Co-design for implementing patient participation in hospital services: a discussion paper

In Patient Education and Counseling

Authors

Eva Marie Castro[a*], Simon Malfait[b], Tine Van Regenmortel[c], Ann Van Hecke[b], Walter Sermeus[d], Kris Vanhaecht[de]

Author names and affiliations

[*]Corresponding author: evamarie.castro@soc.kuleuven.be, Tel: +0032495852480

[a] Faculty of Social Sciences, KU Leuven, 3000 Leuven, Belgium

[b] Faculty of Medicine and Health Sciences, Department of Public Health – University Center for Nursing and Midwifery, Ghent University, Ghent University Hospital, Ghent, Belgium

[c] Faculty of Social Sciences - HIVA, University of Leuven, Leuven, Belgium; Tilburg University, Tilburg School of Social and Behavioral Sciences, Tranzo, Tilburg, Netherlands

[d] Leuven Institute for Healthcare Policy, Department of Public Health & Primary Care, University of Leuven, Leuven, Belgium

[e] Department of Quality Management, University Hospitals Leuven, Leuven, Belgium

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1. Introduction

Patient participation is increasingly being recognized as a key component in healthcare. Patients' experiences and knowledge are considered as complementary and equal to professionals' knowledge [1], **both in individual care contexts and in healthcare organization** [2,3]. Direct patient participation methods have been proven to lead to patient-centeredness and better care [4], but **developing** and **implementing them is often a complex matter** [5,6]. The use of the co-design methodology could offer a solution for **designing and implementing** these complex interventions. **The so-called "Experience-Based Co-Design" is a specific form of co-design in healthcare**. **"Experience-based" refers to how patients feel about the used healthcare services and how well they serve their needs. 'Co-design' indicates that both patients and healthcare professionals act as designers of the healthcare services.** Also, it can be seen as an implementation strategy as it has the potential to counter **reluctance within healthcare teams** [7]**.** Overall, EBCD is a rigorous participatory approach that enables both staff and patients to (re)design services together by sharing experiences, identifying priorities, implementing and evaluating improvements in care and service provision.[8]

2. Background of EBCD

EBCD has already been used **in several** countries, in at least 57 projects, and in a variety of settings [9]. It originates from design science and draws on the idea that products and services could be improved by involving the end-user in their design. By combining insights from design science, organizational learning and patient engagement, Bate and Robert (2006) [10] **transferred** this user-centered approach into the healthcare context. Using a range of qualitative methods, the approach seeks to capture and understand how people actually experience a process or service in healthcare. Key moments that shape a person's overall experiences ("touch points") are identified. Patients and hospital staff then jointly set priorities and seek solutions. A full version of EBCD includes eight stages: (1) gathering **hospital** staff experiences through clinical observations, (2) filmed in-depth narrative- based interviews with patients or families, (3)editing the interviews in a 30-minute trigger film,(4) staff feedback event to review themes from staff interviews To identify priorities for improving services, (5) patient feedback event to view the edited film and to identify priorities for improving services, (6) joint event bringing staff, patients or families together to share their experiences of a service and identify their shared priorities for improvement, prompted by an edited 30-minute trigger film (7) co-design groups of staff, patients or families working on implementing improvements relating to identified priorities, and (8) an evaluation/celebration event [11]. **Recently**, accelerated versions of EBCD **have been** designed and tested using video interviews from a national database [12]. The innovative aspect of this co-design

method lies in patients' active involvement throughout the entire improvement process, including implementation.

3. Methods

To illustrate the fit between **co-design and implementing** complex healthcare interventions, we elaborated on three multiple-case studies using co-design to (re)design and evaluate a patient participation intervention introduced by the researchers. Applicability of the interventions, based on theoretical knowledge, needed to be discussed with those who would benefit from them or might be harmed by them. Therefore, patients and hospital staff evaluated, fine-tuned and designed the proposed interventions in interviews and group meetings. Two important considerations in the evaluation of interventions were desirability and feasibility. Although the three studies used co-design, they varied in terms of scope, length and complexity.

The first study aimed to design and implement the "experts-by-experience intervention". This intervention concerned the involvement of "experts by experience" (trained patients) in the delivery and evaluation of hospital services [13,14]**. Experts by experience were systematically involved to support their peers and provide feedback to hospital staff about the care and its organization. The intervention took place in three settings of a large university hospital in Belgium. In each setting, a full co-design trajectory was performed. Experts by experience were, together with other patients and healthcare staff, involved in the co-design process. Adaptation were made to the original EBCD-version. First, participants were informed about the co-design trajectory by means of a video message. Second, discharged patients (>1year) were also included to provide a broader perspective on healthcare by including patients who had already processed their physical and mental problems. Third, researchers provided literature-based knowledge during the process to equally combine experiential knowledge, practical knowledge and scientific knowledge. Lastly, staff interviews were filmed to treat patients and hospital staff equally. The two latter adaptations are grounded in the responsive evaluation and the empowerment evaluation methodology which served as a framework in our study** [15,16]**. Reflecting on our approach, the embedding of co-design in the two well-established evaluation frameworks increased mutual understanding and facilitated an open dialogue among stakeholders. To ensure full participation of the experts by experience it was necessary to conduct an extensive co-design trajectory where all aspects of the intervention and its implementation were discussed together (e.g. goals of their engagement, tasks and roles, practical organization, dissemination of the project). However, our approach was costly and time consuming.**

The second study aimed to develop and implement the Tell-us Cards in eight services in six hospitals. The Tell-us Card is a tool, which facilitates communication between nurses and patients

by inviting patients to write on the Tell-us Card what is important for them concerning hospital discharge. The card offers the possibility to identify patients' preferences and needs to be acted upon by nurses [17–20]**. Admitted patients and nurses were selected in each hospital service to participate in the co-design trajectory to tailor the tool for the local context. Due to the practical nature of the Tell-us cards, the co-design process was comprehensively shortened. Film-editing in the third stage was replaced by using audio fragments from the interviews of both nurses and patients. The sixth, seventh and eighth stage were held together. In our opinion, the co-design approached was supportive in tailoring the intervention and creating acceptance on the ward. However, a more substantial and comprehensive explanation of the intervention to prepare the stakeholders would have been useful. The duration of the shortened trajectory was sufficient.**

The third study used the co-design trajectory to design and implement bedside handovers on nursing wards. Bedside handover is a process where the shift-to-shift report between nurses is delivered at the patient's bedside to improve the patient's involvement [21]**. The goal was to use bedside handovers [17–19] as new standard in fourteen services in eight hospitals. Admitted patients and nurses were involved to fine-tune the intervention. To reduce length and intensity of the co-design process, adaptations were made to the classic EBCD-trajectory. First, all respondents received an information brochure in combination with verbal explanation. Second, patients were selected on availability (i.e. present on the ward). Third, instead of using an edited film, written quotes from patients were used in the third stage of the co-design trajectory. As the intervention was quite straight-forward, the sixth and seventh stage were merged. Finally, the celebration event was not organized but comprised of a gift in the final session. The adaptions were made from a perspective of cost-effectiveness. Looking back to our co-design trajectories, our approach enabled us to tailor the intervention for both patients and nurses, without cutting to much in time resources. Moreover, the confrontations with patients were valuable to overcome barriers that were initially reported by nurses. As such, we consider co-design as an appropriate implementation strategy. However, we experienced one difficulty: by using written quotes from patients instead of videos, nurses were confronted with patients' opinions quite late in the trajectory.**

Based on observations, recordings and field notes of the 25 co-design trajectories in 15 general and university hospitals in Flanders, two research teams analyzed and triangulated their observations using the five phases of Atkins and Murphy's model of reflection: awareness, describing the situation, analysis of feeling and knowledge, assessment of the relevance of knowledge, identifying and learning. Experienced barriers and enablers were described, analyzed, and translated into nine points of action and recommendations [22].

4. Points of action and recommendations

4.1. Preparation of co-design

Co-design is not feasible without preparation and implementation efforts. Sufficient preparation to ensure **patients and staff feel comfortable with the method** is highly recommended. Both patients and hospital staff should be prepared for the interviews. Being interviewed is usually a new and exciting experience, especially if interviews are (video-/audio)-recorded. For some participants, this method can even be slightly frightening and prevent patients from speaking freely. To create trust and **put participants at ease**, we suggest providing patients with a detailed explanation of the trajectory and the purpose of the interviews, not solely on paper but also on film/in person. Preparations and planning are important, but so is 'letting things go', as not everything is controllable. For example, **some patients abandoned the project** and continuing to pursue these patients is not recommended as it contravenes the principle of patient self-determination, which should be respected in all co-design trajectories.

4.2. Recruitment of patients and hospital staff

Patients as well as hospital staff should be purposefully recruited. Patients had difficulties extrapolating their individual experiences because of their health condition (e.g. still processing a traumatic experience). **Therefore**, patients with a less recent hospital experience were also included. In terms of patient recruitment, the three studies showed that it was desirable to collaborate with a head nurse or physician to facilitate initial contact with participants, although the risk of selection bias increased [23]. To support acceptance and successful implementation of an intervention a multidisciplinary sample of hospital staff should be recruited. An open but critical mindset and willingness to collaborate in this empowering participatory trajectory are essential for both hospital staff and patients. Furthermore, to **assess** the intervention, hospital staff **should** feel free to give constructive feedback.

4.3. Practical support

The **effect** of contextual factors such as practical arrangements should not be underestimated. Some examples to take into consideration are reachability, accessibility of the location, name badges so that participants can be addressed personally, catering so that participants feel welcome, a little present to thank the participants, etc. It was useful to have an additional person onsite to help patients with these logistic arrangements (e.g. transport), to support all stakeholders during several activities (e.g. giving additional explanation in smaller groups) and to assist the moderator by safeguarding the research process (e.g. making field notes based on observations). This type of support services and practical

assistance are necessary to allow the moderator to focus on enabling interaction and effective group discussions.

4.4. Group cohesion

An important task of the moderator is to facilitate group cohesion by taking group dynamics into account. Group dynamics refers to a system of behaviors and psychological processes occurring within or between (a) social group(s) [24]. Facilitation of group cohesion can be challenging as it might be hampered by inequalities associated with traditional roles of patients and healthcare professionals, in which patients mainly rely on healthcare professionals' knowledge and where healthcare professionals tend to use a rather paternalistic approach. This approach was sometimes observed **in** the first part of a joint meeting: the group of patients sat on one side of the table and the group of professionals on the other side of the table. Patients barely spoke. Next, the moderator showed the filmed interviews. **To** facilitate group cohesion professionals and patients were asked to reflect on their activity in small mixed groups. During the second part of the meeting, the two "subgroups" spontaneously took mixed seating positions at the table, **resulting in** an open discussion of the various experiences. Apparently, the combination of showing the edited films and the reflection exercise in mixed subgroups was very valuable to achieve connectivity.

4.5. Combination of methods and tools

In an attempt to overcome the lack of (participatory) ideation tools provided in EBCD [25], we used specific, mostly qualitative, research methods in combination with creativity-oriented methods to organize the meetings. Amongst others, rating scales, imaginary cases and other focus group techniques such as written citations and video quotes were used [26,27] next to several interactional materials such as notepapers and feedback on presentations. The combination of these methods and tools proved appropriate and in line with the aim of the meeting and its participants, provided guidance, interaction, variety, and trustworthiness in an informal atmosphere.

4.6. Ensuring mutual respect

All participants need to experience that their **point of view is** taken seriously. Ensuring mutual respect, avoiding unnecessary jargon and safeguarding an equal distribution of patients and staff are indispensable. We suggest avoiding meeting with more professionals than patients or vice versa. **Including more patients than professionals** may lead to the assumption that the patient's voice is not be as powerful as the professional's. The moderator **should** create a safe environment, in which an open, respectful and authentic dialogue between participants with differing perspectives can take place.

This can be achieved by interviewers adopting an open attitude themselves, having participants introduce themselves informally, using humor, and specific methods such as Metaplan, **in which participants first write down ideas on slips of paper before they are discussed in group.** Only those who are willing to provide extra explanation, do so.

4.7. Common ground

Searching for common ground should be one of the key objectives of a co-design trajectory. This is achieved by first exploring the experiences of patients and healthcare professionals in separate groups, followed by an integration in a joint group. This process allows participants to first differentiate, share basic assumptions and subsequently move towards integration, aiming to determine the common denominator. **It** can be supported by identifying, mapping and comparing the differences rather than ignoring them [28,29]. Again, the use of ideation tools is indispensable.

4.8. Avoiding participant drop-out

Drop-out and short hospital stay causing discontinuous involvement of participants might disrupt equality and perhaps empowerment [15]. Three ways to achieve continuous involvement are to include discharged patients, reward them for their contribution, and capturing the interviews of patients as well as those of hospital staff, in videos, recordings or written quotes. By showing these to the participants, they gain insight into each other's perspective, which provides a solid basis for further exchange of ideas. Including the quotes from hospital staff is not part of the original version of EBCD. **The statements** could be confrontational for patients, who still need the support and care of the staff during their hospital stay. However, in our experience, professionals who are willing to participate in a co-design trajectory refrain from disrespectful or offensive statements.

4.9. Knowledge convergence

Aiming to effectively co-design interventions, all voices should be heard: those of healthcare professionals and their practical knowledge, of patients and their experiential knowledge and of researchers and their theoretical knowledge (i.e. by a preceding literature review). Following the empowerment theory, this combination of different types of knowledge will lead to more sustainable and accepted interventions in practice [15]. The EBCD method upholds this principle through the use of group meetings, in which different types of knowledge converge. However, in our experience the frequency of knowledge convergence (i.e. the duration and comprehensiveness of the co-design trajectory) should be determined by the complexity and concreteness of the proposed intervention. For example, the first study (i.e. the involvement of experts by experience) was more complex (more

interacting components [30]) than the second (i.e. Bedside Shift Reporting) and third study (i.e. Tell-us Cards). Therefore, in the first study we conducted the full EBCD trajectory but in the second and third study, researchers felt this would not have an added value. As such, in light of a balance between costs and benefits, we suggest adjusting the number of meetings to prevent unnecessary overshooting.

5. Conclusion

We reported the value of co-design in studies on **implementing** complex patient participation interventions, and provided insights from a researcher's perspective.

Two **conclusions can be drawn from our findings**. First, although the effects and process of co-design have been reported frequently [31,32], practical advice on how and when to use it remains limited. We are convinced that co-design can be helpful as a participatory research method in healthcare **thanks to its** combination of several research methods and the systematic convergence of stakeholder perspectives. **We found co-design to** facilitate group dynamics resulting in constructive collaboration. **Furthermore**, we retrieved one of the foundations of EBCD (user involvement in product improvement) and included the innovative aspects of EBCD such as the dynamic sequence of several meetings, in varied forms, using several methods, all enhancing a perpetual motion of evaluating and (re-)designing an intervention.

Second, we consider co-design a useful tool for designing, evaluating and implementing **complex** patient participation-related interventions. **We found the** practical step-by-step approach of co-design, in which the perspectives of patients and healthcare professionals are brought together, **to be** a critical factor in overcoming reluctance in practice and designing methods tailored to patients and healthcare practitioners. We **consider it** necessary to adapt the approach to the proposed intervention, using either an extended or accelerated trajectory, **depending on the scope of the intervention.** A balance between costs and benefits should be taken into account when planning co-design.

Overall, co-design can be considered as the future method for quality improvement, research, intervention development and implementation. In this reflective paper, we suggest nine recommendations for further use, grounded in the empowerment evaluation within a societal responsible framework of costs and benefits.

6. References

[1] J.F. Caron-Flinterman, J.E.W. Broerse, J.F.G. Bunders, The experiential knowledge of patients: a new resource for biomedical research?, Soc. Sci. Med. 60 (2005) 2575–84. doi:10.1016/j.socscimed.2004.11.023.

[2] J. Loder, L. Bunt, J. Wyatt, Doctor know: a knowledge commons in health, London, 2013.

[3] G. Embuldeniya, P. Veinot, E. Bell, M. Bell, J. Nyhof-Young, J.E.M. Sale, N. Britten, The experience and impact of chronic disease peer support interventions: a qualitative synthesis., Patient Educ. Couns. 92 (2013) 3–12. doi:10.1016/j.pec.2013.02.002.

[4] E. Nilsen, H. Myrhaug, M. Johansen, S. Oliver, A. Oxman, Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review), Cochrane Database Syst. Rev. (2010) CD004563. doi:10.1002/14651858.CD004563.pub2.

[5] S. Malfait, K. Eeckloo, L.L.M.A. Van Hecke, The Influence of Nurses ' Demographics on Patient Participation in Hospitals : A Cross-Sectional Study, Worldviews Evidence-Based Nurs. (2017) 1–8.

[6] D.A. Richards, Complex Interventions in Health: An Overview of Research Methods., Routledge, New York, 2015.

[7] D.A. Tyler, M. Lepore, R.R. Shield, J. Looze, S.C. Miller, To Culture Change: Nursing Home Administrators' Use of Education, Training, and Communication., Gerontol. Geriatr. Educ. 35 (2014) 321–36. doi:10.1080/02701960.2013.837049.

[8] P. Bate, G. Robert, Bringing user experience to healthcare improvement : the concepts , methods and practices of experience-based design -, Int. J. Integr. Care –. 8 (2008) 6200.

[9] S. Donetto, P. Pierri, V. Tsianakas, G. Robert, S. Donetto, P. Pierri, V. Tsianakas, G.R. Experience-, Improvement : Realizing Participatory Design in the Public Sector Experience- based Co-design and Healthcare Improvement : Realizing Participatory Design in the Public Sector, Des. J. An Int. J. All Asp. Des. 6925 (2015) 227–248. doi:10.2752/175630615X14212498964312.

[10] P. Bate, G. Robert, Experience-based design: from redesigning the system around the patient to co-designing services with the patient, Qual. Saf. Health Care. 15 (2006) 307–310. doi:10.1136/qshc.2005.016527.

[11] V. Tsianakas, G. Robert, J. Maben, A. Richardson, C. Dale, T. Wiseman, Implementing patient-centred cancer care : using experience-based co-design to improve patient experience in breast and lung cancer services, Support Care Cancer. 20 (2012) 2639–2647. doi:10.1007/s00520-012-1470-3.

[12] L. Locock, G. Robert, A. Boaz, S. Vougioukalou, C. Shuldham, J. Fielden, S. Ziebland, M. Gager, R. Tollyfield, J. Pearcey, Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement, Heal. Serv. Deliv. Res. 2 (2014). doi:10.3310//hsdr02040.

[13] T. Borkman, Experiential Knowledge: A Analysis of Self-Help Groups, Soc. Serv. Rev. 50 (1976) 445–456.

[14] E.M. Castro, T. Van Regenmortel, K. Vanhaecht, W. Sermeus, A. Van Hecke, Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review, Patient Educ. Couns. (2016). doi:10.1016/j.pec.2016.07.026.

[15] D. Fetterman, A. Wandersman, Empowerment Evaluation, Am. J. Eval. 28 (2007) 179–198. doi:10.1177/1098214007301350.

[16] T.A. Abma, R.E. Stake, Stake's Responsive Evaluation: Core Ideas and Evolution, New Dir. Eval. (2001) 7–22.

[17] E. Jangland, M. Carlsson, E. Lundgren, L. Gunningberg, The impact of an intervention to improve patient participation in a surgical care unit: A quasi-experimental study, Int. J. Nurs. Stud. 49 (2012) 528–538. doi:10.1016/j.ijnurstu.2011.10.024.

[18] N.L. Sehgal, A. Green, A.R. Vidyarthi, M.A. Blegen, R.M. Wachter, Patient whiteboards as a communication tool in the hospital setting: A survey of practices and recommendations, J. Hosp. Med. 5 (2010) 234–239. doi:10.1002/jhm.638.

[19] N.L. Sehgal, M. Fox, A.R. Vidyarthi, B.A. Sharpe, S. Gearhart, T. Bookwalter, J. Barker, B.K. Alldredge, M.A. Blegen, R.M. Wachter, A multidisciplinary teamwork training program: The Triad for Optimal Patient Safety (TOPS) experience, J. Gen. Intern. Med. 23 (2008) 2053–2057. doi:10.1007/s11606-008-0793-8.

[20] M. (2017). van Belle, E., Zwakhalen, S. M., Caris, J., Van Hecke, A., & Heinen, Tailoring of the Tell-us

Card communication tool for nurses to increase patient participation using Intervention Mapping, J. Clin. Nursing. (2017).

[21] C.D. Anderson, R.R. Mangino, Nursing Administration Quarterly, Nurs. Adm. Q. 30 (2006) 112–122.

[22] K. Atkins, S. and Murphy, Reflective practice, Nurs. Stand. 8 (1994) 49–56.

[23] S. Hahn, S. Puffer, D.J. Torgerson, J. Watson, Methodological bias in cluster randomised trials, BMC Med. Reserach Methodol. 8 (2005) 1–8. doi:10.1186/1471-2288-5-10.

[24] T. Franz, Group Dynamics and Team Interventions: Understanding and Improving Team Performance, 1st Editio, Wiley-Blackwell, Chichester, 2012.

[25] S. Bowen, K. Mcseveny, E. Lockley, D. Wolstenholme, A. Dearden, S. Bowen, K. Mcseveny, E. Lockley, D. Wolstenholme, How was it for you ? Experiences of participatory design in the UK health service, Int. J. CoCreation Des. Arts. 9 (2013) 230–246. doi:10.1080/15710882.2013.846384.

[26] E. de Bono, Six Thinking Hats: An Essential Approach to Business Management, 1st U.S. e, Little Brown and Company, Boston, 1985.

[27] T. Miaskiewicz, U.N. De Lisboa, C. De Campolide, K.A. Kozar, Personas and user-centered design: How can personas benefit product design processes?, Des. Stud. 32 (2011) 417–430. doi:10.1016/j.destud.2011.03.003.

[28] M. Weisbord, S. Janoff, Don’t Just Do Sometehing Stand There: Ten Principles for Leading Meetings that Matter, Berett-Koehler, San Francisco, 2007.

[29] B. Hans, Vanleke Lesley, Co_creation. 13 Myths debunked, 2016.

[30] P. Craig, P. Dieppe, S. Macintyre, S. Michie, Developing and evaluating complex interventions : the new Medical Research Council guidance, BMJ. 1655 (2008) 1–6. doi:10.1136/bmj.a1655.

[31] R. Wright, K. Lowton, G. Robert, C. Grudzen, P. Grocott, Using Experience-based Co-design with older patients , their families and staff to improve palliative care experiences in the Emergency Department : A re fl ective critique on the process and outcomes, Int. J. Nurs. Stud. 68 (2017) 83–94. doi:10.1016/j.ijnurstu.2017.01.002.

[32] R. Tollyfield, Facilitating an accelerated experience-based co-design project, Br. J. Nurs. 23 (2014)

136–41.