*, so our tools are developed and maintained within a living philosophy [31], especially, in relation to the performance ratings, where living evidence-based network meta-analyses will need to be complemented by expert elicitation, to improve the quality of the BEANs for many person-important criteria. Elicitation could possibly be in the form of living expertise-based network meta-analyses [47].

Settings

Our decision resources are designed to be practical for use at home in the community. This use may or may not be prior to some arranged or contemplated clinical consultation, depending on the individual person-as-researcher's wishes. Their subsequent use in the clinical setting would be subject to the clinician's agreement. Practicality in the home situation is the key to use of a resource designed to increase involvement. This will necessarily involve persons-as-researchers being allowed to make their own time and resource trade-offs in pursuing the complexity and depth offered.

Results

As implied in the Comparator and Outcomes sections of the protocol, our underlying hypothesis concerns the person-as-researcher who is equipped with a prescriptive, transparent, expected value-based opinion—an opinion that combines their criterion importance weights with the Best Estimates Available Now for how well each of the available options performs on each of those outcomes. The hypothesis is that this person-as-researcher is more likely to be able to position themselves as an active participant in a clinical encounter, if they wish, than someone who has engaged with a descriptive decision aid that attempts to work with their existing cognitive processes and stresses the importance of information. The precise way this hypothesis is tested will need to be setting-specific and condition-specific, and these details will be spelled out in the individual project protocols.

Discussion

Other Considerations

The most advanced involvement of patient representatives in health research design and activity has been in OMERACT (Outcome Measures in Rheumatology) [48]. While important effects have been achieved, especially in adding person-important criteria such as fatigue to core outcome measures, the picture is not all rosy. Some participants in meetings have felt that “Dealing with hierarchical power relations and strongly opinionated professionals was experienced as mentally challenging. A recurring barrier reported by patients was a lack of feedback on provided contributions. At times they felt that their experiential knowledge was not accepted as a valid source for scientific research, nor seen as relevant compared to

the expert knowledge of professionals” [48]. While this approach is likely to become more popular and effective, it will always be confined to a small number of patients. We seek much wider involvement through the open-access resources outlined in this paper.

Clinical decision making occurs as the final “bedside” stage of most translation models of the research-into-practice process. In many ways, it is the most complex stage to understand, to assess, and to intervene. We believe the Callard model is the most appropriate one for a person-centered health care system [49]. The user, now person-as-researcher, is separately placed in the middle of the model, rather than at the end of a translation pathway, or at one point in a cyclical translational system. Consequently they have direct impact on, and input into, all stages on the forward translation continuum from “bench to bedside”. In a small but significant modification to the Callard model, we suggest the person-as-researcher at the center is equipped with a decision support tool based on person-important criteria. The BEANs in their personalized resource represent the product of all necessary and practical forward translations needed at the point of decision, while the assessed quality of the BEAN for each cell constitutes the basis for backward translation to research priorities. In contrast (but not opposition) to the James Lind Alliance approach, which focuses on developing specific questions for researchers [50], priorities are indicated by the potential score gains for options from higher quality criterion ratings, given the criterion weights.

Conclusions

Even a superficial overview of recent calls for increased user involvement in health care systems reveals a complex mix of motivations and interpretations. These are reflected in the diversity of terms and interpretations for both user (client, customer, patient, person) and involvement (participation, engagement, activation, emancipation). It is not surprising, then, that many and varied approaches to increasing user involvement have been canvassed, and implemented in some cases, without serious, comparative empirical evaluation.

In the light of this, our paper has had two purposes. The first explicit aim is to offer our specific person-as-(n-of-1) researcher approach that increases the individual's involvement in health care practice and health care research simultaneously. The basis of the approach, through online interactive decision tools available as open access resources, differs significantly from most others on offer, and these differences extend to the theoretical and empirical bases of the aids. These have been described at length. The second implicit aim is to call attention to the need for careful and thorough specification, evaluation, and resourcing of programs or projects set up to achieve the broad aim of increased user involvement. Since there will be many considerations and stakeholders in play, both conceptual clarity and policy transparency make some form of multi-criteria analysis almost essential as policy decision support. A technique such as MCDA can ensure that the specifications of the options and criteria are precise and comprehensive. It will also ensure that the ratings of the options on each of the multiple criteria, which are likely to vary among stakeholders, are elicited and processed in a way that makes their provenance transparent.

Web-based decision resources such as those we produce can provide fast and efficient access to the results of slower thinking and encourage individuals to take a more involved role in their health production by viewing themselves as researchers involved in ongoing n-of-1 type studies.

Some basic distinctions, such as those between science and non-science, research and practice, community and individual, and lay and professional become somewhat blurred and will need to be rethought in the light of this approach. We encourage others to engage with us in this rethinking.

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Authors' Contributions

JD and MKK jointly developed the reconceptualization of the person as researcher and of online decision aids as a decision resource that could become an open one. JD wrote the initial draft, which MKK revised. GS's and JBN's comments were incorporated in the final version by JD. All authors approved this version.

Conflicts of Interest

Jack Dowie has a financial interest in the Annalisa software used in the Annalisa-based decision aids and the current implementation of the MyDecisionQuality instrument at the University of Sydney but does not benefit from its use there.

Multimedia Appendix 1

Video demonstration of MyDecisionQuality.

[[MP4 File \(MP4 Video\), 923KB - resprot_v3i4e61_app1.mp4](#)]

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Abbreviations

BEAN: best estimate available now

MCDA: multi-criteria decision analysis

MDQ: MyDecisionQuality

OMERACT: Outcome Measures in Rheumatology

PICOT: Populations, Interventions, Comparators, Outcomes, Timings, Settings

PSA: prostate-specific antigen

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Who should decide how much and what information is important in person-centred health care?

Mette Kjer Kalsoft¹, Jesper Bo Nielsen², Glenn Salkeld³ and Jack Dowie⁴

Abstract

Most guidelines for clinical practice, and especially those for the construction of decision support tools, assume that the individual person (the patient) needs to be in possession of information of particular sorts and amount in order to qualify as having made an 'informed decision'. This often implicitly segues into the patient having made a 'good decision'. In person-centred health care, whether, in what form, and with what weight, 'information' is included as a criterion of decision quality is a matter for the person involved, to decide in the light of their own values, preferences, and time and resource constraints.

Keywords

decision quality, decision support, informed decision, multi-criteria decision analysis

It seems taken-for-granted by many interested in a patient's health care decision making, and in providing decision support for it, that only an informed decision can be a good decision, let alone the best possible decision. Being informed is proposed as a necessary, almost sufficient, condition of decisional empowerment, even when there can be no guarantee that the information is translated into understanding. The irony is that this orthodoxy has largely been arrived at without input from those making the decisions.

It is time to question this orthodoxy. Decision quality is a multi-dimensional concept and, therefore, by definition, its assessment is sensitive to the criteria used to determine it and the preference weights attached to them. Currently, decision quality is assessed formally or informally by methods which are dominated by the externally defined and assessed information state of the patient. As a result, he or she is denied the right to decide the attributes of a good decision and assign his or her own personal importance weights to those considerations including how much and what information is important to him/her.

Against the background of the vast literature on normative, prescriptive and descriptive approaches to decision making (Lipshitz and Cohen¹ provide an accessible introduction), we do not have the absurdly broad aim

of defining a good decision. We merely seek to make a narrow point concerning the place currently assigned to 'being informed' in assessing the quality of a clinical decision. From the perspective of person-centred health care, the assumption that 'being informed' can, and should, be defined external to the individual at the point of decision, needs to be challenged. This includes questioning the closely related assumption that the relative importance to be attached to information criteria in evaluations of clinical decision quality and decision support tools can be defined without reference to the preferences of the individuals in the specific clinical setting.

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Person-centred decision making

Let us take an example from daily life. An individual, as a consumer researcher, wants to buy a refrigerator. With appliances of most sorts, people regard best practice decision making as consulting trustworthy comparison websites and magazines, ones that go beyond expressing opinions, or recording 'likes', to numerically rate the alternative products on a set of attributes or criteria. They want these decision support tools to give them ratings that can be trusted because they are produced free of any conflict of interest or other biases. We will refer to them as the BEANs – Best Estimates Available Now. The consumer does not know, and does not want to know, why this refrigerator is given a 4*/80% rating on 'reliability', and a 3*/60% rating on 'environmental impact', and another one the opposite ratings. Feeling justified in assuming a common sense, lay understanding of the terms 'reliability' and 'environmental impact', they do not have neither the time nor motivation to find out more about what these concepts mean, in terms of the mechanical functioning of the refrigerator, the quality of its components, the emissions it produces or whatever else contributes to these ratings made by the expert assessors. They do not want to know more about how a refrigerator works.

Some may wish to establish whether consumers have made 'an informed decision' by seeing how well they score on a test of refrigerator knowledge. Giving considerable and *fixed* weight to knowledge in their measures of decision quality, consumers' decisions might be regarded as poor quality, because their knowledge subscore is low.^{2,3} In contrast, consumers may regard themselves as having made good decisions, indeed the best possible decisions they could make, given the time and cognitive effort they are willing to devote to research into the decision-making process including accessing and accumulating knowledge deemed important, even essential, by others.

But surely health care decisions are different from buying refrigerators? Choosing between surgery and medical options for newly-diagnosed cancer, or pain management for chronic osteoarthritis, is not like buying a household appliance, is it? In fact, nothing really changes for the individual, whom we now conceptualize as a researcher conducting a continuing, informal n-of-1 study into his/her health. The affective and emotional differences between the two situations may well produce differences in the decision-making process, but the patient accepts that this will not necessarily enhance the quality of the decision – as he/she defines it. Patients may become interested in finding out more about their medical condition than they would about refrigerators, and actually do so. But unless it leads to a change in a performance

rating for an available option on one of their criteria – especially the 'BEAN' for a criterion they weigh heavily – the additional information they now possess is decision-neutral. People-as-researchers may feel better informed in some sense, but they realize they will not necessarily be in a position to make a better decision and therefore have not ended up more *decisionally* empowered. They may even simply have become more anxious and regretful about the opportunity costs of acquiring the information, in the form of the foregone benefits from other activities in which they could have engaged.

Have these patients made an 'informed' decision? According to themselves and us, absolutely, since they have consulted a transparent set of option performance ratings on relevant criteria, originating from a source that they have decided is the *most* trustworthy. They have combined these with their criterion importance weights. Their decision quality score may well be low according to an instrument that weights highly the knowledge that they are assumed by others to need to make an 'informed' decision. The growing number of condition-specific decision quality instruments being developed, notably by Karen Sepucha and colleagues, all give very heavy weight to a knowledge subcomponent.⁴⁻⁶ There could be no clearer confirmation of the issue at stake here than the title of one of the background papers to these projects: 'How does feeling informed relate to being informed?'⁷

Trust

Trust is crucial here. In either shared or unshared decision making, trust relates to the inputs into decision making, since we have left behind the notion of an agency relationship, previously dominant in conceptualising medical practice. Trust is always a matter of degree, rather than a binary all or nothing, whether it relates to the BEANs provided by the clinician, or by a decision support tool. Furthermore, it is always the *relative* trustworthiness of the sources that matters. Even if there is only one, dubious, source, it will be the most trustworthy. Unless, that is, the person rates his/her own estimates as more trustworthy than the best source, since – it is easy to forget – these will always be the ultimate assessment. So we envisage an individual regarding the respected consumer magazine's BEANs on refrigerators as the most trustworthy in relation to that purchase decision. People's task in health care decisions, given a restricted willingness to devote time and energy to processing information, is to assess the trustworthiness of the available sources of BEANs for the outcomes and other criteria important to them. They would expect a clinician, or a team developing the ratings for a decision aid, to be highly

trustworthy and to be provided with evidence for this, especially in the case of an aid.

The key information the person-as-researcher requires is labelling that ensures he/she will get 'what it says on the tin' when they open an aid. With this meta-information, they can make an informed choice about which tins of what size to open.

The other major problem with any imposed information requirement is that it condemns many on the continuum of health literacy, and especially health numeracy, to receiving little or no help. We fully support attempts to reduce health illiteracy and innumeracy, especially their decision-focused forms. However, it is too much to expect of a decision support tool – or a clinician – to overcome the limitations of previous education and socialization in these respects. Moreover, it is important to accept that even if aid users are able to register and report the relative numbers of sad and smiley faces in frequency diagrams, or repeat back '1 in x' statements – about which there is considerable doubt^{8,9} – this does not in any way ensure that they can meaningfully incorporate the numerical probabilities they have correctly registered (say 10% and .05%, or 1 in 10 and 1 in 2000), into their decisions. This is not to say that a decision aid should not contain help in this respect, including guidance on how the person can best avail themselves of what it offers, and information on the bases of that offering. It is to suggest that much of this should be provided on an opt-in basis.

The wider contexts of person-centred health care

Nothing in what we have said is intended to imply that the community is not entitled to apply community-level criteria and weights to what it provides, or allows to be provided, to whom, under what conditions, and at what cost, in the pursuit of goals such as efficiency, equity and justice. Formal laws and regulations (including those on informed consent and clinician liability) and resource allocation policies (including reimbursement decisions) will be the context in which the individual decision is made, and they will frequently be in conflict with what an individual sees as best for him/herself, given personal criteria and weights. External consequences for others may trump individuals' preferences, as in the case of infectious diseases. But that is life as lived in society.

Trickier are the issues of social responsibility or morality which are not dealt with formally. Apart from issues of environmental and social impact (such as those arising from hormonal treatments and opioids), there are all those that arise in resource-constrained and interdependent systems simply as a result of those constraints and interdependencies. In these cases, we

say two things. First, it is not the function of individual decision support tools to mandate the inclusion or exclusion of 'social' criteria in an individual's set, such as concern for others' health, or insist that these be given specific weights. Those are tasks for the bodies politic and cultural, through education and debate. However, the support should permit and facilitate inclusion or exclusion of such 'externalities', to the maximum practical degree possible, as items in a 'Pick Your Own' criteria menu made available to the person-as-researcher. Second, that in order to be regarded as having made a high-quality decision, the individual should not be required to be *informed* about the social criteria they do select, other than having the processed BEANs available to them from a trustworthy source.

Normative checklists for decision support tools, such as those constructed in accordance with the guidelines of the IPDASi collaboration,¹⁰ are clearly intended to promote person-as-patient empowerment. But most decision aids that comply with these guidelines are designed for use only within the context of shared decision making, in which the person is assigned the status of patient. In many cases, the support can be accessed only within the clinical encounter, or with provider permission. They all perpetuate the idea that only a decision informed in a particular way and to a particular extent can be a good decision.

We do not need the concept of an 'informed decision', only that of a good, better or best possible decision. For none of these will there be a definition that is not multi-dimensional and therefore preference-sensitive. The question is to whose preferences should the definition be sensitive? There can only be one answer: the patient's – or the person's if they are not a patient.

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Related papers [A-G]

A number of peer-reviewed papers besides the five included were published in the course of my research. In all cases it was felt my contribution warranted first author status. The seven related papers [A-G] all drew on the same MCDA/Annalisa-based approach and software as those submitted in this thesis. They are briefly mentioned here to give an indication of the wider scope of the research undertaken during my thesis period.

- [A] **Without a reconceptualisation of ‘evidence base’ evidence-based person-centred healthcare is an oxymoron** was the third in the sequence of reconceptualisations prompted by the empirical experiences. It argues that the evidence base in person-centered care should be the unsynthesised matrix of performance rates on the person's important criteria, not the pre-synthesised option evaluations (using group average preferences) that constitute the conventional evidence base. The synthesis of performance rates with the person's importance weights should only occur at or near the point of decision.
- [B] **Enhancing informatics competency under uncertainty at the point of decision: a knowing about knowing vision** writes up the probability elicitation and evaluation instrument ‘PROBER’ for the first time since the software was revised. It makes the case for healthcare providers, who routinely make clinical probability judgements, gaining insight into 'how much they know about how much they know' via visual feedback, and being able to distinguish between their calibration and discrimination competencies. This reflected an interest stimulated by the probability elicitation exercises undertaken with expert clinicians in the context of developing the IBD decision aid.
- [C] **Can a Discrete Choice Experiment contribute to person-centred care?** was produced out of a concern that the need for elicitation of the individual person's preferences at or near the point of decision - and particularly the development of tools to support this elicitation - was threatened by claims in numerous studies using the Discrete Choice Experiment (DCE) approach that establishing group-level average preference results could somehow facilitate clinical decision making. (DCEs are perhaps the main technique used in health economic evaluation studies of public preferences.)
- [D] **Addressing preference heterogeneity in public policy by combining Cluster Analysis and Multi-Criteria Decision Analysis: Proof of Method** took up the challenge of how individual level importance weights, such as those emerging from widespread individual use of MCDA-based decision aids, could contribute to population-level policy making by way of clustering of the preferences of individuals, including ‘persons-as-researchers’.
- [E] **Bringing feedback in from the outback via a generic and preference-sensitive instrument for course quality assessment** was the result of dissatisfaction with standard forms of student feedback in teaching and the realisation that a dually-personalised course assessment instrument could be developed, providing a Student Reported Outcome Measure (STROM) equivalent to MyDecisionQuality as a Patient-Reported Outcome Measure (PROM), for formative but, possibly, also for summative use.

- [F] **Health informatics can avoid committing symbolic violence by recognizing and supporting generic decision-making competencies** argues that failing to recognise and exploit a widespread form of functional decision literacy, leads to the symbolic violence experienced within healthcare consultations by individuals at any and all levels of general literacy. Many highly literate persons resort to the same range of avoidant and other undesirable strategies observed in those of low basic literacy. The alternative response we propose exploits the generic decision literacy which comes in the form of the ability to access the decision-relevant resources provided by comparison websites and magazines. Our MCDA-based approach extends this approach to healthcare options and permits the incorporation of personal criterion weights in furtherance of person-centred care.
- [G] **Enhancing both provider feedback and personal health literacy: dual use of a decision quality measure** sets out a protocol for a study to establish the feasibility of using a web-based survey to simultaneously supply healthcare organisations with feedback on a key aspect of the care experience they provide and increase the generic health decision literacy of the individuals responding. The focus is on the person's involvement in decision making, an aspect of care which is seriously under-represented in current surveys from the perspective of person-centred care. By engaging with an instrument to assess decision quality the person can, in the one action, provide a retrospective evaluation of a past decision making experience in a specific provider context and enhance their competency in future decision making in any setting.
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