



DESIGN4 HEALTH

**Extract of the
Proceedings of the 5th International
Conference on Design4Health
Sheffield 4th – 6th September 2018**

Editors: Kirsty Christer, Claire Craig & Dan Wolstenholme

ISBN: 978-1-84387-421-8

727. A Design-led Process for Disseminating The Concept of Shared Decision Making

Canan Akoglu¹, Kathrina Dankl¹, Karina Dahl Steffensen^{2,3}

¹*Design School Kolding, Denmark*

²*Institute of Regional Health Research, University of Southern Denmark, Denmark*

³*Center for Shared Decision Making, Lillebaelt Hospital, Denmark*

ABSTRACT *Design researchers and practitioners have started to collaborate with experts in diverse areas such as healthcare, education and business especially during the last two decades. In healthcare, design researchers and practitioners have been exploring ways on how to involve patients more actively in engaging in their own healthcare and wellbeing. In this respect, patient-centred care and shared decision making are timely approaches in modern healthcare systems, where designers can leave a stamp by collaborating with stakeholders such as clinicians, patients and relatives to create better healthcare services.*

Starting from the above perspective, this paper explores the role of design in raising awareness and disseminating the concept of shared decision making based on patient campaigns in Vejle Hospital in Denmark so that patients and relatives would seek for a higher degree of involvement in making decisions for their own treatment and/or examinations. The study that is presented here is part of a 3-year collaborative project which includes enhancing clarity and understanding of a patient decision aid via design and creating ways for successful implementation through involving patients, relatives and clinicians in the design process between Vejle Hospital- The Patients Cancer Hospital and Design School Kolding in Denmark.

Keywords: shared decision making, co-creation, patient campaigns, patient decision aids

Introduction

Contemporary design research calls for involving all stakeholders as design partners to ensure that needs are met and ideas and knowledge of relevant actors are incorporated in future design solutions (Sanders and Stappers 2014; Manzini and Coad 2015). Healthcare is one of the significant fields where design can support advance through timely co-creational methods. Shared decision making (SDM), a central column of patient centred care, is exemplar for a co-creational design approach: without participation of patients, relatives and clinicians, no shared decision will be taken. SDM concerns cooperation between patient and clinician when decisions are to be made about diagnosis, treatment or follow-up which are preferable for the patient. This includes use of evidence-based information concerning options, benefits, harms, uncertainties and medical counselling and support to explore the patient's own values and preferences (Barry and Edgman-Levitan 2012). However in order to being able to implement SDM in clinical practice, it is fundamental that stakeholders share the vision of SDM (Coulter 2017; Stiggelbout et al. 2012). 'Patient activation' is thus found to be vital to create a patient push and request for SDM to consequently oblige clinicians and management to implement SDM into clinical practice.

The partnership that this paper covers is a long-term collaboration between Design School Kolding and The Patients Cancer Hospital in Denmark. Cancer care is a complex and on-going treatment process involving multiple health professionals and with a treatment trajectory where patients are facing difficult decisions at multiple time points. In such circumstances, it is considered important to inform and involve patients, to engage them in decisions about their care wherever possible and to help them retain a sense of control (Katz, Belkora, and Elwyn 2014). The collaboration of the two institutions contains the design of a general patient decision aid, adaptable to different types of cancers as well as its successful implementation into clinical practice. For the latter task, four main steps have been carried out: 1) conducting a co-creation workshop on how to implement the concept of shared decision making and make it a success by involving different types of stakeholder groups, 2) testing visual directions of the patient campaigns, 3) conducting a second co-creation workshop for developing campaign prototypes, and a 4) final testing of visual directions of the patient campaigns. These steps formed the basis for a patient campaign to foster the active involvement of patients and relatives and to make sure that SDM is requested from bottom-up. In this context, co-creation enabled a shared value creation as the basic foundation for a project success.

The following sections explore literature on implementation challenges in SDM and research on patient campaigns for SDM, before introducing empirical data following the four-step process.

Shared Decision Making and Challenges in Implementation

In recent years, efforts to implement SDM have been made (Coulter et al. 2015; Steffensen et al. 2018). Nevertheless, SDM is not widely used in clinical practice, including in cancer care and

several studies suggest that oncologists often do not involve patients in the decision-making process to the extent the patient desires (Tariman et al. 2009; Stacey, Samant, and Bennett 2008).

In addition, little attention has been paid to organizational and system level factors in which these interactions and decisions are embedded, and how to modify these to ensure that SDM becomes part of routine practice. Successful implementation of SDM in routine care is dependent on a number of factors including attitude, culture, skills, knowledge and management support to be realized (Müller, Hahlweg, and Scholl 2016). Not only it is important to involve key stakeholders (clinicians and hospital executives), but also to inform and teach patients about SDM and to validate that it is reasonable to ask for involvement in health care decisions about their own treatment. Although research shows that implementation is a key challenge in SDM, surprisingly little research points to co-creational methods as a way to address the well-known barriers such as the necessity for shared value generation or the harmonization of different stakeholder perspectives.

Co-creation to Support Implementing Shared Decision Making

Co-creation is explained as an act of cooperative creativity with the goal to create something together (Sanders and Stappers 2008). An essential aspect of it is the participation of stakeholders at the same time in the same context to generate ownership for the solutions (Brandt, Binder, and Sanders 2012, 145). A variety of studies cover patients and clinicians as co-designers of healthcare services (Robert et al. 2015; Mannonen, Kaipio, and Nieminen 2017; Rothmann et al. 2016; Bate and Robert 2006). However, when applied to SDM, we did not find studies on the methodology and value of co-creational approaches to improve the implementation of SDM. We would thus like to point to two studies that address design as a vital element in relation to the implementation of SDM. In the first study, the role of service design has been addressed and iterative design research approach has been put forward as an influential way to foster the implementation of SDM since it differs from typical social scientific methods based on a linear tactic by Griffioen et al. (2017). They especially point to five foundational principles of service design such as user-centeredness, co-creation, sequencing, evidencing and holism as possessing potential for the implementation of SDM. The paper is positioned as 'a call on service designers and healthcare professionals to combine their efforts to improve the implementation of shared decision-making in healthcare' (Griffioen et al. 2017, 194), but does not give insight into patient campaigns specifically. This is done by another study, AskShareKnow, as part of the Magic Program in the UK. In this research project, targeted to support SDM in the National Healthcare Service, a patient campaign was launched. AskShareKnow involves the following three questions: What are my options? What are the possible benefits and harms of those options? How likely are each of those benefits and harms to happen to me? Including 'What will happen if I do nothing?' (Shepherd et al. 2016, 1161). A study on the effect of the campaign showed that 'Enabling patients to view a short video clip before an appointment to improve information and involvement in healthcare consultations is feasible and led to a high uptake of question asking in consultations.' (Shepherd et al. 2016, 1160).

In this study, the format of a video clip was used to convey the information. The methods for designing the campaign or its co-creational efforts remain unclear though.

Based on the challenge of implementing SDM and the relative lack of research on adequate methods to do so, this paper explores how a design-led co-creative process could contribute to raising awareness and disseminating the SDM concept through patient campaigns: How can a design-led co-creative process raise awareness and support the dissemination of SDM through patient campaigns? What methods/methodology help(s) to create a shared value and vision among patients, relatives and clinicians?

Empirical Data

Creating the patient campaigns consists of the following four main phases in which 120 patients and relatives have participated:

- 1) Co-creation workshop I: Implementing the concept of SDM by involving patients, relatives and clinicians;
- 2) First round testing for the visual directions ;
- 3) Co-creation workshop II: Prototyping communication strategies to create better dissemination of SDM for patients, relatives and clinicians ;
- 4) Final testing for the visual directions.

This process led to three design outcomes: a) Posters, b) Postcards spread out in the waiting rooms, c) Two videos introducing the concept of SDM and the generic patient decision aid to be played in the waiting rooms and on the Centre for Shared Decision Making's website.

1) Co-creation workshop I

The first workshop aimed at creating mutual empathy and learning among patients, relatives, doctors and nurses. It fostered the development of first implementation ideas based on the different needs of the participants who have been recruited by the Centre for Shared Decision Making and thus had ties with the institution as former patients/relatives and current employees, ages between mid-forties and mid-seventies.

The main themes put forward by the patients and relatives were: more information about SDM and patient decision aids; patient campaigns using different types of media such as TV advertisements, information letters to be delivered to patients' homes and posters in the hospital waiting areas were needed; the style of information was preferred to be in a more informal way to increase the level of understanding.

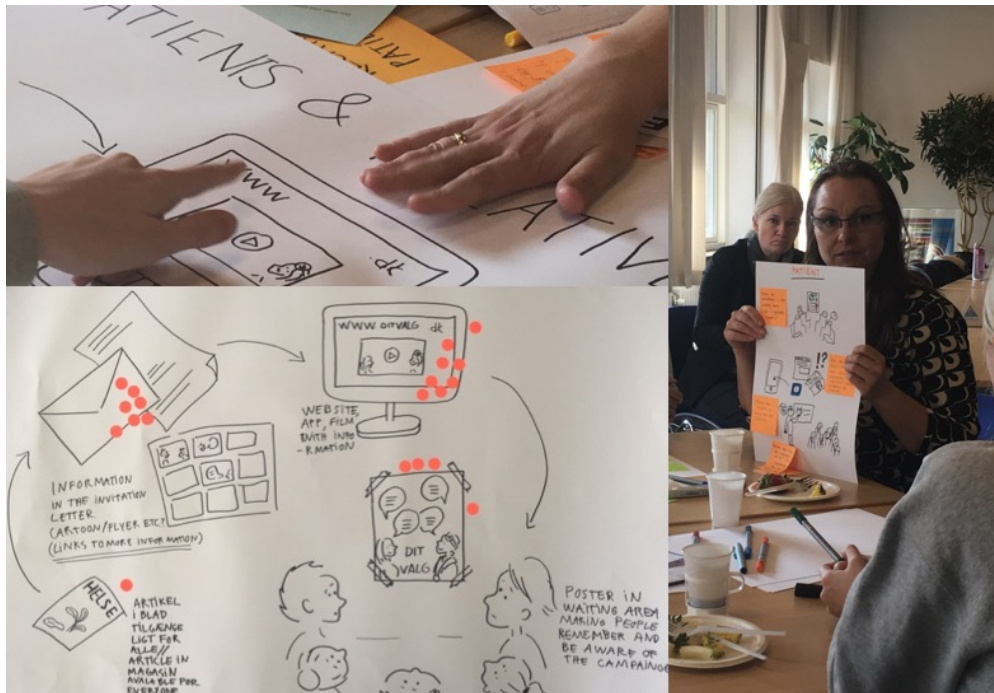


Figure 1: Patients, relatives and clinicians working on implementing the concept of SDM

In the patient and relative group (which clinicians participated in as well), the topic of preparation ahead of the clinical encounter with the healthcare professionals was discussed as essential for a successful implementation of SDM (Figure 1).

2) First Round Testing for the Visual Directions

Based on the findings from the first co-creation workshop, posters with different visual options were developed and tested with 47 patients and relatives through voting and mini-interviews in the hospital.

The main findings of this test phase were using calming colours and images of human beings (instead of illustrations). This choice was explained by enhanced trustworthiness and empathy that would lead to welcoming and friendly information for patients and relatives especially while they waited in a quite vulnerable situation in the hospital.

3) Co-creation workshop II

The purpose of this co-creation workshop which 10 clinicians, 2 patients and 1 relative participated in was to create ownership and prototypes of posters explaining the concept of SDM. The workshop also aimed at ensuring that the dissemination of SDM considered the plurality of different stakeholder voices to build a straightforward communication mode.



Figure 2: Highlights from the workshop process; patients, relatives and doctors working together

4) Comparing The Two Finalist Visual Styles

In this testing phase, two options were compared by 73 patients and relatives through votes and mini-interviews (Figure 3).



Figure 3: Two options to be tested for finalizing the visual direction

Final Version

Min sygdom, mit liv, fælles beslutninger

Min sygdom, mit liv, fælles beslutninger

My health, my life, shared decision

Would the doctor know what is best for me?

Help me, tell me what is important for you

We should remember to explain that

Yes, that will...

Because, here at the hospital, we use shared decision making

It is you who is the expert in your life

You know what is important for you and what is important to take into account

Hvad betyder det?

Mon der bliver taget hensyn til mig når...

Ja det vil der...

For her på sygehuset bruger vi Fælles Beslutningstagning

Det er dig der er ekspert i dit liv

Du ved hvad der betyder noget for dig, og hvad der er vigtigt vi tager højde for

Extract of Proceedings of the 5th International Conference on Design4Health, Sheffield, UK, 4th – 6th September 2018.

Using a design-led co-creative approach to develop a shared value and vision helped the design development team to receive different feedbacks and expectations from the relevant stakeholder groups. Working closely with all stakeholders supported the process of generating ownership and thus created a basis for a successful implementation in this specific project.

Discussion and Conclusion

This study aimed at exploring the role of design in raising awareness for the concept of SDM and its implementation through a co-created patient campaign. It thereby explored the two main research questions: How can a design-led co-creation process raise awareness and support the dissemination of SDM through patient campaigns? What methods help to create a shared value and vision among patients, relatives and clinicians?

A design-led co-creation process for creating patient campaigns resonates the core concept of SDM which is 'without participation of patients, relatives and clinicians, no shared decision will be taken'. The patient campaign per se was developed with the goal in mind to raise awareness and disseminate SDM, however through the design-led and co-creative approach already the development process itself fosters the active generation of a potential core group of testimonials. Those stakeholders involved, ideally happen to be 'lead users', with a greater knowledge base and background information on SDM to spread among their peer groups. Consequently, this approach has the capacity for positive implementation trade-offs such as improved acceptability. A potential drawback is to attract a balanced set of participants (physical and cognitive capabilities, socio-economic background, age) and to make sure that stakeholder voices are considered on equal terms to truly create potential ownership and ambassadors for the dissemination and implementation of SDM. The limitations of the design-led co-creation approach not only concern its dependence on a management environment that welcomes different stakeholders' views, but also on patients, relatives and clinicians who would be willing to actively engage throughout the process. Patients with cancer are likely to be a vulnerable situation and might not be able to spend extra time to work on this topic.

In turning to what methods help to create a shared vision, we suggest that creating a mutual understanding among different stakeholder groups and providing a space for them to learn from each other (perspectives, experiences, etc.) build a common ground first. In contrast to top-down approaches as well as more traditional social science approaches (e.g. interviews with each stakeholder group separately) the setting of co-creation workshops enables diverse expertise to form one solution jointly in the same room. Potential methodological additions to raise the level of evidence and evaluation of co-creational approaches would be: testing options that interpret on the outcomes of the previous phases through voting, short-written feedback and mini-interviews could potentially give clarity about the choices of patients and relatives; another co-creation workshop for generating the messages of patient campaigns could contribute to foster ownership and ambassadorship not only for patients and relatives but also for clinicians.

References

- Barry, Michael J, and Susan Edgman-Levitan. 2012. 'Shared Decision Making—the Pinnacle of Patient-Centered Care'. *New England Journal of Medicine* 366 (9): 780–81.
- Bate, Paul, and Glenn Robert. 2006. 'Experience-Based Design: From Redesigning the System around the Patient to Co-Designing Services with the Patient'. *BMJ Quality & Safety* 15 (5): 307–10.
- Brandt, Eva, Thomas Binder, and Elizabeth B-N Sanders. 2012. 'Ways to Engage Telling, Making and Enacting'. *Routledge International Handbook of Participatory Design*. Routledge, New York, 145–81.
- Coulter, Angela. 2017. 'Shared Decision Making: Everyone Wants It, so Why Isn't It Happening?' *World Psychiatry* 16 (2): 117–18.
- Coulter, Angela, Martin Härter, Nora Moumjid-Ferdjaoui, Lilisbeth Perestelo-Perez, and Trudy Van Der Weijden. 2015. 'European Experience with Shared Decision Making'.
- Griffioen, Ingeborg, Marijke Melles, Anne Stiggelbout, and Dirk Snelders. 2017. 'The Potential of Service Design for Improving the Implementation of Shared Decision-Making'. *Design for Health* 1 (2): 194–209.
- Katz, Steven J, Jeffrey Belkora, and Glyn Elwyn. 2014. 'Shared Decision Making for Treatment of Cancer: Challenges and Opportunities'. *Journal of Oncology Practice* 10 (3): 206–8.
- Mannonen, Petri, Johanna Kaipio, and Mika P Nieminen. 2017. 'Patient-Centred Design of Healthcare Services: Meaningful Events as Basis for Patient Experiences of Families.' In , 206–10.
- Müller, Evamaria, Pola Hahlweg, and Isabelle Scholl. 2016. 'What Do Stakeholders Need to Implement Shared Decision Making in Routine Cancer Care? A Qualitative Needs Assessment'. *Acta Oncologica* 55 (12): 1484–91.
- Robert, Glenn, Jocelyn Cornwell, Louise Locock, Arnie Purushotham, Gordon Sturmey, and Melanie Gager. 2015. 'Patients and Staff as Codesigners of Healthcare Services'. *Bmj* 350: g7714.
- Rothmann, Mette Juel, Dorthe Boe Danbjørg, Charlotte Myhre Jensen, and Jane Clemensen. 2016. 'Participatory Design in Health Care: Participation, Power and Knowledge'. In , 127–28. ACM.
- Sanders, Elizabeth B-N, and Pieter Jan Stappers. 2008. 'Co-Creation and the New Landscapes of Design'. *Co-Design* 4 (1): 5–18.
- Sanders, Liz, and Pieter Jan Stappers. 2014. 'From Designing to Co-Designing to Collective Dreaming: Three Slices in Time'. *Interactions* 21 (6): 24–33.
- Shepherd, Heather L, Alexandra Barratt, Anna Jones, Deborah Bateson, Karen Carey, Lyndal J Trevena, Kevin McGeechan, Chris B Del Mar, Phyllis N Butow, and Ronald M Epstein. 2016. 'Can Consumers Learn to Ask Three Questions to Improve Shared Decision Making? A Feasibility Study of the ASK (AskShareKnow) Patient–Clinician Communication Model® Intervention in a Primary Health-care Setting'. *Health Expectations* 19 (5): 1160–68.
- Stacey, Dawn, Rajiv Samant, and Carol Bennett. 2008. 'Decision Making in Oncology: A Review of Patient Decision Aids to Support Patient Participation'. *CA: A Cancer Journal for Clinicians* 58 (5): 293–304.
- Steffensen, Karina Dahl, Mette Vinter, Dorthe Crüger, Kathrina Dankl, Angela Coulter, Brad Stuart, and Leonard L Berry. 2018. 'Lessons in Integrating Shared Decision-Making Into Cancer Care'. *Journal of Oncology Practice* 14 (4): 229–35.

Stiggelbout, Anne M, Trudy Van der Weijden, MP De Wit, Dominick Frosch, France Légaré, Victor M Montori, Lyndal Trevena, and G Elwyn. 2012. 'Shared Decision Making: Really Putting Patients at the Centre of Healthcare'. *Bmj* 344 (S 28).

Tariman, Joseph D, DL Berry, B Cochrane, A Doorenbos, and K Schepp. 2009. 'Preferred and Actual Participation Roles during Health Care Decision Making in Persons with Cancer: A Systematic Review'. *Annals of Oncology* 21 (6): 1145–51.