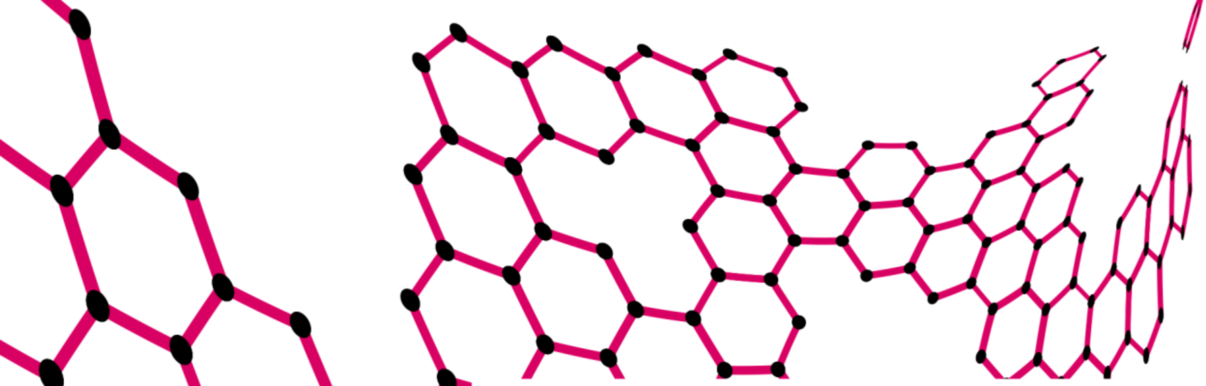

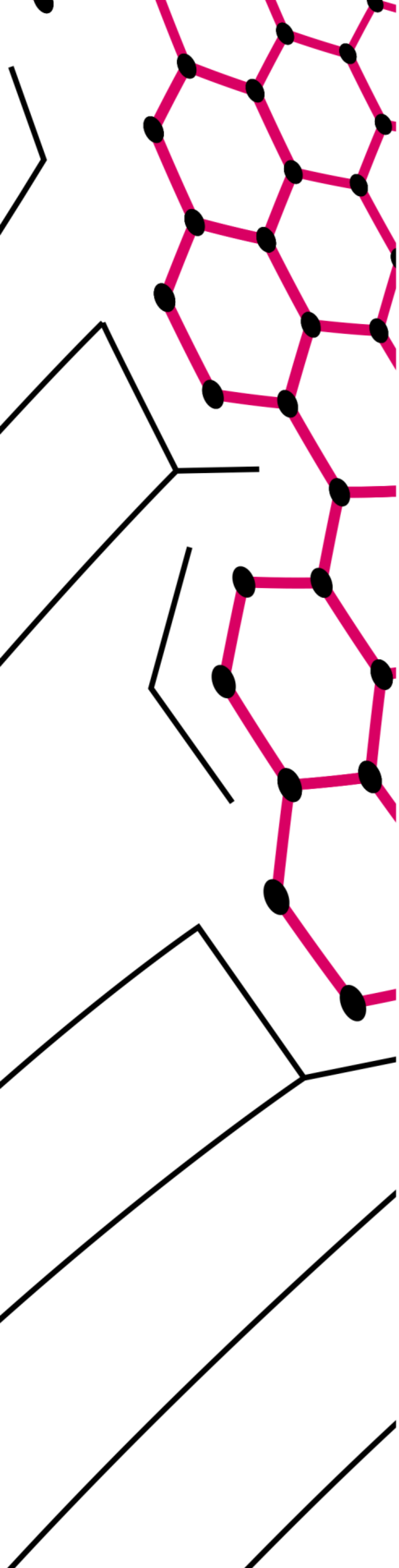

MASTER THESIS

AN INQUIRY INTO THE WAYS IN WHICH PATIENTS CAN BE INCLUDED IN THE IMPLEMENTATION OF HEALTHCARE INNOVATIONS

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Abstract

Background: Despite the growing recognition of the positive consequences of patient participation, the existence of general preconditions and the availability of guidelines on a national and international level and the legal push for it, the use of patient participation in healthcare in general is still limited. One reason appointed for this is a lack of knowledge about different patient participation methods and how to apply them.

Objectives: The purpose of this study was to identify methods that can be used by professionals of (healthcare) organisations to involve patients in the implementation phase of healthcare innovations and rank them on usefulness.

Design and method: A literature study was performed to define patient participation in healthcare innovations and to identify the added value of patient participation in healthcare innovations and evidence-based methods to do so. A Delphi study was performed to identify patient participation methods used or known by health professionals and to rate these methods on usefulness. Respondents were identified by their organisations of employment, which particularly focussed on innovation in Dutch healthcare. The Delphi study consisted of three rounds of data collection and was conducted in ten weeks during the period April till July 2018.

Results: Twenty patient participation methods were derived from the literature study and five additional methods were derived from the Delphi study. Of all patient participation methods, the following five were found to be most useful by the respondents: patients participate in work groups, advisory groups/client councils, brainstorm sessions, focus groups, and users' panels. In total, 30% (n=6) of the methods derived from the literature study and 60% (n=3) of the methods derived from the Delphi study are stated to be useful according to the respondents (≥4.0 on a five-point Likert scale). No significant relations were identified based on the data collected. However, when grouping the respondents by organisations it appeared that the appreciation of patient participation methods corresponds with the rating of usefulness of patient participation in general; respondents who rated the usefulness of patient participation methods relatively high also rated patient participation in general relatively high, and vice versa. Further, respondent's familiarity with patient participation methods within the top-five most useful methods is 1.3 times higher than the average familiarity with patient participation methods.

Discussion and conclusions: A list of twenty-five patient participation methods that can be applied to the implementation of healthcare innovations was derived. It was observed that a gap between evidence-based patient participation methods and methods found to be useful by health professionals may exist, since a relatively large proportion of all the patient participation methods suggested by respondents was ranked as useful. Moreover, the method ranked as most useful was one of these suggested methods. When also taking into account respondent's increased familiarity with methods ranked as most useful, it can be stated that bias arising from the familiarity principle and/or a specific frame of reference might have been present. Further research is needed to verify the findings of this research and to deepen them. When the findings of this research can be verified, one step is taken towards filling the knowledge gap on different patient participation methods and how to apply them.

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1. Introduction

Patient participation is a subject of increased importance during the past years (Leys & Reyntens, 2007; Bovenkamp, Grit, & Bal, 2008; CBO, 2009). This is exemplified by the increased involvement of patients in decision-making regarding health policy (Thurston, 2005), treatment (Elwyn, 2010; Brown R. B., 2011), health technology assessment (Gagnon, 2011), and research (Boote, 2002; Caron-Flinterman, 2005). The consequences of patient participation can be found both at the individual (Averill, 1973; Thompson, 1983; Bandura, 2004) and national levels (World Health Organization, 2004; Hibbard, Greene, & Overton, 2013).

With increasing healthcare demand and costs, innovation in healthcare is also a subject with rising attention (CBO, 2009). In general, the purpose of innovation in healthcare is to optimise healthcare (processes). Considering the complex nature of healthcare (both business and social), it can be stated that innovation in healthcare influences financial and business actions, as well as its operations (Weberg, 2009).

1.1 Current knowledge

Despite the growing recognition of the positive consequences of patient participation, the existence of general preconditions and the availability of guidelines on both the national and international levels (Petriwskyja, 2014; Phillips, Street, & Haesler, 2016) and the legal push for it (CBO, 2009), the use of patient participation in healthcare in general is still limited. Several reasons can be appointed for this. One reason that is appointed for the limited use of patient participation in healthcare is the assumed lack of consensus on how patient participation should be put into practice on different organisational levels and the lack of consensus on how the level of patient participation should be measured (Renedo, 2015). Another reason that is appointed for the limited use of patient participation in healthcare is a lack of knowledge about different patient participation methods and how to apply them (Groene, Lombarts, Klazinga, Alonso, Thompson, & Sunol, 2009; Elg, Witell, Poksinska, Engström, Dahlgaard-Park, & Kammerlind, 2011; Wensing, 2015; Boaz, et al., 2016). In line with this is the call for insights into what, where, and how methods can be implemented in real-world clinical settings, that are both effective and efficient so that it is possible, given the restraints of a real-world setting (i.e. workload pressure, complex organisational systems), to increase active patient participation (Bovenkamp, Grit, & Bal, 2008; Grande, Faber, Durand, Thompson, & Elwyn, 2014).

Specifically with regards to the Netherlands, research is conducted in the past few years on the participation of different kinds of patients or patient groups (i.e. children, elderly, chronic ill people) within different healthcare domains (i.e. research, guideline and policy development, quality and safety improvement) (ZonMW, 2013). Since most of this research is exploratory of nature, it is seen as a starting point for further exploration and evaluation of putting patient participation into practice. The goal is to gain evidence-based knowledge and to use this to achieve a higher level of patient participation in Dutch healthcare (Dedding & Slager, 2013).

1.2 Aim of the study

This research aims to provide insights into different evidence-based methods to include patients in the implementation phase of healthcare innovations on the one hand and to provide insights into the methods used in practice on the other hand. Furthermore, insights are provided into which methods are most useful according to experts in practice. The term 'experts' refers to a wide range of professionals from the Dutch healthcare sector that are in some way involved in processes that aim for innovating healthcare. Patient participation methods resulting from this research are combined into an overview, supplemented with key-information about the methods. This overview can be used as a decision aid and will be of added value for (healthcare) professionals who will be supported in choosing the most appropriate patient participation method.

1.3 Research questions

In order to gain insights into different patient participation methods that can be used in the implementation phase of healthcare innovations and to put this information into an overview that supports (healthcare) professionals in choosing the most appropriate patient participation method for the implementation phase of healthcare innovations, the following research question and sub-questions are answered:

"What patient participation methods can enable professionals of (healthcare) organisations within the Netherlands to involve patients in the implementation of healthcare innovations within their organisation?"

1. What are the evidence-based methods to involve patients in the implementation phase of healthcare innovations?
2. What methods to involve patients in the implementation phase of healthcare innovations do experts in practice use?
3. What methods to involve patients in the implementation phase of healthcare innovations do experts in practice find useful?

Due to practical reasons regarding the limited timeframe available for this research, it is chosen to narrow the scope of the research down to the implementation phase of healthcare innovations.

1.4 Relevance

1.4.1 Scientific relevance

The scientific relevance of this research is dual. First, the results of this research provide insights into different patient participation methods and how to apply them from the perspective of both literature and practice. With this, the knowledge gap around different patient participation methods and how to apply them is decreased. Second, results of this research give insights into the proportion of respondent's familiarity with methods provided by literature on the one hand and whether or not respondents come up with patient participation methods not provided by the literature on the other hand. The relevance of knowing this lies in the determination of overlap of patient participation methods recognised by literature and practice. When it turns out that patient participation methods provided by literature and methods provided by practice are overlapping, it might be the case that scientific knowledge is diffused to practice and/or literature provides information on methods that are of current interest of practice. When it turns out that patient participation methods provided by literature and methods provided by practice are not overlapping, it might be the case that scientific knowledge does not reach practice and/or literature provides knowledge about patient participation methods that are not of current interest of practice. When it is known whether or not this overlap exists in the first place, these insights might be used as a starting point for further scientific research or practice-driven research on this topic, so that the aforementioned reasons for the limited use of patient participation can be decreased or even removed. It might also be possible that new reasons for the limited use patient participation come to light. The latter notion is seen as a reasonable possibility considering the timeframe in which patient groups, the government, and supranational organisations like WHO already advocate getting patient participation more embedded in healthcare.

1.4.2 Social relevance

Although the scientific relevance and the social relevance seem to be strongly related to each other, there is one aspect to this research that entirely contributes to social relevance. The overview of patient participation methods resulting from this research can support healthcare providers in choosing the most appropriate patient participation method to use in the implementation phase of healthcare innovations. When involving patients in this phase of the innovation process, the performance of new healthcare products or services can be increased (Gruner & Homburg, 2000; Alam, 2002; Cui & Wu, 2016), which is beneficial for both the healthcare sector and the public.

2. Theoretical framework

2.1 Concepts and definitions

To understand the research questions and their relevance to its full scope, the theoretical framework starts with defining the concept of patient participation, which is complemented with a description of the interrelatedness of ‘patient participation’, ‘patient empowerment’, and ‘patient-centeredness’ and an explanation of their differences and similarities. The practical context of this research will be described subsequently by discussing the added value of patient participation as such, the relevance of innovations in healthcare, and the added value of patient participation in healthcare innovations.

2.1.1 Interrelatedness of ‘patient empowerment’, ‘patient participation’, and ‘patient-centeredness’

Patient empowerment

The concept of empowerment is studied within different academic research fields, such as psychology, economics, education, and healthcare, and can be defined in many different ways. However, it can be stated that the core of empowerment is formed by the idea of legal or physical power (Bridges, Loukanova, & Carrera, 2008). The word ‘power’ originates from the Latin substantive ‘potere’, which means ‘to be able to’ or ‘to have the ability to choose’. According to the Merriam-Webster dictionary, the term ‘empowerment’ in general can be defined as “the state of being empowered to do something: the power, right, or authority to do something” (Merriam-Webster, n.d.). Different types and levels of empowerment in general can be distinguished, such as individual and organisational empowerment. (Rappaport J. , 1984; Rappaport J. , 1987; Zimmerman, 1990). When focussing on empowerment from a healthcare perspective, patient empowerment can be distinguished. The concept of patient empowerment, in which the individual level, the family level, and the community level can be distinguished, arose from the urge of patients taking a more active place in decision-making processes about their own health and quality of life (Castro, Regenmortel, van, Sermeus, & Hecke, 2016). This concept got embedded in healthcare in the 1960s as a result of the aim for democratization and got further embedded in the 1970s and 1980s when the self-help movement occurred (Rappaport J. , 1987; Kieffer, 1984). Due to its complex and paradoxical nature, uncertainty exists about the definition and measurement of the concept of patient empowerment (Barr, Scholl, Bravo, Faber, Elwyn, & McAllister, 2015).

Patient participation

With the emergence of patient participation, the active role of patients in their health and healthcare is even further expanded than with patient empowerment, both on the individual and collective level (Souliotis, 2016). Specifically in the Netherlands, the cause of the shifting approach of healthcare from a rather paternalistic view towards ‘patient participation’ can be found in the combination of four factors. The first factor is the increased popularity of the argument of democratisation within society, which originated from dissatisfaction with the closed political system within the Netherlands in the 1960s. Hereby, the increased density of televisions per household played a big role in informing people about public matters. In addition, the national level of education relatively increased (Herweijer, 2010). For this reason, people got more empowered and participation of a broader range of stakeholders in the management of companies and organisation in different sectors occurred (CBO, 2013). Besides this, the authority of the Catholic and Protestant Church diminished, whereby people regained freedom over their own political choices (Parlement en Politiek, 2018).

The second factor is the relative increase of the amount of chronic ill people, which is the result of an ageing society, improved treatment of life-threatening diseases and a change of lifestyle and consumption patterns (NYFER, 2005). It is stated that living with and managing a chronic disease in combination with the structural and often frequent contact with healthcare providers, and thus relatively much experience with healthcare, make that especially chronic ill people develop a high degree of expertise and wisdom in their own disease (Wilson, 1999). With this change in public clinical needs, a healthcare system that is more focused on long-term care, the collaboration between different kinds of healthcare providers, in which the patient itself has an active role, and training in fulfilling this patient-role is required (CBO, 2013; NYFER, 2005).

The third factor is the increased privatization of the healthcare sector. Based on the aim for increased democratization and the relative increase of chronic ill people, government policies were designed to regulate the healthcare market and make it more demand-driven instead of supply-driven. An example of this is the introduction of increased market forces in healthcare in 2006 when the health insurance fund was replaced by private health insurance (Ministerie van Volksgezondheid, Welzijn en Sport, 2016). Now that this demand-driven organisation of the healthcare market gets more and more embedded, the government takes a less prominent role in the organisation of this market and puts the responsibility back in the hands of the parties involved in the healthcare market, like healthcare suppliers, health insurance companies, and the Dutch Health Authority (NzA). The philosophy behind this is that patients will choose healthcare services and products that meet their personal preferences and represent a certain level of quality. By this, healthcare suppliers get obliged to offer healthcare services that meet these criteria set by patients (CBO, 2009).

The fourth and last factor is the change in law and regulation within healthcare. After a lobby of twenty years, the first legal regulation to strengthen the patients' position in healthcare in the Netherlands became effective in the mid 1990s. The last legal regulation with this goal became effective in 2008 (CBO, 2009).

Definition of patient participation

Patient participation as such can be interpreted in many different ways, dependent on the context used. In general, roughly two different interpretations can be distinguished (Dedding & Slager, 2013). Patient participation can be interpreted as patients simply ‘participating’ or ‘being present’ in healthcare. A more profound interpretation of patient participation states that all stakeholders actively involved in a certain matter have equal voices and classical power relations change (Sahlsten, Larsson, Sjöström, & Plos, 2008). Both interpretations can be assumed valid, but difficulties occur when the first interpretation of patient participation is confused with the second (Dedding & Slager, 2013). Given the context and the purpose of this research, the more profound interpretation of patient participation is assumed appropriate. Therefore, the following definition is referred to with ‘patient participation’ in this research: “making use of the unique experience and expertise of patients, with the aim to improve quality of care” (CBO, 2013). The organisational levels on which this takes place and the extent to which particular patient groups are actively involved in these processes may differ.

Patient-centeredness

Even though the subject of patient-centeredness has been researched comprehensively over the past decades, no unambiguous definition of patient-centeredness can be distinguished. Its definition and conceptualisation seem to be strongly dependent on the context used. For example, patient-centeredness can be put into practice from a personal/patient perspective, but also from a family or relationship perspective. Both contain another purpose and require a different strategy (Mead & Bower, 2000; Hughes, Bamford, & May, 2008).

2.1.2 Differences and similarities of ‘patient empowerment’, ‘patient participation’, and ‘patient-centeredness’

The major similarity between the versatile concepts of patient empowerment, patient participation, and patient-centeredness is the fact that all of these concepts illustrate the shift from a paternalistic view on healthcare towards a more participation-based view on healthcare. The connecting facet is the redistribution of power between professionals on the one hand and the patient on the other hand, whereby the autonomy of the patient is increased (Castro, Regenmortel, van, Sermeus, & Hecke, 2016). Aside from this similarity, also some differences between the methods exist. So originated the concept of empowerment from a series of political movements, while patient-centeredness has a medical background, specifically originating from psychology and psychotherapy, and patient participation originated from a series of both social and clinical evolutions, like the aforementioned increased level of information and the diminished power of church (Holmström & Röing, 2010; Parlement en Politiek, 2018). Aside from this, also a difference can be distinguished in terms of the organisational levels the concepts are embedded in. So is patient-centeredness solely situated at the micro level, while patient empowerment and patient participation can also be situated at a meso or macro level due to their multidimensional and multilevel nature (Castro, Regenmortel, van, Sermeus, & Hecke, 2016).

All in all, it can be stated that patient empowerment is a much broader concept than solely patient participation and patient-centeredness. Patient-centeredness, in turn, can be seen as a precondition to facilitating patient empowerment, while patient participation can be seen as a facilitator for achieving a patient-centred approach in healthcare (Castro, Regenmortel, van, Sermeus, & Hecke, 2016). Others, however, argue that patient participation is a means of accomplishing patient empowerment whereby patient-centeredness is not necessarily an intermediate concept (Bovenkamp, Grit, & Bal, 2008). Since in both cases the concept of patient participation contains a strong accent on an active role of patients in their own care and healthcare in general and it can be seen as a stimulator of at least patient empowerment, the concept of patient participation is chosen to play a key-role in this research.

2.2 Practical context of patient participation

2.2.1 Added value of patient participation

Although lack of consensus on patient participation being solely a means to an end or also a purpose as such (CBO, 2013; Groenewegen, Kroneman, van Erp, Broeren, & van Birgelen, 2016), several consequences of patient participation can be distinguished. These consequences can be categorised into the level they occur on.

Individual level

It can be stated that the added value of patient participation originates from the concept of ‘personal control’, since the belief in one’s efficacy to exercise control may underlie all forms of personal behaviour and the change of this behaviour (Bandura, 2004). In general, this means that the belief of a person having control over some situation leads to positive consequences, regardless of whether this control is actually exercised or only experienced. Examples of these positive consequences are superior coping and adaption, positive mental and physical health and a reduction of stress. When it comes to patients’ participation specifically in their own care, examples of these positive consequences are increased motivation and stimulated performance, which positively influences medical outcomes (Averill, 1973; Thompson, 1983; Groene, Lombarts, Klazinga, Alonso, Thompson, & Sunol, 2009). For example, shared decision-making (SDM), a method in which patients play an active role regarding decision-making in their own care process, is associated with increased patient knowledge, satisfaction, adherence with treatment, and improved outcomes (Greenfield, Kaplan, & Ware, 1985; Street & Voigt, 1997; Kennedy, et al., 2002; Macfarlane, Holmes, Gard, Thornhill, Macfarlane, & Hubbard, 2002; Dam, Horst, Borne, Ryckman, & Crebolder, 2003; Ward, Sundaramurthy, Lotstein, Bush, Neuwelt, & Street, 2003). With regard to costs, negative relations have been found between the level of engagement in own care and billed care costs (Groene, Lombarts, Klazinga, Alonso, Thompson, & Sunol, 2009; Hibbard, Greene, & Overton, 2013). Also, negative correlations have been found for one’s belief in helplessness and morbidity and mortality, and positive correlations have been found for one’s belief in efficacy to exercise control and improved health (Peterson & Seligman, 1987; Peterson & Stunkard, 1989).

National level

On top of health promotion by (the illusion of) personal control, patient participation can lead to improved patient experience and outcomes, which benefits society in general (Hibbard, Greene, & Overton, 2013; Baker, 2014). Besides this, patient participation can lead to an improved efficiency of healthcare systems as a whole when patients are supported in expressing their opinion, experience, and true preferences and this user-knowledge is integrated in health services and products (Richardson, 1983; World Health Organization, 2004; CBO, 2009; Coulter, A., 2012).

2.2.2 Putting patient participation into practice

Patient participation can be put into practice by means of patient participation methods, whereby selection of the most appropriate method in a specific situation within a specific setting depends on the following selection criteria: starting position, available time, available budget, available staff members, the purpose of patient participation, the information to be derived from patients, the phase of the innovation or improvement process patients will participate in, level within the organisation, the use of experience experts or patient representatives, patient characteristics (i.e. age, reading and writing skills, mobility, health literacy), and desired frequency of deriving information from patients (representatives) (CBO, 2013).

2.2.3 Relevant context factors of patient participation

Evidence about relevant context factors influencing patient participation as defined in this research (i.e. making use of the patients' unique experience and expertise on different organisational levels) is very limited. However, influencing factors to patient participation in patient safety, influencing factors related to patient participation in guideline development and influencing factors related to patient empowerment in general can be distinguished.

Influencing factors to patient participation in patient safety can be divided into five categories: patient-related (i.e. demographic characteristics), illness-related (i.e. illness severity), healthcare professional-related (i.e. healthcare professionals' expertise and beliefs), healthcare setting-related (i.e. primary or secondary care), and task-related (i.e. whether the required patient safety behaviour challenges clinicians' clinical abilities) (Davis, Jacklin, Sevdalis, & Vincent, 2007).

Influencing factors related to patient participation in guideline development can be divided into four categories: patient representative-related (i.e. level of education, sickness-related and guideline-related expertise, social and communicative skills), chairman-related (i.e. level of experience, appreciation of patient participation, sense of urgency), process supervisor-related (i.e. experience, level of involvement with project), and professional-related (i.e. level of experience, appreciation of patient participation, sense of urgency). Apart from this, the stage within development patients are engaged in is related to successful patient participation in guideline development (Broerse, Pittens, & Lange-Tichelaar, 2013).

Influencing factors that are related to patient empowerment in general can be divided into three categories: personal resources (i.e. problem-solving skills, health literacy, communication skills), cultural/social/environmental factors (i.e. socioeconomic status, cultural background, gender roles/expectations), and intrapersonal factors (i.e. depression, anxiety, hope, meaning, positivity). In this context, the construct of healthcare empowerment is defined as the process and state of being engaged, informed, collaborative, committed, and tolerant of uncertainty regarding healthcare (Johnson, 2011). Since patient empowerment as defined by Johnson (2011) is considered as lying closest to the definition of patient participation as defined in this research and no relevant context factors could be found for patient participation in particular, it is chosen to focus on the relevant context factors of patient empowerment in this research.

2.3 Innovation in healthcare

The term ‘innovation’ can be interpreted in many different ways, and with these different interpretations come different definitions (Lorenz, 2010). A definition of innovations in general is as follows: “an idea, practice, or object experienced as new by an individual or other unit of adoption” (Rogers, 2003). Another, more profound definition of innovation is as follows: “the intentional introduction and application within a role, group, or organization, of ideas, processes, products or procedures, new to the relevant unit of adoption, designed to significantly benefit the individual, the group, or wider society” (West, 1990). The latter definition is used in the context of this research since it specifically addresses the intention of innovations to be significantly benefitting. In line with this definition, innovations in healthcare are often embodied in new services, new ways of working or new technologies, which contribute to improved healthcare, improved health, decreased healthcare, and/or reduced suffering from illness, of which the latter is specifically important from a patients’ point of view (Lansisalmi, Kivimaki, Aalto, & Ruorane, 2006; Berwick, 2008).

In general, innovation processes are often non-linear and iterative and characterised as a four-stage process whereby the stages of ‘problem identification’, ‘idea generation’, ‘idea evaluation’, and ‘implementation’ can be distinguished as general phases of the innovation process (Farr, Sin, & Tesluk, 2003; Anderson, De Creu, & Nijstad, 2004; Tran & Voyer, 2015). In this research, the focus lays on the implementation stage of healthcare innovations. In this stage, the plan that occurred from the previous stages of the innovation process is carried out when a satisfactory response to the initial problem is found. When this response is not found, the ‘problem identification’ stage is gone through again (Tran & Voyer, 2015). No distinction is made between different types of innovations in this research.

2.3.1 Added value of patient participation in healthcare innovations

Patient participation in healthcare innovation processes is often acknowledged as being important, but evidence about this remains very limited (Van, McInerney, & Cooke, 2015; De Freitas, Dos Reis, Silva, Videira, Morava, & Jaeken, 2017). However, user-involvement in innovations in general can be beneficial due to the profound understanding of user needs on which the innovation can be aligned and the new product or service performance can be increased (Gruner & Homburg, 2000; Alam, 2002; Cui & Wu, 2016). In line with this, recent literature is focussing on the added value of designing policies to stimulate user-directed innovations. These policies focus on suppressing the barriers of user-(directed) innovations (i.e. non-development, under-development, and under-diffusion) that obstruct the social welfare optimum of these innovations to be reached (Svensson & Hartmann, 2018). The benefit of user-involvement in innovations is also underpinned by the argument of user-involvement being beneficial in innovations in the public sector. It is stated that user-knowledge is a source of new ideas and creative solutions, resulting in usable, useful, and desirable public services (Haukipuro, Väinämö, & Arhippainen, 2014; Simmons & Brennan, 2017). Because the healthcare sector is part of the public sector, it is assumed that the benefits occurring from user-involvement in the public sector also apply to patient involvement in the healthcare sector.

3. Methodology

The methodology section consists of two parts. The first part contains the methodology of the literature study and the second part contains the methodology of the Delphi study.

3.1 Literature study

To be able to answer the research question, the sub-questions had to be answered. The first sub-question, "What are the evidence-based methods to involve patients in the implementation phase of healthcare innovations?" was answered by performing a literature study. This literature study consisted of two parts. Scientific literature was studied in the first part and a part of grey literature, i.e. literature "that which is produced on all levels of government, academics, business, and industry in print and electric formats, but which is not controlled by commercial publishers" (Schöpfel & Farace, 2010), was studied in the second part.

Besides answering the first sub-question, the purpose of the literature study was to provide input for the Delphi study. Patient participation methods derived from the literature and definitions and preconditions of these methods formed the basis of the Delphi study so that the second and third sub-question could be answered.

3.1.1 Scientific literature

To structure the study of scientific literature, the Participation Toolkit of the Scottish Health Council was used as a starting point for selecting methods that are effective in involving patients in healthcare innovation processes (Scottish Health Council, 2014). This Toolkit was designed by the Scottish Health Council and consists of 32 methods that can be used to involve patients, healthcare professionals, and members of the public in their own healthcare and in the design and delivery of healthcare services. According to the Scottish Health Council, all methods in the toolkit are tested in practice by all kinds of stakeholders within the healthcare sector (Scottish Health Council, n.d.). To determine which of the methods presented in the Participation Toolkit could be relevant for the context of this research, i.e. effective involvement of patients in the implementation of healthcare innovations, all of the 32 methods were searched for in Medline, Scopus, Science Direct, and PubMed, which belong to the main scientific, medical databases (University of Cambridge, n.d.) and are fully accessible via the University of Twente. When a method provided by the Participation Toolkit was found in one or more databases and met all the inclusion criteria set for scientific literature within this research, the method was put into the category 'Scientific literature'. The inclusion and exclusion criteria for scientific literature are presented in Table 1 (p. 12). If databases allowed doing so, results were limited to the human medical field. No restrictions according to the date of publishing were set.

Table 1

Inclusion and exclusion criteria for scientific literature

Study characteristics	**Inclusion criteria**	**Exclusion criteria**
Population	Patients or patient representatives in general or specific patient groups or representatives of specific patient groups	People other than patients or patient representatives
Intervention	Patient participation method	
Outcomes	Increased patient participation	No increased patient participation or decreased patient participation
		Not appropriate to use in the implementation phase of healthcare innovations
Setting	Clinical setting	Non-clinical setting
Study design	Systematic literature review, literature study, interview, experts' opinion, case study	Study designs other than literature review, literature study, interview, experts' opinion, case study
Report criteria	Article found via Medline, Scopus, Science Direct, and PubMed	Article not found via Medline, Scopus, Science Direct, and PubMed
	Article in English or Dutch	Article in a language other than English or Dutch
	Free full access via University of Twente	Payment required for full access

Besides the literature study with the Participation Toolkit as starting point, a literature study with more general search terms (henceforth 'primary part extended literature study') was performed to make sure methods other than the methods provided in the Participation Toolkit were included in this research as well. The same four databases were consulted, the same inclusion and exclusion criteria for scientific literature were applied, and the same selection options within the databases were applied.

- "Patient participation" OR "Patient engagement" OR "Patient involvement" AND "method*" AND "innovation*" AND "implementation*"
- "Patient participation" OR "Patient engagement" OR "Patient involvement" AND "innovation*" AND "implementation*"
- "Patient participation" OR "Patient engagement" OR "Patient involvement" AND "innovation*"

To make sure all evidence of the methods derived from this primary part of the extended literature study was covered, and the appropriateness of the methods within the context of this research could fully be ensured, the methods were searched for in a secondary part of the extended literature study. The following combination of terms was searched for: "*name of the method**" AND "innovation*" AND "implementation*". The same four databases were consulted, the same inclusion and exclusion criteria for scientific literature were applied, and the same selection options within the databases were applied.

3.1.2. Grey literature

To make sure grey literature is covered as well, websites of 'Nivel' and 'Participatiekompas' were searched on patient participation methods (Participatiekompas, n.d.; Nivel, n.d.). Participatiekompas is part of ZonMW and aims to provide an overview of available knowledge and experience about patient participation in research, policy, and quality of healthcare in the Netherlands. Methods and tools that can be used to facilitate patient participation are presented on their website and are categorised by the goal that is to be achieved by patient participation. In this research, the category 'Implementation' was consulted. Nivel is a research organisation for healthcare in the Netherlands. All studies performed by or in collaboration with Nivel are presented on their website. The term "participatie", which is Dutch for "participation", is searched for on their website. All hits were manually searched on 'implementation of healthcare innovations'. The inclusion and exclusion criteria for grey literature are presented in Table 2 (p. 14).

3.1.3 Validity and confidence

For practical reasons regarding the limited timeframe of this research, only the Dutch organisations 'Nivel' and 'Participatiekompas' were consulted (Participatiekompas, n.d.; Nivel, n.d.). Because these organisations contribute to only a small proportion of grey literature, it can be stated that grey literature is not fully covered in this research. However, the grey literature was used only as a complementing element in literature study, whereby it is assumed that the consequences of not covering all grey literature are limited.

Table 2

Inclusion and exclusion criteria for grey literature

Study characteristics	Inclusion criteria	Exclusion criteria
Population	Patients or patient representatives in general or specific patient groups or representatives of specific patient groups	People other than patients or patient representatives
Intervention	Patient participation method	
Outcomes	Increased patient participation	No increased patient participation or decreased patient participation
	Increased patient participation	Not appropriate to use in the implementation phase of healthcare innovations
Setting	Clinical setting	Non-clinical setting
Study design	Systematic literature review, literature study, interview, experts' opinion, case study, survey, observation	Study designs other than literature review, literature study, interview, experts' opinion, case study, survey, observation
Report criteria	Article in English or Dutch	Article in a language other than English or Dutch
	Free full access via University of Twente	Payment required for full access

3.2 Delphi study

The second and third sub-question, "What methods to involve patients in the implementation phase of healthcare innovations do experts in practice use?" and "What methods to involve patients in the implementation phase of healthcare innovations do experts in practice find useful?" were answered by performing a Delphi study.

3.2.1 The Delphi technique

An online Delphi study was conducted via SurveyMonkey®. By using the Delphi technique, the methods derived from the literature study were complemented with experts' opinions and a consensus process on the definitions and preconditions of these methods was performed. In this research, the Delphi technique has several advantages over other techniques that facilitate this kind of consensus-process. In comparison with the consensus-development conference, the Delphi technique is less time-consuming from a researchers' perspective (McGlynn, Kosecoff, & Brook, 1990). Given the limited timeframe of this study, the Delphi technique was therefore considered as superior. In comparison with the Nominal Group Technique (NGT), the Delphi technique was less time-consuming from a participant's perspective since participants were not needed to personally attend any meeting, while this is required when participating to the NGT (McMillan, King, & Tully, 2016). Besides this, the Delphi technique was assumed beneficial because a relatively great number of experts from different organisations and different levels within these organisations could be included fully anonymously. Hereby, the domination of the consensus process by one or few dominant experts was avoided (Jairath & Weinstein, 1994).

In this research, it was determined that a minimum number of fifteen and a maximum number of fifty respondents was required for the Delphi study. This relative broad range was set because different parties with different frames of reference and possibly different experiences and opinions were involved in the Delphi (Witkin & Altschuld, 1995; Ludwig, 1997).

3.2.2 Selection of respondents

Experts (henceforth 'respondents') from field labs within the Dutch healthcare sector, healthcare professionals of Samenwerkende Topklinische OpleidingsZiekenhuizen (henceforth STZ) hospitals, and professionals of other Dutch organisations or companies that specifically focus on innovating healthcare were invited to participate in the Delphi study (Table 3, p. 16). STZ hospitals are an association of hospitals that aim to improve healthcare in a patient oriented way (STZ, n.d.). Field labs can be described as a collaboration between different stakeholders from the healthcare sector, the educational sector, the scientific sector, and the business sector. Field labs are specifically established to develop, test, evaluate, and implement healthcare innovations quickly and successfully and transcend the borders of first and second line care (Health Valley Netherlands, n.d.). Other companies or organisations that specifically focus on innovation in healthcare can be categorized by hospitals (Haga Ziekenhuis, Maxima Medisch Centrum, Radboud UMC, Rijnstaete, and VU Medisch Centrum), a patient organisation (Patiëntenfederatie), a long-term care facility (Siza), a rehabilitation clinic (Sophia Revalidatie), and research institutes (Vilans and Rathenau Instituut).

Recruitment strategy

Respondents were recruited by contacting the selected healthcare organisations by telephone or e-mail. When respondents agreed to take place in the Delphi study, they were officially invited by e-mail. The respondent information letter (Appendix 1) and the informed consent (Appendix 2) were sent as attachments. With the respondent information letter, respondents were informed about the goal of the study and what was expected of them, which was filling in an online questionnaire three times, with an estimated average completion time of fifteen minutes per questionnaire, over the duration of eight weeks. In the respondent information letter, it is also stated that respondents are provided with the findings of this research and a customized advice on patient participation in the implementation phase of healthcare innovations from Ikone when fully applying to all three rounds of the Delphi study. This incentive was part of the recruitment strategy.

Table 3

Parties invited to participate in the Delphi study

Field labs

1. Field lab Disabled Care
2. Field lab Elderly Care
3. Field lab First Line Care
4. Field lab Revalidation Care
5. Field lab Second Line Care

Topklinische OpleidingsZiekenhuizen (STZ)

6. Amphia
7. Antonius Ziekenhuis
8. Bernhoven
9. Catharina Ziekenhuis
10. Canisius Wilhelmina Ziekenhuis
11. Deventer Ziekenhuis
12. Elisabeth-TweeSteden Ziekenhuis
13. Franciscus Gasthuis, Vlietland
14. Gelre Ziekenhuizen
15. Haaglanden Medisch Centrum
16. Isala Klinieken
17. Jeroen Bosch
18. Maasstad Ziekenhuis
19. Martini Ziekenhuis
20. Meander Medisch Centrum
21. Medisch Centrum Leeuwarden
22. Medisch Spectrum Twente
23. Noordwest Ziekenhuisgroep
24. Onze Lieve Vrouwen Gasthuis
25. Spaarne Gasthuis
26. Viecuri Medisch Centrum
27. Zuyderland Medisch Centrum

Additional organisations

28. Haga Ziekenhuis
29. Rathenau Instituut
30. Maxima Medisch Centrum
31. Radboud UMC
32. Rijnstaete
33. Siza
34. Sophia Revalidatie
35. Vilans
36. VU Medisch Centrum
37. Patiëntenfederatie

3.2.3 Ethical approval

Since humans are directly involved in the Delphi study, the study design had to be approved by the Ethics Committee (University of Twente, 2018). The ethics committee that was asked for approval is affiliated with the faculty of Behavioural, Management and Social Sciences (BMS) of the University of Twente. The request form can be found in Appendix 3. The application number related to the approval was 18420.

3.2.4 Delphi study – general

After every round of the Delphi study, respondents were reminded via e-mail to respond to the questionnaire if they had not done this within one week of receiving the initial invitation to the questionnaire. For practical reasons regarding the limited timeframe of this research, two weeks after inviting respondents to the first round of the Delphi study, data collection was closed regardless of the response rate. Results were analysed and the second round of the Delphi study was designed on the basis of these results. The same mechanism was applied for the second round. More response time was available for the third round of the Delphi, since this was the last round of the Delphi study and results derived from this were not needed for designing another questionnaire.

3.2.5 Delphi study – first round

Purpose

The purpose of the first round of the Delphi study was dual. The first purpose was to gain insights into the familiarity of respondents with patient participation methods derived from the literature study and the second was to gain insights into whether or not respondents knew of any additional patient participation methods for the implementation phase of healthcare innovations that were not yet provided in the first round of the Delphi study. Aside from this, also general information about the respondents was gathered so that population characteristics could be identified.

Procedure

Only if respondents indicated to be familiar with a patient participation method, they were referred to more in-depth questions about there familiarity with the method. By adjusting the questionnaire real-time to the respondents' answers, the questionnaire was kept as short as possible which contributed to an optimized response rate.

Results

The first round resulted in a list of patient participation methods suggested by respondents. All methods were peer-reviewed for their relevance within the context of this research by the author of this research. The same inclusion and exclusion criteria as applied in the literature study were used for this. The patient participation methods that were stated to be appropriate to be included in this research by the author of this research were added to the second round of the Delphi study.

3.2.6 Delphi study – second round

Purpose

The purpose of the second round of the Delphi study was to determine whether or not the respondents agreed with the definitions and preconditions of the patient participation methods derived from the literature study and the first round of the Delphi study.

Procedure

If respondents indicated to disagree with the definitions and/or preconditions, they were referred to a comment field to write down their version of the definition and/or preconditions.

Results

The second round resulted in qualitative data, which were analysed manually. The assumptions/adjustments of respondents were combined with the initially presented definitions and preconditions of patient participation methods. This led to co-constructed definitions and preconditions of patient participation methods that were presented to respondents in the third round of the Delphi study.

3.2.7 Delphi study – third round

Purpose

The purpose of the third round of the Delphi study was to gain insights into the experienced or estimated usefulness of all patient participation methods derived from the literature study and the first round of the Delphi study.

Procedure

The methods were presented to respondents together with the definitions and preconditions that were co-constructed in the second round of the Delphi study. A five-point Likert scale, running from 1 (totally not useful) to 5 (very useful) was used. Also, a comment field was added per multiple-choice question.

Results

The third round of the Delphi study involved the rating of patient participation methods on usefulness. The results of this round were tested on normality using Q-Q plots (Griffith, 2007). Data was also converted into histograms so that (deviation from) normality could be studied more in detail (McClave, Benson, & Sincich, 2007). If data could be considered as normally distributed (H0), the mean and standard deviation was calculated, so that a one-way ANOVA could be performed to compare all patient participation methods on the rated usefulness (Griffith, 2007). If data could be considered as not normally distributed (H1), the mean, median, and interquartile range were calculated (Rumsey, 2012). The Kruskal-Wallis test was used to compare all patient participation methods on rated usefulness. After this, the key variable ‘organisation’ was divided into two categories, respectively ‘hospital’ and ‘non-hospital’, so that the Mann-Whitney U test could be performed to compare groups on the rated usefulness of patient participation methods. The categories ‘hospital’ and ‘non-hospital’ refer to the nature of the organisation respondents are employed with. The key variable ‘employment’ was not divided into groups, since no logical grouping could be formed.

3.2.8 Validity and confidence

A measure that is taken to improve the validity of the Delphi study is the presentation of all patient participation methods in both English and Dutch. Because some of these methods might be known solely by their English or Dutch name the chance of recognition of the methods by respondents is optimised, whereby the validity of the results arising from this is optimised as well.

4. Results

The results section is divided into two parts. The first part contains results derived from the literature study and the second part contains results derived from the Delphi study.

4.1 Literature Study

4.1.1 Scientific literature

Participation Toolkit as a starting point

In total, twelve of the thirty-two patient participation methods provided by the Participation Toolkit of the Scottish Health Council were found in one or more of the four scientific databases and met the inclusion criteria set within this research. The following methods are therefore included in the research: brainstorm sessions, citizens' juries, (digital) storytelling, dragons' den, emotional touchpoint method, focus groups, mystery shopping, nominal group technique, patient diaries, process mapping, shadowing, and surveys and questionnaires. Table 4 (p. 20) provides a detailed overview of all patient participation methods derived from scientific literature.

Primary part of the extended literature study

As can be seen in Figure 1, a total of six studies was derived from the primary part of the extended literature study, namely: user profiles/personas, online expert panel, open community forum, provider-consumer dialogue, Discrete Choice Experiments (DCE), and shared decision-making. An overview of the search strategy of the primary part of the extended literature study for included and excluded studies can be found in Table 5 (Appendix 8.4).

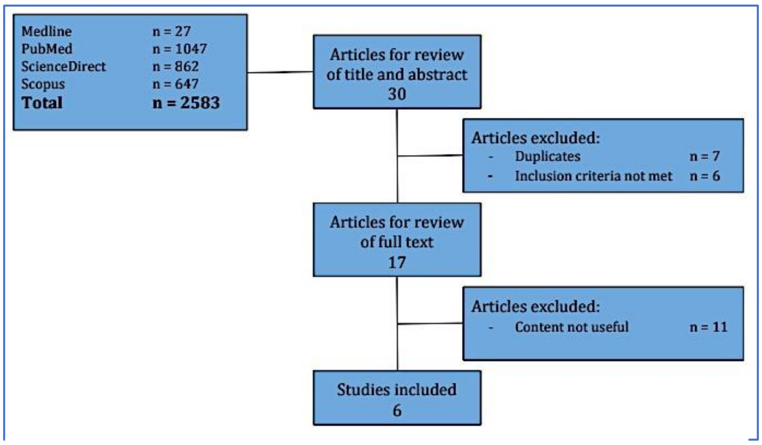
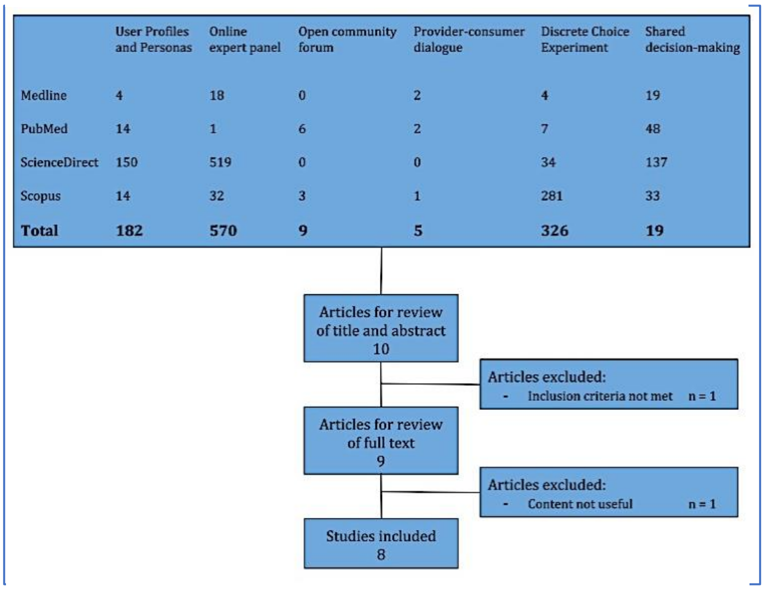


Figure 1 Flow diagram of study selection of primary part extended literature study



	User Profiles and Personas	Online expert panel	Open community forum	Provider-consumer dialogue	Discrete Choice Experiment	Shared decision-making
Medline	4	18	0	2	4	19
PubMed	14	1	6	2	7	48
ScienceDirect	150	519	0	0	34	137
Scopus	14	32	3	1	281	33
Total	**182**	**570**	**9**	**5**	**326**	**19**

Figure 2 Flow diagram of study selection secondary part extended literature study

Secondary part of the extended literature study

When searching the methods found in the primary part of the extended literature study with the search terms "*name of the method**" AND "innovation*" AND "implementation*", a total of eight studies was eventually stated useful, according to the inclusion and exclusion criteria set for scientific literature within this research (Figure 2, p. 19). Among these studies, appropriate evidence for two of the six patient participation methods was found, namely 'personas' and 'Discrete Choice Experiments' (DCE) (Table 4). 'Shared decision-making' was excluded from this research because the extended part of the literature study provided evidence about this method being an umbrella term and not one specific method to involve patients in the implementation phase of healthcare innovations could be derived from this. The methods 'online expert panel', 'open community forum', and 'provider-consumer dialogue' were also excluded from the research. Both 'online expert panel' and 'open community forum' were excluded because of lack of evidence about the appropriateness of these methods in the healthcare setting, which is an inclusion criterion in this research. 'Provider-consumer dialogue' was also excluded from this research on these terms. However, the literature study about 'provider-consumer dialogue' brought up the term 'co-creation dialogue'. To determine whether this search term was more adequate than 'provider-consumer dialogue', the literature study was extended by searching for this method in the databases used in this literature study. Yet, there was no sufficient evidence and 'co-creation dialogue' was also excluded from the research. An overview of the search strategy of the secondary part of the extended literature study for included and excluded studies can be found in Table 6 (Appendix 8.4).

Table 4
Patient participation methods derived from scientific literature

Method	**Author**	**Study design**	**Peer-reviewed**	**Definition**	**Preconditions**
Brain-storm sessions	CBO (2013)	Mixed method, guidebook	Yes	A group session whereby new ideas or solutions for innovation or improvement in care are generated	All possible relevant stakeholders are represented.
Citizen Juries	Elwood, et al. (2010), Street, et al. (2014)	Case study (n=1), literature review (n=37)	Yes	A tool that permits citizens to engage with evidence, deliberate and deliver recommendations on a range of complex and demanding topics. Outcomes of using the tool can inform policy and practice.	Representative group of ±14 participants. Participants have an equal right to be heard.
(Digital) story-telling	Lal, et al. (2015), Pederson, (2016)	Literature review complemented with experts' opinions, case study (n=2)	Yes	A two-three minute multi-media video clip that includes narrative, visual (digital video, photographs, artwork), and performance (music, voice) mediums for the purpose of expressing an individual or community story.	Use the following words to structure the story: what, whereby, why, and what now. Availability and knowledge of technical equipment.
Discrete Choice Experiments (DCE)	Mangham, et al. (2009)	Literature review, complemented with case	Yes	A quantitative technique for eliciting individual preferences. It can be uncovered how individuals value selected attributes of a programme, product or service by	Ensure that the attributes and corresponding levels are appropriate and valid.

		studies (n=2)		asking them to state their choice over different hypothetical alternatives.	
Dragons' den	Bowen, et al. (2013)	Interviews (n=9) & case study (n=1)	Yes	(Innovative) ideas are presented to dragons (persons with relevant expertise), who thereafter decide which idea is most preferable in their opinion.	Carefully determine which issues are eligible for this method. Inform participants before the method takes place to enhance substantive discussions.
Emotional touch-point method	Kuis, et al. (2017)	Interviews (n=31)	Yes	Touchpoints are identified to improve quality of care products or services. Touchpoints represent the key moments or events that stand out for those involved as crucial to their experience of receiving care.	-
Focus groups	Raats (2017)	Mixed method, guidebook	Yes	A homogenous group of 7-10 participants discusses their ideas, motives, interests, and way of thinking about a specific topic.	Homogenous group of 6-12 participants.
Mystery shopping	Moriarty, et al. (2013)	Case study (n=85)	Yes	Mystery patients use innovative products or services to evaluate the limitations of these products or services and to address areas of improvement.	Conduct method unexpectedly and incognito.
Nominal group technique	McMillan, et al. (2014), McMillan, et al. (2016)	Literature study (n=8), case study (n=21)	Yes	A structured process which facilitates the generation, discussion, and ranking of participant ideas.	Maximum of seven participants. Structure the process (silent generation, round robin, clarification, and voting).
Patient diaries	Elg, et al. (2011)	Case study (n=3)	Yes	Diary that is kept by patients (digital or analogue) at the request of the researcher and is usually structured into time, events, persona or units of interest so that it represents the everyday life of the patient and ideas can be generated on the bases of that.	Availability and knowledge of technical equipment in case diary is kept digital.
Personas	Fore, et al. (2013), Holden, et al. (2017)	Interviews & observations (n=36), surveys (n=30)	Yes	Empirically derived user-archetypes that are used to gain a robust understanding of target end users such as patients.	Create a persona on the basis of observations or interviews, so that the persona is most likely to represent the actual (patient) group.
Process mapping	Trebble, et al. (2010)	Literature study	Yes	A form of a clinical audit that examines how the patient journey can be managed, using the patient's	Provide a facilitator (not substantive involved in the

				perspective to identify problems and suggest improvements.	method) who visualises the map so that participants can focus on the content of the meeting.
Shadowing	DiGioia, et al. (2011)	Mixed methods, guidebook	Yes	A committed and empathic observer follows a patient or healthcare professional throughout a selected (care) process to view and capture the details of the entire experience from the point of view of the shadowed person.	-
Surveys & questionnaires	Davies, et al. (2008), Davies, et al. (2011)	Case study (n=1), case study (n=2)	Yes	Method whereby input on specific domains from relevant stakeholders is gathered by asking questions.	Carefully determine and operationalize variables.

For practical reasons, only the most important preconditions of patient participation methods are shown in Table 4. Further, as can be seen in Table 4, no preconditions could be found for two of the patient participation methods. An explanation that applies to the shadowing method is that execution of this method can vary with the purpose of the method. No valid explanation could be found for the emotional touchpoint method. Because certain preconditions were applicable to almost all patient participation methods, these preconditions are assumed valid for patient participation methods in general. The general preconditions are as follows:

1. The patient participation method is facilitated by persons who are qualified for this or who are reasonably considered capable of doing this.
2. Information provision and language are adjusted to participants of the patient participation method.
3. The method is practised in an environment that is considered safe enough for patients to share their opinion and experience.

4.1.2 Grey literature

A total of six methods was derived from grey literature, namely: Advisory groups/client councils, comments cards, mirror meetings, patient journey, round-table workshops, and users' panels. Table 7 (p.23) provides a more detailed overview of these methods. It is assumed as remarkable that no methods not already provided by the Scottish Health Council or Participatiekompas were provided by Nivel.

Table 7
Patient participation methods derived from grey literature

Method	**Author**	**Document type**	**Definition**	**Preconditions**
Advisory groups / Client councils	ParticipatieKompas (n.d.)	Article, based on interviews (n=3)	A board that can be consulted for a broad variety of topics for input, feedback, or experience-based expertise.	Clearly state purpose, operating procedure, and degree of influence of the board.
Comments cards	Scottish Health Council (2014)	Toolkit	Making cards and post boxes available for service users to communicate with the organisation to obtain feedback.	Make sure continuity of method is guaranteed.
Mirror meetings	Vennik, et al. (2013)	Guidebook	A group meeting of patients facilitated by an independent moderator, with the goal obtain feedback on and information about a certain care product or service.	Direct confrontation of patients' experiences and healthcare professionals should be carefully managed.
Patient Journey	Participatiekompas (n.d.)	Practical framework	A graphical representation of events (both medical and personal) a patient experienced.	Determine the scope of the journey before beginning the method.
Round-table workshops	Scottish Health Council (2014)	Toolkit	Participants (groups with interest in particular service/product) are enabled to make a full contribution to discussions on issues of shared concern and to generate ideas for action.	Pay specific attention to the consensus-part, since a relatively wide range of opinions is addressed.
Users panels	Scottish Health Council (2014)	Toolkit	User-feedback about their experience and expectations is used to review products and services.	Panel members are representative for (future) end-users.

4.2 Delphi Study

Due to the size of the three questionnaires, an overview of all questions is not submitted to this research report. However, access to the questionnaires can be requested from the author. Only data from experts that fully completed all three rounds of the Delphi study are included in the results section. Of the 54 invited respondents, 29 were willing to take part in the Delphi study. Of them, 100% fully completed the first round of the survey (n=29), 87% fully completed the second round (n=25), and 76% fully completed the third round of the survey (n=19). All respondents agreed with informed consent.

4.2.1 First round

Background characteristics of respondents

The majority of respondents are employed with an academic hospital (37%) and a top clinical hospital (26%) and the minority of respondents are employed with a field lab, a research institute, and a patient organisation (all 6%). The employment of the majority of respondents fall into the category of manager (37%) and the employment of minority of respondents fall into the category of project member (6%). Respondents rated the usefulness of patient participation on average with 89.2 on a scale from zero to hundred, where zero is 'totally not useful' and hundred is 'very useful'. A more extended overview of the rated general usefulness of patient participation can be found in Table 8 (Appendix 8.5). The majority of respondents had recent experience with patient participation (32%), followed by monthly experience (26%), daily (16%), other (16%), ever (6%), and never (6%). Respondents that indicated to have 'other' experience with patient participation state the following: "*Depending on the projects, this varies from daily to monthly*", *"Multiple times per month"*, and *"In the past, multiple times"*.

Familiarity with presented patient participation methods

Of all presented patient participation methods, respondents are most familiar with 'Surveys & questionnaires' (100%) and 'Brainstorm sessions' (95%) and are least familiar with 'Discrete Choice Experiment' (26%) and 'Emotional touchpoints' (21%) (Table 9).

Table 9

Respondents' familiarity with evidence-based patient participation methods

Patient participation method	**Familiar** (n=19) (% of total)
Emotional touchpoints	4 (22%)
Discrete Choice Experiment	5 (26%)
Citizen juries	8 (42%)
Nominal group technique	9 (47%)
Comment cards	10 (53%)
Personas	11 (58%)
(Digital) storytelling	12 (63%)
Patient diaries	12 (63%)
Dragons' den	13 (68%)
Mystery shopping	13 (68%)
Roundtable workshops	13 (68%)
Focus groups	14 (74%)
Shadowing	14 (74%)
Mirror interviews	15 (79%)
Users' panels	15 (79%)
Patient journey	16 (84%)
Advisory groups/Client councils	17 (89%)
Process mapping	17 (89%)
Brainstorm sessions	18 (95%)
Surveys & questionnaires	19 (100%)
Average familiarity	13 (68%)

The average rate of familiarity with methods is 67%. Respondents are actively involved in applying methods they have indicated to be familiar with in 53%. Respondents who are familiar with the nominal group technique, brainstorm sessions, and surveys and questionnaires are relatively most often involved in applying the method with respectively 75%, 83%, and 89%. Absolutely, respondents are most often involved in applying surveys and questionnaires (n=17), followed by brainstorm sessions (n=15), and advisory groups/client councils, process mapping, and users' panels (n=11).

In general, the roles of 'other' and 'process supervisor' are most common with respectively 33% and 31%. Respondents that selected 'Other', indicated to have fulfilled the following roles: orienting on possibilities to involve patients, listener, interviewer, idea generator, pitcher, host/hostess, and analyser.

Patient participation methods suggested by respondents

The following patient participation methods to use in the implementation phase of healthcare innovations are suggested by respondents: card sorting, cognitive walkthrough, co-design sessions, context mapping, contextual inquiry, cultural probes, design games, design probes, hackathons, inserting a feedback button, involving patients in workgroups, in-depth interviews, making use of the crowd, making use of user-data, patient as researcher, patient as member of management teams, paper prototyping, rapid prototyping, sharing patient stories on intranet, speak out loud-method, and usability testing. Of these methods, the following five methods met the previously set inclusion criteria for scientific and/or grey literature and were included in the second round of the Delphi study: context mapping, involving patients in workgroups, in-depth interviews, continuous feedback, and speak-out loud method. An extended overview of the grounds on which the other methods are excluded can be found in Table 10.

Table 10

Grounds for the exclusion of suggested patient participation methods

Method	**Reasoning for exclusion**
Card sorting	Not specifically appropriate for the healthcare setting since method is used in website design.
Cultural probes	Very similar to context mapping. The context mapping method is chosen to be superior according to the inclusion and exclusion criteria.
Rapid prototyping	Focused on designing a prototype, whereby the method is not considered appropriate to use in the implementation phase of healthcare innovations.
Usability testing	Focused on product design, whereby the method is considered not appropriate to use in the implementation phase of healthcare innovations.
Design probes / Design boxes	Focused on product design, whereby the method is considered not appropriate to use in the implementation phase of healthcare innovations.
Contextual inquiry	Very similar to shadowing. The shadowing method is chosen to be superior according to the inclusion and exclusion criteria.
Co-design sessions	Common ground with both the design and implementation of innovations. Because the method is not specifically stated appropriate for the healthcare setting and the implementation phase of healthcare innovations, it is chosen to exclude the method from the research.
Paper prototyping	Focused on product design, whereby the method is considered not appropriate to use in the implementation phase of healthcare innovations.
Design games	Focused on product design, whereby the method is considered not appropriate to use

	in the implementation phase of healthcare innovations.
Cognitive walkthrough	Method is useful in detecting errors in prototypes and is therefore not considered specifically for the healthcare setting and the implementation phase of healthcare innovations.
Patient as researcher	Focused on research, whereby the method is not considered appropriate to use in the implementation phase of healthcare innovations.
Hacktetons	Focused on design, whereby the method is considered not appropriate to use in the implementation phase of healthcare innovations.
Share patient stories on social media and intranet	Very similar to the patient journey method and storytelling. Patient journey and storytelling are chosen to be superior, according to the inclusion and exclusion criteria.

4.2.2 Second round

Agreement with definitions and preconditions of patient participation methods

Of all presented definitions of methods to involve patients in the implementation phase of healthcare innovations ‘Patient diaries’, ‘Patient journey’, and ‘Surveys and questionnaires’ scored highest on the category ‘agree’ with 95% of all votes, ‘Nominal group technique’ scored highest on ‘do not know’ with 37%, and ‘Advisory groups / Client councils’ scored highest on ‘disagree’ with 42%. Of all presented preconditions for successful use of the methods to include patients ‘Advisory groups / Client councils’ and ‘Patient journey’ scored highest on the category ‘agree’ with 95% of all votes, ‘(Digital) storytelling’ scored highest on ‘disagree’ with 63%, and ‘Nominal group technique’ scored highest on ‘do not know’ with 37%.

The consensus process

With regard to the presented definitions, it was observed that a considerable proportion of the suggestions made by respondents originate from a lack of knowledge about the (purpose of the) patient participation methods or key-aspects to define the methods. Respondents stated the following: *“What is not-expert knowledge?”*, *“What is representative?”*, and *“What is ‘cognitively influenced’?”*. Only when one or more suggestions about the same aspects were made or when a suggestion made was assumed as useful within the scope of this research, the particular definition was adjusted. With regard to the presented preconditions, it is notable that some suggestions made were contrary with preconditions provided by the literature. Only when two or more respondents suggested the same preconditions that are contradictory to the literature, the suggested preconditions were incorporated. In all other cases, the literature was assumed superior to the contradictory suggestions.

In general, it can be stated that suggestions made by respondents resulted in more in-depth definitions and preconditions, as can be seen in Table 11 (Appendix 8.6). The precondition ‘*Give feedback to participants about the results of using the method’* or a variant on this is mentioned the most. Furthermore, respondents also made suggestions about dealing with privacy-sensitive data relatively often when they were asked about preconditions of the 25 patient participation methods. The suggestions made are as follows: *“Include dealing with privacy-sensitive information in informed consent”, “pay attention to ethical aspects, such as (…) who has access to data and where it will be* *stored", "make sure patient data is used and stored safely"*, and *"ensuring the safety of data that is obtained"*. Furthermore, dealing with privacy-sensitive data is not only a topic of high interest of respondents, but also of the Dutch government. The interest of the Dutch government on the topic of dealing with privacy-sensitive data is exemplified by the AVG legislation, which went into effect in the Netherlands during this research. The purpose of the AVG legislation is improving personal data protection through stricter rules (Rijksoverheid, 2018). Since this privacy legislation became effective only recently and respondents suggested the topic multiple times, it is chosen to explicitly highlight the following requirement for all patient participation methods in this research: Data derived from the use of patient participation methods is treated conform AVG legislation. Compliance with the AVG-legislation covers compliance with all suggestions made by respondents of the Delphi study about dealing with privacy-sensitive information. An extensive overview of the consensus process for the definitions and preconditions of the patient participation methods can be requested from the author of this research.

4.2.3 Third round

According to the Q-Q plots and the histograms, data could not be considered normally distributed and H0 was rejected. The mean, median, and interquartile range of the rating of all patient participation methods can be found in Table 12. As can be seen in this table, respondents in general rated 'Patients participate in workgroups' as most useful (4.47), followed by 'Advisory groups / Client councils', 'Brainstorm sessions', 'Focus groups', and 'User panels' (all 4.11). Respondents rated 'Comments cards' (2.84) and 'Citizen juries' (3.00) as least useful. The Kruskal-Wallis test resulted in no statistically significant differences between the medians of all patient participation methods with 95% confidence since a significance level of 0.05 is exceeded (Table 13, p. 28). This means that there is no significant difference in the rating of patient participation methods with regards to the employment of respondents. The Mann-Whitney U test resulted in no statistically significant differences between groups 'hospital' and 'non-hospital' with 95% confidence since the significance level of 0.05 is exceeded (Table 14, p. 29). This means that there is no significant difference in the rating of the patient participation methods with regards to hospitals and non-hospital organisations. This lack of significance might be due to the relatively small study population or no existing difference between the groups that were compared. Despite none of the results reached statistical significance, there are some findings worth discussing.

Table 12
Mean, median and interquartile range of rating of patient participation methods

	N		**M**	**Mdn**	**Percentiles**		
	Valid	Missing			25	50	75
Advisory groups/client councils	19	0	4.11	4	4	4	5
Brainstorm sessions	19	0	4.11	4	4	4	5
Context mapping	19	0	3.99	4	3	4	5
Continuous feedback	19	0	4.05	4	4	4	5

In-depth interviews	19	0	4.00	4	3	4	5
(Digital) Storytelling	19	0	3.63	4	3	4	4
Dragons’ den	19	0	3.53	4	3	4	4
Emotional touchpoints	19	0	3.47	4	3	4	4
Surveys & questionnaires	19	0	3.95	4	4	4	4
Focus groups	19	0	4.11	4	4	4	5
Users’ panels	19	0	4.11	4	4	4	5
Mystery shopping	19	0	3.44	3	3	3	4
Nominal group technique	19	0	3.42	3	3	3	4
Patient diaries	19	0	3.63	4	3	4	4
Patients participate in workgroups	19	0	4.47	5	4	5	5
Patient journey	19	0	4.05	4	3	4	5
Personas	19	0	3.37	3	3	3	4
Process mapping	19	0	4.05	4	4	4	4
Comments cards	19	0	2.84	3	2	3	4
Shadowing	19	0	3.95	4	3	4	5
Speak out aloud	19	0	3.42	4	2	4	4
Mirror meetings	19	0	3.63	4	3	4	4
Discrete Choice Experiments	19	0	3.11	3	3	3	4
Roundtable workshops	19	0	3.32	3	3	3	4
Citizens juries	19	0	3.00	3	2	3	4

Table 13
Kruskal-Wallis test

	Kruskal-Wallis H	**df**	**Asymp. Sig.**
Advisory groups/client councils	7.99	6	0.238
Brainstorm sessions	2.63	6	0.854
Context mapping	7.64	6	0.266
Continuous feedback	3.14	6	0.792
In-depth interviews	8.79	6	0.186
(Digital) storytelling	5.82	6	0.444
Dragons’ den	5.36	6	0.499
Emotional touchpoints	3.10	6	0.796
Surveys & questionnaires	5.73	6	0.455
Focus groups	5.66	6	0.463
Users’ panels	7.96	6	0.241
Mystery shopping	5.44	6	0.489
Nominal group technique	9.97	6	0.126
Patient diaries	5.95	6	0.429
Patients participate in workgroups	5.89	6	0.436
Patient journey	8.83	6	0.183
Personas	5.26	6	0.511
Process mapping	5.51	6	0.481
Comments cards	3.46	6	0.749
Shadowing	6.31	6	0.389
Speak out loud	5.76	6	0.451

Mirror meetings	6.45	6	0.375
DCE	2.49	6	0.870
Roundtable workshops	2.83	6	0.831
Citizens’ juries	3.96	6	0.682

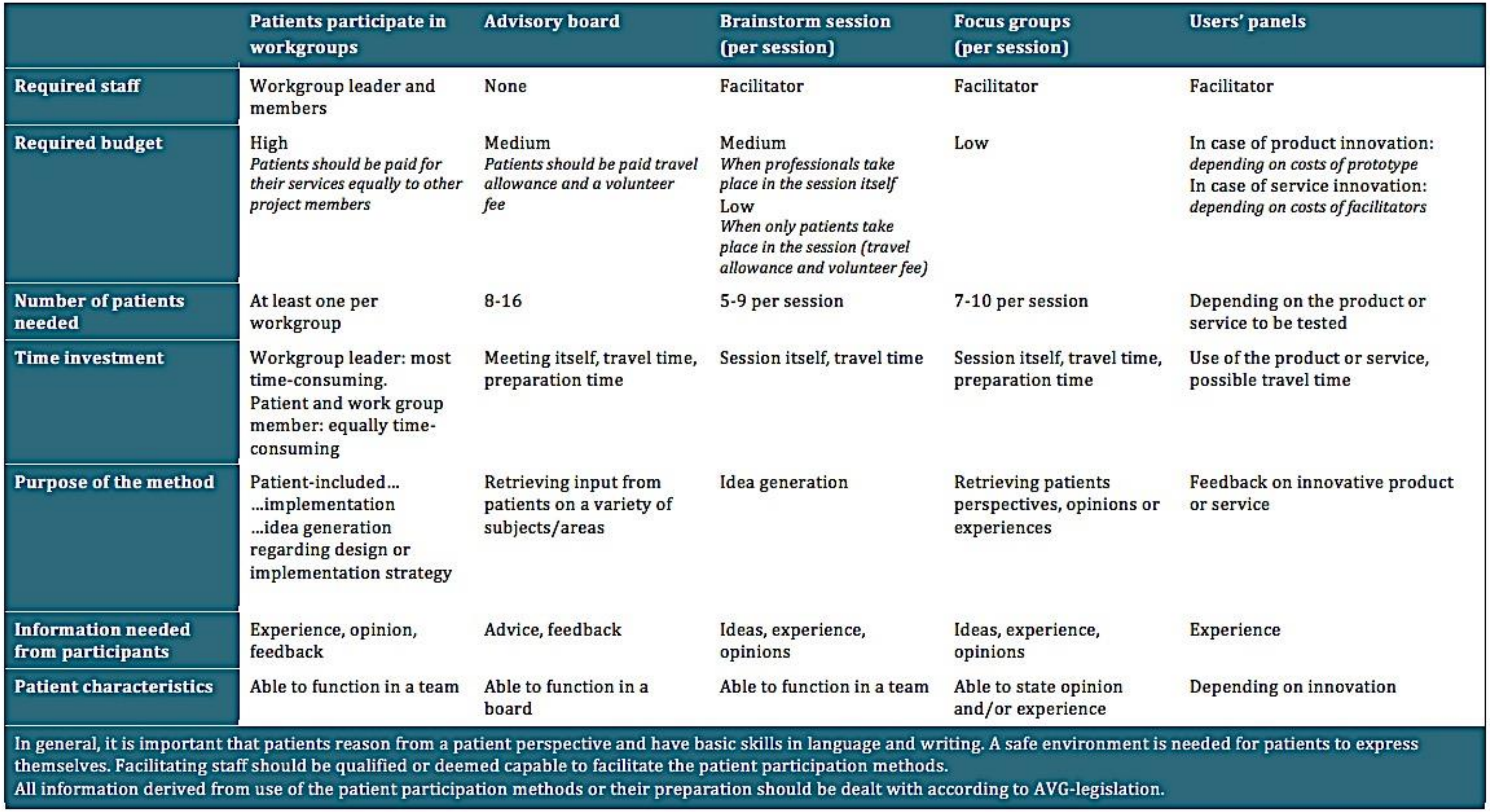
Table 14
Mann-Whitney U test

	Mann-Whitney U	Wilcoxon W	Z	Asymp. Sig. (2-tailed)	Exact Sig. [2*(1-tailed Sig.)]
Advisory groups/client councils	37	103	-0.625	0.532	.600
Brainstorm sessions	28.5	64.5	-1.41	0.158	.206
Context mapping	37	73	-0.615	0.539	.600
Continuous feedback	42.5	108.5	-0.139	0.889	.904
In-depth interviews	29	95	-1.307	0.191	.238
(Digital) storytelling	41.5	107.5	-0.226	0.821	.840
Dragons’ den	36	72	-0.707	0.48	.545
Emotional touchpoints	39.5	75.5	-0.404	0.686	.717
Surveys & questionnaires	28.5	94.5	-1.436	0.151	.206
Focus groups	37	103	-0.676	0.499	.600
Users’ panels	34.5	100.5	-0.838	0.402	.442
Mystery shopping	38	104	-0.519	0.604	.657
Nominal group technique	42.5	108.5	-0.138	0.89	.904
Patient diaries	30.5	96.5	-1.219	0.223	.272
Patients participate in workgroups	39.5	105.5	-0.42	0.674	.717
Patient journey	36.5	72.5	-0.655	0.512	.545
Personas	43.5	109.5	-0.043	0.965	.968
Process mapping	24	90	-1.924	0.054	.109
Comments cards	40	106	-0.354	0.723	.778
Shadowing	32.5	98.5	-1.006	0.314	.351
Speak out loud	38	74	-0.515	0.607	.657
Mirror meetings	33	99	-0.993	0.321	.395
DCE	37	73	-0.652	0.514	.600
Roundtable workshops	42.5	108.5	-0.137	0.891	.904
Citizens’ juries	18	54	-2.276	0.023	.33

Of the top-five patient participation methods rated as most useful in general (i.e. ‘Patients participate in workgroups’, ‘Advisory groups / Client councils’, ‘Brainstorm sessions’, ‘Focus groups’, and ‘User panels’), two were provided by grey literature, two were provided by scientific literature, and the remaining one was provided by respondents in the first round of the Delphi study. The average familiarity with methods within this top-five is 70%, which is 1.3 times higher than the average familiarity with all methods (53%). When looking at the top-ten of patient participation methods rated as most useful, it appears that three out of five methods suggested by respondents made it to this top-ten, whereof the method rated as most useful (i.e. ‘Patients participate in work groups’) was one. Since the familiarity with the methods suggested by respondents could not be measured for all of the respondents, these results should be interpreted carefully. With regards to the organisation respondents are employed with, the highest average rating of all patient participation methods in general is assigned by the patient organisation (4.08), followed by the field lab (4.00). The lowest average rating of all patient participation methods is assigned by general hospitals (3.32), followed by top clinical hospitals and the research institute (both 3.6), as can be seen in Table 15 (Appendix 8.7). The respondent who rated patient participation methods highest on average (patient federation, 4.08) also rated the usefulness of patient participation in general highest of all respondents (100%). On the contrary, the respondent who rated patient participation methods second highest on average (field lab, 4.00) rated the usefulness of patient participation in general lowest of all respondents (75%). The respondents who rated patient participation methods in general lowest on average (general hospitals, 3.32) rated the usefulness of patient participation in general second lowest on average (75.5%). The respondents who rated patient participation methods in general second lowest on average (top clinical hospitals and research institute, 3.32) rated the usefulness of patient participation in general third (88.6%) and fourth lowest (90%) on average, respectively. This means that in most cases the segment of rating (high or low) of patient participation methods and the usefulness of patient participation in general is similar with regards to the organisation of employment of respondents. This relation was found to a much lesser extent with regards to the employment of respondents as can be seen in Table 16 (Appendix 8.7).

Visualisation of results

In order to support (healthcare) professionals in choosing the most appropriate patient participation method for the implementation phase of healthcare innovations, an overview is made of the general top-five of patient participation methods rated on usefulness. Information that is needed for professionals to put these methods into practice is adjusted to this overview. Since none of the data of the third round of the Delphi study turned out to be significant, a visualisation of results is limited to the general top-five of patient participation methods ranked on rated usefulness. The following methods are presented in the overview: patients participate in workgroups, advisory groups/client councils, brainstorm sessions, focus groups, and user panels (Figure 9).



	Patients participate in workgroups	**Advisory board**	**Brainstorm session (per session)**	**Focus groups (per session)**	**Users' panels**
Required staff	Workgroup leader and members	None	Facilitator	Facilitator	Facilitator
Required budget	High *Patients should be paid for their services equally to other project members*	Medium *Patients should be paid travel allowance and a volunteer fee*	Medium *When professionals take place in the session itself* Low *When only patients take place in the session (travel allowance and volunteer fee)*	Low	In case of product innovation: *depending on costs of prototype* In case of service innovation: *depending on costs of facilitators*
Number of patients needed	At least one per workgroup	8-16	5-9 per session	7-10 per session	Depending on the product or service to be tested
Time investment	Workgroup leader: most time-consuming. Patient and work group member: equally time-consuming	Meeting itself, travel time, preparation time	Session itself, travel time	Session itself, travel time, preparation time	Use of the product or service, possible travel time
Purpose of the method	Patient-included… …implementation …idea generation regarding design or implementation strategy	Retrieving input from patients on a variety of subjects/areas	Idea generation	Retrieving patients perspectives, opinions or experiences	Feedback on innovative product or service
Information needed from participants	Experience, opinion, feedback	Advice, feedback	Ideas, experience, opinions	Ideas, experience, opinions	Experience
Patient characteristics	Able to function in a team	Able to function in a board	Able to function in a team	Able to state opinion and/or experience	Depending on innovation

In general, it is important that patients reason from a patient perspective and have basic skills in language and writing. A safe environment is needed for patients to express themselves. Facilitating staff should be qualified or deemed capable to facilitate the patient participation methods.
All information derived from use of the patient participation methods or their preparation should be dealt with according to AVG-legislation.

Figure 9 Overview top-five of most useful rated patient participation methods applicable in the implementation phase of healthcare innovations

5. Discussion

This research was performed in order to identify and to gain insights into patient participation methods to apply in the implementation phase of healthcare innovations. Both literature and Dutch experts in practice were consulted. Per sub-question, the results are discussed and connected to the theory discussed in this research, followed by the considerations arising from this. Also the validity and confidence of the results and the strengths and limitations of the research are discussed.

5.1 Patient participation methods derived from the literature

The first sub-question resulted in a list of twenty patient participation methods. All of these methods can be applied in the implementation phase of healthcare innovations, but none of these methods is specifically appropriate for this phase. Besides this, much overlap in the search for patient participation methods in grey literature was encountered.

As stated in the theory, several reasons for limited patient participation can be appointed (Groene, Lombarts, Klazinga, Alonso, Thompson, & Sunol, 2009; Renedo, 2015; Wensing, 2015; Boaz, et al., 2016), of which one is the assumed lack of knowledge about different patient participation methods and how to apply them. The fact that no evidence could be found about methods that are specifically applicable in the implementation phase of healthcare innovations underpins this lack of knowledge and strengthens the assumed reason for the limited use of patient participation.

With regards to the overlap in patient participation methods, it might be possible to assume the overlap as underpinning the evidence of the patient participation methods that were encountered. In line with this, the overlap could be interpreted as a confirmation of the findings. However, it might also be possible that the overlap indicates that the variety of search terms used was too limited, whereby the same patient participation methods are encountered. On top of this, it might also be possible that the overlap indicates that the patient participation methods found are all the patient participation methods available in the part of grey literature studied within this research. Yet, too limited information is available to determine the exact reason for the overlap as described.

When knowledge is gained about patient participation methods, which methods to apply in which innovation phase, and how to apply these methods in these innovation phases, the aforementioned reason for the limited use of patient participation might be resolved. This knowledge could be gained through scientific research. A study design where theory and practice come together, like action research, might be particularly appropriate for this given the need for practical applicable scientific evidence (Bovenkamp, Grit, & Bal, 2008; Grande, Faber, Durand, Thompson, & Elwyn, 2014).

5.2 Patient participation methods used by experts

With the second sub-question, insight was gained into patient participation methods used by respondents. With regards to the patient participation methods suggested by respondents of the Delphi study, it appeared that only five out of the thirteen methods suggested could actually be added to the list of patient participation methods. Reasons for not including suggested patient participation methods were mainly related to the design-oriented nature of the methods, which is not necessarily relevant in the phase of implementation of innovations.

Of all patient participation methods, respondents were involved in applying the method they indicated to be familiar with in 53% of the cases. Absolutely, respondents were most often involved in surveys and questionnaires (n=17), brainstorm sessions (n=15), advisory groups/client councils (n=11), process mapping (n=11), and users' panels (n=11). Several similarities can be distinguished between these methods regarding the patient's role, the (healthcare) organisation's role, and the characteristics of the patient participation method. With regards to the patient's role, it can be stated that this role is generally limited to the patient providing the (healthcare) organisation or company with personal information about their patienthood. Yet, 'Advisory groups/client councils' is an exception to this since in this case the patient's role also contains an advising component, whereby the patient's role is more pro-active in nature and whereby collaboration between the (healthcare) organisation or company and the patient can be stated as more equal compared to the other four patient participation methods. Another similarity with regards to the patient's role is the possibility of reviewing processes, products, and/or services. With regards to the (healthcare) organisation's role, it can be stated that this role requires a proactive attitude to extract information from the patient, whereby feedback of results of applying the patient participation method is given to participants of the method. Particularly the latter is considered important by respondents included in this research. With regards to characteristics of the patient participation methods, it can be stated that all methods can be performed both one single time and repeatedly (with or without a fixed frequency), although this is generally not the case with advisory groups/client councils.

With regards to the theory, the multi-interpretable nature of patient participation, which ranges from patients simply 'participating' or 'being present' in healthcare (Dedding & Slager, 2013) to the notion of both patients and professionals actively involved in a certain matter having equal voices and classical power relations change (Sahlsten, Larsson, Sjöström, & Plos, 2008), might be related to the findings about which patient participation methods are used in practice. It is reasoned that the way that (healthcare) organisations or companies interpreted patient participation might influence their choice of applying a method. In case of this research, the overrepresentation of patient participation methods that require the patient to be rather passive (four out of five) might imply that respondents within this research interpret patient participation relatively passive. This relatively particular frame of reference within the study population is also underpinned by the fact that most patient participation methods suggested by respondents were oriented on product or service design (Ogden & Lo, 2011).

To draw conclusions, further research can be performed in two areas. First, it should be determined whether or not there is a statistically significant difference in the use of patient participation methods between methods with a passive patient role and methods with an active patient role. If this difference in the use of patient participation methods can be detected, it should be determined whether or not the choice for a specific patient participation method relates to the way patient participation is interpreted. When this is known, it might be possible to draw conclusions according to the acceptance of certain patient roles with patient participation methods and the interpretation of patient participation by (healthcare) organisations or companies as a whole. Second, research should be performed in order to determine whether the limited knowledge about patient participation methods and how to apply them is related to the choice of participation methods with a certain patient role. When it is known if this is the case, targeted interventions to create a broader knowledge of patient participation methods in practice and broader evidence in literature can be applied. When the knowledge about patient participation methods is broadened, the use of these methods might also be broadened.

5.3 Useful patient participation methods according to experts

The third sub-question resulted in a list of patient participation methods rated on usefulness. The methods ‘Patients participate in workgroups’, ‘Advisory groups / Client councils’, ‘Brainstorm sessions’, ‘Focus groups’, and ‘Users’ panels’ were stated to be most useful according to respondents of the Delphi study. Several similarities can be distinguished between these methods regarding the patient’s role, the (healthcare) organisation’s role, and the characteristics of the patient participation method. With regards to the patient’s role, it can be stated that all methods require an active patient role, whereby personal information about patienthood is of value. With regards to the (healthcare) organisation’s role, it can be stated that this role requires a proactive attitude to extract information from the patient, whereby feedback of results of applying the patient participation method is given to participants of the patient participation method. With regards to characteristics of the patient participation methods, it can be stated that all methods are applied groupwise and can be performed both one single time and repeatedly (with or without a fixed frequency), although, again, this is generally not the case with advisory groups/client councils. Furthermore, four out of the top-five patient participation methods ranked on rated usefulness are part of the top-nine of methods ranked on respondent’s familiarity with the methods. It is assumed remarkable that the average familiarity with methods within the top-five most useful methods is 1.3 times higher than the overall average familiarity with patient participation methods. Also, it is observed that in most cases respondents who rated patient participation methods relatively high also rated the usefulness of patient participation in general relatively high (and vice versa). Therefore, it is suspected that the segment of rating (high or low) of patient participation methods and the usefulness of patient participation in general is related to each other according to the employment of respondents. On top of this, it can be stated remarkable that the stakeholders ‘advisors’ and ‘project leaders’, who presumably have prominent voices in the determination of strategies and (the course of) projects in general, do rate patient participation methods on average lowest and second lowest.

Despite only four out of five methods within the top-five useful patient participation methods could be measured on familiarity, it is strongly suspected that the increased familiarity (1.3 times higher) with these methods implicates the presence of the familiarity principle (Liao, Yeh, & Shimojo, 2011). This is underpinned by the fact that methods respondents are least familiar with are rated relatively low on usefulness. Also, the frame of reference of respondents could play a role in this (Ogden & Lo, 2011), since it is assumed possible that respondents rated methods they have practiced or know that others in their professional environment have practiced influenced their understanding of the methods and their judgement on usefulness of the methods. Whether or not the familiarity principle and/or frame of reference were present and biased results can not be determined on the basis of the collected data since the relation between familiarity with patient participation methods and their rated usefulness did not reach statistical significance. However, it can be stated that a gap between theory and practice exists given the proportion of respondents' unfamiliarity with evidence-based patient participation methods. This unfamiliarity can possibly be due to the fact that scientific knowledge does not reach practice, whereby health professionals are not getting familiar with (new) evidence-based patient participation methods. By this, the familiarity principle and frame of reference are maintained, assumed that they are present. It might also be the case that literature provides evidence about patient participation methods that are not of current interest of experts in practice, as appointed in Chapter 1. However, due to the relatively small sample size of this research, these findings can only be assumed as expectations. Aside from this, given the influential position of advisors and project leaders, it is considered possible that these stakeholders play key roles in the embedding, or the absence of the embedding, of patient participation in the implementation of healthcare innovations. With regards to this, it might be fruitful to put a focus on these kinds of key stakeholders when intervening on the embedding of patient participation in healthcare.

To determine whether or not the familiarity principle and/or the frame of reference influences to experienced or estimated usefulness of patient participation methods, further research is needed. Qualitative research, like in-depth interviews, might be appropriate for this since individual information can be collected at a comprehensive level. If it is detected that the familiarity principle and/or the frame of reference play a role in the experienced or estimated usefulness of methods, targeted interventions to decrease this familiarity-incentive can be applied. This can be done by broadening the familiarity of methods among professionals or by making professionals aware of the possible bias as a result of their familiarity with particular patient participation methods. When the familiarity-incentive is decreased or taken away, professionals might select patient participation methods on different (method-specific) characteristics, whereof more effective use of patient participation methods might be a consequence.

5.4 Validity and confidence

With regards to the literature study, it can be stated that the extension of the literature study improved the confidence of the literature study in general since the extended literature study provided new insights into patient participation methods, whereby four methods were yet excluded from the research because the appropriateness of these methods was not stated to be sufficient enough. With regards to the Delphi study, it can be stated that the validity and the transferability of results in general might be biased due to the fact that there might be the case of both the familiarity principle and the frame of reference principle. Aside from this, the study population of this research can be stated as relatively small and quite specific. First, because all respondents are involved in innovations in healthcare and second because ‘hospitals’ represent the biggest proportion of the group ‘organisation respondents are employed with’ and ‘managers’ represent the biggest proportion of the group of ‘employment of respondents’. Since there might be the case of the familiarity principle and/or the frame of reference principle, the transferability of results to the Dutch healthcare sector as a whole might be limited as a result of this.

5.3 Strengths and limitations

Several strengths and limitations are associated with this research. The major limitation is related to the Delphi study performed in this research. Because respondents had little incentive to participate in this study and the required time-investment of respondents was relatively high, the study had to be kept as short as possible. As an example, almost 15% of respondents dropped out before the actual beginning of the Delphi study and 14% of respondents dropped out after the first round. Especially the consensus process on definitions and preconditions of patient participation methods was affected by this and could not be performed optimally. Given the limited timeframe of this study, it was not possible to include mixed-methods, whereby some results remained shallow. As suggested, further research should focus on verifying and deepening the results found in this study to draw valid conclusions. Besides this, it should be taken into account that the validity and/or confidence of results might be negatively influenced by several circumstances. First, the biggest proportion of parties invited to participate in the Delphi study are hospitals and only two research institutes and one patient organisation are invited to the study. This might have caused bias with regards to a skewed proportion of represented organisations and/or companies. Also, bias with regard to a skewed proportion of employment of respondents might have been present. This was unable to control before or during the study since it was unsure what kind of employment respondents would have. On top of this, with the use of the Likert scale to measure experienced or estimated usefulness of patient participation methods, respondent’s frame of reference could have influenced the results (Ogden & Lo, 2011). Also, the familiarity principle could have played a role in this preference decision (Liao, Yeh, & Shimojo, 2011). Because both the frame of reference and the familiarity principle could have biased results and the study population was relatively small, the chance of reaching statistically significant results in the third round of the Delphi study was also relatively small.

The major strength of this research is associated with the extensive literature research. Evidence-based patient participation methods were structured and complemented with experts' knowledge. By combining theory and practice, new insights into patient participation methods, their current use within practice and their usefulness are gained. The overview resulting from this forms a compact and structured guideline for future patient-included implementers of healthcare innovations.

6. Conclusion

All in all, it can be stated that the research question, “What patient participation methods can enable professionals of healthcare organisations within the Netherlands to involve patients in the implementation of healthcare innovations within their organisation?” is answered by combining the information gained from answering the three sub-questions central to this research. Answering the first sub-question resulted in a list of twenty evidence-based patient participation methods, answering the second sub-question resulted in an additional number of five patient participation methods used in practice, which were added to the list of patient participation methods, and answering the third sub-question resulted in the ranking of these 25 patient participation methods on their usefulness according to experts in practice. The ranking of these 25 patient participation methods based on their usefulness, and especially the top-five of this ranking, is considered to form the answer to the research question. The following patient participation methods are part of the top-five patient participation methods: patients participate in workgroups; advisory groups / client councils; brainstorm sessions; focus groups; and, users’ panels. Two of these methods are derived from scientific literature, two of these methods are derived from grey literature, and one of these methods is derived from the Delphi study. The method found to be most useful by respondents (patients participate in workgroups) is derived from the Delphi study and thus suggested by the same respondents. Moreover, 60% (n=3) of all methods derived from the Delphi study and only 35% (n=7) of all evidence-based methods derived from literature made it to the top-ten of methods rated as useful. On top of this, the average familiarity with patient participation methods in the top-five of methods rated as is 1.3 times higher than the average familiarity with all patient participation methods. Also, during the consensus process on definitions and preconditions of presented evidence-based patient participation methods, it was observed that a considerable proportion of the suggestions made by respondents originated from a lack of knowledge about the (purpose of the) patient participation methods or key-aspects to define the methods. Because of this, a gap between theory and practice is suspected. This suspected gap is in line with the literature stating that a lack of knowledge about different patient participation methods and how to apply them currently exists and that people in practice are calling for insights into what, where, and how methods can be implemented in real-world clinical settings, that are both effective and efficient. With this research, one step towards closing this gap between theory and practice is taken. With the list of 25 patient participation methods derived from both literature and practice, more clarity is provided on the variety of patient participation methods applicable in the implementation of healthcare innovations in the Netherlands. With the co-constructed definitions and preconditions of these methods, more clarity is provided on the ‘what, where, and how’ of patient participation methods. However, given several limitations of this research, this research should be used as a starting point for further research so that the findings of this research can be verified and deepened. Given the seemingly cohesive relation of theory and practice in the matter of (the lack of knowledge about) patient participation (methods), action research might be appropriate for this since this method allows theory and practice to go hand in hand.

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8. Appendix

8.1 Appendix 1. Respondent information letter

Deelnemersinformatie onderzoek ‘Patiëntparticipatie in de implementatiefase van zorginnovaties’

Tegenwoordig staat het nut van samenwerking met patiënten buiten kijf. Echter, hoe deze samenwerking dan het best gerealiseerd kan worden blijft vaak toch een lastig vraagstuk. Het onderzoek ‘Patiëntparticipatie in de implementatiefase van zorginnovaties’ wil hier verandering in brengen door verschillende participatiemethodieken te valideren.

Wat vragen wij?

Er wordt gewerkt met een Delphi-methode, waaraan grondig literatuuronderzoek vooraf is gegaan. Middels de Delphi vormen respondenten gezamenlijk tot een top-5 van participatiemethoden. Dit wordt gedaan door methoden om patiënten te laten participeren binnen de implementatie van innovaties in drie rondes te rangschikken. Het invullen van iedere vragenlijst zal gemiddeld 15 minuten duren. Voor de tweede vragenlijst dient van tevoren een kort document gelezen te worden. De eerste vragenlijst zal in de week van 23/04/2018 worden verstuurd per e-mail. Hiervoor heeft u een week om te reageren. De tweede vragenlijst zal in de week van 07/05/2018 worden verstuurd en de derde vragenlijst in de week van 28/05/2018.

Wat brengen wij?

Naar verwachting wordt het onderzoek eind juli 2018 afgerond. Als tegemoetkoming voor deelname worden bevindingen van het onderzoek, in combinatie met een telefonisch adviesgesprek op maat, te zijner tijd met u gedeeld. We hopen op deze manier gezamenlijk een stap te kunnen zetten in het betrekken van patiënten bij zorg!

Voor vragen kan u op werkdagen altijd bellen naar XXX of mailen naar XXX@student.utwente.nl of info@ikone.nl.

8.2 Appendix 2. Informed consent

Titel onderzoek:

NL: “Onderzoek naar methodieken om patiëntparticipatie binnen de implementatiefase van zorginnovaties te faciliteren”

ENG: *“Patient participation in the implementation of healthcare innovations – A research on how patients can be included in the implementation of healthcare innovations”*

Verantwoordelijke onderzoeker:

Jooske Wilgenhof

Aan de deelnemer:

Als deelnemer binnen dit onderzoek verklaar ik op een voor mij duidelijke wijze te zijn ingelicht over de aard, de methode en het doel van het onderzoek. Ik weet dat de gegevens en resultaten voortkomend uit dit onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden en dat het onderzoek binnen Universiteit Twente en IKONE gedeeld wordt. Mijn vragen zijn naar tevredenheid beantwoord.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud mij daarbij het recht voor om op elk moment, zonder opgaaf van reden, mijn deelname aan dit onderzoek te beëindigen.

N.B. Instemming is te voltrekken door de eerste vraag van de eerste enquête met ‘akkoord’ te beantwoorden.

Namens de onderzoeker:

Ik, Jooske Wilgenhof, verklaar het volgende. Ik heb een schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden. Compensatie voor deelname wordt alleen toegekend indien alle rondes van de Delphi studie door de deelnemer zijn afgerond.

8.3 Appendix 3. Request form Ethical Committee

UNIVERSITEIT TWENTE. Gedragswetenschappen

COMMISSIE ETHIEK (CE) FACULTEIT GEDRAGSWETENSCHAPPEN

AANVRAAGFORMULIER BEOORDELING
VOORGENOMEN ONDERZOEK DOOR CE, VERSIE 2

1. Achtergrond proefpersonen

1. Betreft het een medisch-wetenschappelijk onderzoek?

NB: Medisch-wetenschappelijk onderzoek wordt in deze context gedefinieerd als 'onderzoek dat als doel heeft het beantwoorden van een vraag op het gebied van ziekte en gezondheid (etiologie, pathogenese, verschijnselen/symptomen, diagnose, preventie, uitkomst of behandeling van ziekte), door het op systematische wijze vergaren en bestuderen van gegevens. Het onderzoek beoogt bij te dragen aan medische kennis die ook geldend is voor populaties buiten de directe onderzoekspopulatie.'

Nee

2. Titel

2b. Datum van de aanvraag

18-04-2018

2a. Wat is de titel van het onderzoek (max. 50 tekens)?

LET OP: Als u van het SONA systeem gebruik gaat maken, moet hier dezelfde titel worden vermeld als de titel die in SONA zal worden gebruikt. Deze titel zal ook zichtbaar zijn voor de proefpersonen (bij gebruik SONA).

Patiëntparticipatie implementatie zorginnovaties

3. Contactgegevens onderzoekers/uitvoerders

3a. Voorletters

[redacted]

3b. Achternaam

Wilgenhof

3c. Vakgroep (indien van toepassing)

HTSR

3d. Studentnummer

[redacted]

3e. E-mailadres

[redacted]lent.utwente.nl

3f. Telefoonnummer (tijdens het onderzoek):

[redacted]

3g. Indien er meer dan één uitvoerder is, dan graag in het onderstaande invulblok de gegevens (voorletters/achternaam/e-mailadres/telefoonnummers) van alle uitvoerders van het onderzoek invullen.

X

4. Contactgegevens hoofdonderzoeker/begeleidend docent

LET OP: De eerst verantwoordelijke onderzoeker/begeleidend docent is verantwoordelijk voor de bij deze aanvraag verstrekte gegevens en het onderzoek als geheel en verleent (indien van toepassing) met de aanvraag in dit formulier toestemming aan ANDERE PERSO(O)N(EN) (zie vraag 3) om voornoemde onderzoek met proefpersonen uit te voeren.

Deze eerst verantwoordelijke onderzoeker is een gepromoveerde onderzoeker.

4a. Voorletters

P.M.

4b. Achternaam

Carrera

4c. Vakgroep

HTSR

4d. E-mailadres

p.m.carrera@utwente.nl

[redacted] tijdens het onderzoek

5. Beoogde begin- en einddatum onderzoek

5a. Wat is de beoogde begindatum van het onderzoek?

01-02-2018

5b. Wat is de beoogde einddatum van het onderzoek?

31-07-2018

6. Doel en vraagstelling onderzoek

Geef een duidelijke en voldoende uitgebreide omschrijving van het onderzoek, waarmee een voldoende ethische beoordeling mogelijk is.

6a. Wat is het doel van het onderzoek?

Achterhalen of wetenschappelijk bewezen methoden om patiënten te laten participeren binnen de implementatiefase van zorginnovaties door experts vanuit zorgorganisaties worden herkend en erkend als nuttig en kansrijk.

6b. Wat is de vraagstelling van het onderzoek?

Hoe kunnen zorgorganisaties in Nederland in staat worden gesteld om patiënten te betrekken bij de implementatiefase van zorginnovaties die direct betrekking hebben op de zorg zoals patiënten die ontvangen?

7. Binnen welk kader wordt het onderzoek uitgevoerd?

7. Het onderzoek wordt uitgevoerd in het kader van een studie. Het gaat specifiek om een:

Masterthese

8. Aard van het onderzoek

8. Wat is de aard van het onderzoek?

(Online) survey onderzoek

9. Gebruik Proefpersonen uit SONA

9. Wilt u voor uw onderzoek met proefpersonen gebruik maken van SONA?

Nee

10. Omvang aantal sessies

Probeer een zo goed mogelijke schatting te geven van de benodigde duur van het onderzoek.

LET OP: Het onderzoek moet worden aangevraagd in eenheden van 15 minuten.
Proefpersooncredits worden toegekend per standaard eenheid van 15 minuten.

10a. Zal een proefpersoon zijn/haar deelname afronden in één of meerdere sessie(s)?

In meer dan een sessies

10b. Hoeveel sessies zijn in totaal nodig?

Drie

10c. Wat is de duur (in minuten) van de afzonderlijke sessies?

Twintig

10d. Wat is de totale duur van de sessie(s) in minuten?

Zestig

11. Beoogde aantal proefpersonen, verdeling, inclusie en exclusie criteria

11a. Wat is het beoogde aantal proefpersonen?

Vijftien tot twintig

11b. Wat is de beoogde verdeling man/vrouw onder de proefpersonen?

Niet van toepassing

11c. Wat zijn de beoogde inclusiecriteria?

Werkzaam in een Nederlandse organisatie waar zorginnovaties in missie of visie staan ofwel werkzaam in een Nederlandse organisatie die is aangesloten bij een organisatie die innovatie stimuleert en hoog op de agenda heeft staan. Deelnemers hebben ofwel een uitvoerende functie (implementeren innovatie op werkvloer) ofwel een managende functie (managen implementatie vanaf hoger liggend niveau organisatie).

11d. Wat zijn de beoogde exclusiecriteria?

Het zijn van niet-Nederlands taal- en schrijfvaardig van deelnemers

12. Procedure van het onderzoek

12. Wat moet een proefpersoon die aan dit onderzoek deelneemt doen?

Een duidelijke beschrijving van de procedure van het onderzoek (instructies aan de proefpersonen, te meten variabelen, condities, manipulaties, meetinstrumenten) is vereist.

Driemaal een vragenlijst online invullen, waar bij de tweede vragenlijst van tevoren een document ingelezen dient te worden.

13. Is een van de onderstaande situaties van toepassing?

n.v.t.

14. Mogelijke gevolgen van het onderzoek voor de proefpersonen.

14a. Kan het onderzoek mogelijk ongemak en/of risico's opleveren voor de proefpersonen?

Nee

14b. Toelichting

Indien Nee: Graag toelichten.
Indien Ja: Leg uit op welke wijze het ongemak en/of de risico's voor de deelnemende proefpersonen gerechtvaardigd worden in het licht van mogelijke opbrengsten van het onderzoek (voor de proefpersonen en/of andere groepen). Leg ook uit welke maatregelen worden getroffen om ongemak en risico's zoveel mogelijk op te vangen of te beperken.

Er zijn geen risico's verbonden aan het onderzoek.

15. Wilsbekwaamheid proefpersonen

Wilsbekwaamheid houdt in dat de proefpersonen beschikken over het individuele vermogen om zelfstandig beslissingen te nemen.

Proefpersonen zijn wilsbekwaam als zij:
•18 jaar of ouder (meerderjarig) zijn, en
•ieder voor zich in staat zijn tot een redelijke beoordeling van het eigen belang ter zake.
Volwassenen die daartoe niet in staat zijn, zijn wilsonbekwaam.(zie ook www.ccmo.nl/nl/onderzoek-bij-wilsonbekwame-volwassenen)

15a. Zijn de proefpersonen wilsbekwaam?

`Ja`

16. Leeftijdscategorie

16. In welke leeftijdscategorie vallen de proefpersonen?

☑ `Meerderjarig: 18 jaar en ouder (alleen toestemming proefpersoon nodig)`

17. Volledige voorlichting vooraf

17a. Worden proefpersonen (en/of ouders/verzorgers) alvorens zij meedoen aan het onderzoek volledig over doel en inhoud van het onderzoek voorgelicht, bijvoorbeeld door middel van een brochure?

`Ja`

17b. Toelichting

Indien Ja: op welke wijze?
Indien Nee: waarom niet?

`Door middel van een uitnodiging via e-mail.`

17c. Welke informatie ontvangen proefpersonen (en/of ouders/verzorgers) vooraf over het doel en de inhoud van het onderzoek?

`Doel, methode, benodigde input van participanten, geschatte duur deelname, tegemoetkoming voor deelname, samenwerking stichting IKONE en Universiteit Twente.`

18. Informed Consent

18a. Verlenen proefpersonen (en in geval van niet-wilsbekwame proefpersonen: de voogd of ouders/verzorgers) vooraf schriftelijk toestemming voor het onderzoek door middel van een 'Informed Consent' formulier met daarin informatie over doel, aard en duur, risico's en bezwaren?

Het gebruik van een Informed Consent formulier heeft sterk de voorkeur! Een standaard Informed Consent formulier is te vinden op de website van de Commissie Ethiek.

`Ja`

19. Volledige voorlichting achteraf

19. Op welke manier vindt de debriefing plaats? Kunnen proefpersonen (en/of hun ouders/verzorgers) bijvoorbeeld naderhand nog in contact treden met de onderzoeker over het onderzoek?

Indien Ja: op welke wijze?
Indien Nee: waarom niet?

`Contact is mogelijk, net als inzicht in resultaten en adviesgesprek op maat n.a.v. resultaten onderzoek.`

20. Afhankelijkheid proefpersonen

20a. Beschrijf de relatie tussen de hoofdonderzoeker/onderzoekers enerzijds en de proefpersonen anderzijds.

Geen financiële prikkels betrokken en er is geen afhankelijkheidsrelatie. Er is enkel en alleen telefonisch of online contact.

20b. Zijn de proefpersonen, buiten de context van het onderzoek, in een afhankelijke of ondergeschikte positie t.o.v. de onderzoeker?

Nee

20c. Toelichting

Indien Ja: op welke wijze?

-

21. Duidelijkheid t.a.v. terugtrekken

21a. Wordt proefpersonen duidelijk gemaakt dat zij zich te allen tijde zonder verklaring/rechtvaardiging kunnen terugtrekken?

Ja

22. Beloning proefpersonen

LET OP: Alleen voor onderzoek waarbij alleen proefpersoon credits worden gegeven, kan gebruik gemaakt worden maken van het SONA systeem.

22. Welke beloning(en) kunnen proefpersonen ontvangen voor hun deelname aan het onderzoek.

☑ Anders, te weten:

Adviesgesprek vanuit stichting IKONE

23. Opslag en verwerking gegevens

23a. Worden gegevens van het onderzoek vertrouwelijk behandeld en anoniem opgeslagen en verwerkt?

Ja

24. Inzage gegevens

24a. Hebben proefpersonen achteraf inzage in hun eigen gegevens?

Ja

Opmerkingen

Uw reactie

Akkoord. Dank voor de aanvullingen.

Vragen/opmerkingen van onderzoeker, begeleidend docent en commissie

2018-05-16 15:28:09 - Wilgenhof, J.F.:
Onderwerpen 1ste vragenlijst:
- Algemene persoonsinformatie, zoals: organisatie waar respondent werkzaam is, ervaring met patiëntparticipatie en nut van patiëntparticipatie volgens de respondent.
- Inhoudelijke informatie: per methode van patiëntparticipatie wordt gevraagd of de respondent de methode kent of niet. Indien de methode bekend is, worden wat aanvullende vragen gesteld (toegepast binnen organisatie? Zo ja, wat was rol van respondent binnen dit toepassen?
- Open vraag: Kent de respondent andere methodes, die niet zijn genoemd in de vragenlijst?

Dit, om inzicht te krijgen of er verschillen zijn tussen soorten zorgorganisaties en hun standpunten en ervaring

Onderwerpen 2de vragenlijst:
- Methoden worden gepresenteerd, samen met definitie en randvoorwaarden. Respondenten kunnen aangeven het hiermee (on)eens te zijn of niet te weten of dit volgens hen klopt. Indien ze het ermee oneens zijn, krijgen zij de mogelijkheid dit toe te lichten/aan te vullen.

Onderwerp 3de vragenlijst:
- Alle methoden worden door respondenten gerankt op ervaren en, indien dit niet mogelijk is, geschatte kansrijkheid.

Gegevens worden tussentijds nergens opgeslagen. Wel zijn ze beschikbaar via surveymonkey (alleen te betreden door in te loggen met surveymonkey account), waarin de vragenlijsten worden afgenomen.

De respondenten hebben informed consent ontvangen en akkoord gegeven (dit is de eerste vraag vd eerste vragenlijst) voordat zij verdere vragen invullen. In de informed consent staat hoe er met hun gegevens wordt omgegaan. Namen van respondenten worden niet gelinkt aan uitslagen. Zorginstellingen worden wel gelinkt aan uitslagen.

2018-04-23 15:11:26 - Lenferink, A. :
Door de afname van drie online vragenlijsten is er weinig belasting voor de deelnemers. Kan er nog toelichting worden gegeven:
12. Uit welke onderwerpen bestaan de drie online vragenlijsten? Worden gegevens geanonimiseerd verwerkt en waar worden de verzamelde gegevens opgeslagen?

8.4 Appendix 4. Selection process for included and excluded studies

Table 5

Full details of search strategy primary part extended literature study

Database	Search term	# of records	Action	Result
Medline	“Patient participation” AND innovation* AND implementation*	7		
	“Patient participation” AND method* AND innovation* AND implementation*	5	Review 1 article	
	“Patient engagement*” AND implementation AND innovation	10		
	“Patient involvement*” AND implementation AND innovation	5		
PubMed	“Patient participation” AND method* AND innovation* AND implementation*	160	Excluded ‘animals’, review 3 articles	3 articles, whereof 1 was already on the list of evidence-based patient participation methods
	“Patient participation” AND innovation* AND implementation*	220	Excluded ‘animals’, review 4 articles	4 articles, whereof 2 were already on the list of evidence-based patient participation methods and 2 were not accessible for free
	“Patient engagement” AND implementation* AND innovation*	339	Excluded ‘animals’, review 3 articles	3 articles, whereof 2 were not accessible for free
	“Patient involvement*” AND implementation* AND innovation*	328	Excluded ‘animals’, review 5 articles	All seemingly useful articles already provided by previous search terms in PubMed
Science-Direct	“Patient participation” AND method AND innovation* AND implementation*	107		
	“Patient participation” AND innovation* AND “implementation*	117		
	“Patient engagement*” AND implementation* AND innovation*	500	Review 2 articles	2 records, whereof 1 was not accessible for free
	“Patient involvement*” AND implementation* AND innovation*	138		
Scopus	“Patient participation” AND method AND	37		

	innovation* AND implementation*			
	“Patient participation” AND innovation* AND implementation*	90	Review 3 articles	None of the articles accessible for free
	“Patient engagement*” AND implementation* AND innovation*	286	Review 4 articles	3 articles not useful and 1 not accessible for free
	“Patient involvement*” AND implementation* AND innovation*	234	Review 5 articles	4 articles not useful and already provided by previous search terms in PubMed

Table 6

Full details of search strategy secondary part extended literature study

Method	Database	Search term	# of records	Action	Result
User profile/ persona	Medline	Persona* OR User profile* AND innovation* AND implementation*	4	Review 1 article	1 article
	Scopus	Persona* OR User profile* AND innovation* AND implementation*	14		
	Science-direct	Persona* OR User profile* AND innovation* AND implementation*	150	Review 1 article	1 article, by Holden, et al., 2017
	PubMed	Persona* OR User profile* AND innovation* AND implementation*	14	Review 1 article	Not accessible for free
Online expert panel	Medline	“Online expert panel*” AND innovation* AND implementation*	18		
	Scopus	“Online expert panel*” AND innovation* AND implementation*	32		
	Science-direct	“Online expert panel*” AND innovation* AND implementation*	519		
	PubMed	“Online expert panel*” AND innovation* AND implementation*	1		
Open community forum	Medline	“Open community forum*” AND innovation* AND implementation*	0		
	Scopus	“Open community forum*” AND innovation* AND implementation*	3		
	Science-direct	“Open community forum*” AND innovation* AND implementation*	0		
	PubMed	“Open community forum*” AND	6		

		innovation* AND implementation*			
Provider-consumer dialogue	Medline	“Provider-consumer dialogue*” AND innovation* AND implementation*	2	Review 1 article	
	Scopus	“Provider-consumer dialogue*” AND innovation* AND implementation*	1		
	Science-direct	“Provider-consumer dialogue*” AND innovation* AND implementation*	0		
	PubMed	“Provider-consumer dialogue*” AND innovation* AND implementation*	2		
DCE	Medline	“Discrete Choice Experiment*” OR “DCE” AND innovation* AND implementation*	4	Review 1 article	1 article, by Erdem & Thompson, 2014
	Scopus	“Discrete Choice Experiment*” OR “DCE” AND innovation* AND implementation*	281	Review 2 articles	2 articles, by Erdem & Thompson, 2014 and Salloum, et al., 2017
	Science-direct	“Discrete Choice Experiment*” OR “DCE” AND innovation* AND implementation*	34	Review 1 article	1 article, by Kaambwa, et al., 2015
	PubMed	“Discrete Choice Experiment*” OR “DCE” AND innovation* AND implementation*	7	Review 1 article	1 article, by Lock, et al., 2016
Shard decision-making	Medline	“Shared decision-making*” AND innovation* AND implementation*	19	Review 1 article	1 article, by Durand, et al., 2015
	Scopus	“Shared decision-making*” AND innovation* AND implementation*	33		
	Science-direct	“Shared decision-making*” AND innovation* AND implementation*	137		
	PubMed	“Shared decision-making*” AND innovation* AND implementation*	48		

8.5 Appendix 5. Results Delphi study – first round

Table 8

Rated usefulness of patient participation in general, per organisation, and per employment

Rated usefulness patient participation in general		Weighted avg. (n=19)
General		89.2
Per organisation		
	Field lab (n=1)	75
	Hospital, academic (n=7)	92.1
	Hospital, general (n=2)	75.5
	Hospital, top clinical (n=5)	88.6
	Long-term care (n=2)	95
	Patient organisation (n=1)	100
	Research institute (n=1)	90
Per employment		
	Advisor (n=2)	95
	Healthcare professional (n=2)	76
	Manager (n=7)	87.6
	Project leader (n=5)	91.8
	Project member (n=1)	100
	Researcher (n=2)	90

8.6 Appendix 6. Results Delphi study – second round

Table 11

Co-constructed definitions and preconditions of patient participation methods

Method	Co-constructed definition	Co-constructed preconditions
Advisory groups / Client councils	A board that is pro-active and can deliver input, feedback, or experience-based expertise on a variety of topics from a patient's perspective.	Clearly state purpose, operating procedure, and degree of influence of the board. Members have equal voices. The direction should treat the board as an equal player in the areas the board has a right to advice.
Brainstorm sessions	A group session whereby new ideas or solutions for innovation or improvement in care are generated with the aid of brainstorm techniques.	All possibly relevant stakeholders are represented. At least one stakeholder represents the patient perspective. Clearly stat for what purposes the input of the session will be used.
Citizen Juries	Citizens that are as representative as possible for the public and can judge impartial give their opinion about non-expert knowledge or add their vision to a present discussion.	Representative group of ±14 participants. Participants have an equal right to be heard.
Comments cards	Making cards and post boxes available for service users to communicate with the organisation to obtain feedback.	Make sure continuity of method is guaranteed. Give feedback to patients about what is done with their comments.
Context mapping	To get insights into the personal side of the patient. Experience, emotions, needs and wants are mapped, so that innovation can connect to all these aspects.	State clearly that every experience is 'true', even though they can differ per patient.
Continuous feedback	Direct user information is obtained, so that continuous and actual improvements can be implemented.	Make sure that a medium is available to share the feedback. Provide an adequate reporting tool, so that feedback can be processed.
(Digital) story-telling	A two-three minute multi-media video clip that includes narrative, visual (digital video, photographs, artwork), and performance (music, voice) mediums for the purpose of expressing an individual or community story.	Use the following words to structure the story: what, whereby, why, and what now. Availability and knowledge of technical equipment.
Discrete Choice Experiments (DCE)	A quantitative technique for eliciting individual preferences. It can be uncovered how individuals value selected attributes of a programme, product or service by asking them to state their choice over different hypothetical alternatives.	Ensure that the attributes and corresponding levels are appropriate and valid.
Dragons' den	(Innovative) ideas are presented to dragons (persons with relevant expertise), who thereafter decide which idea is most preferable in their opinion.	Carefully determine which issues are eligible for this method. Inform participants before the method takes place to enhance substantive discussions.
Emotional touchpoint method	Touchpoints are identified to improve quality of care products or services. Touchpoints represent the key moments or events that stand out for those involved as crucial to their experience of receiving care.	Give participant the opportunity to share more than only the aspects that seem relevant for the facilitators in the first place.
Focus groups	A homogenous group of 7-10 participants discuss their ideas, motives, interests, and way of thinking about a specific topic.	Homogenous group of 6-12 participants. Make sure participants know about the subject and its scope before the meeting takes place. Give insights into purpose of the meeting and the use and/or dissemination of results. Make sure participants have equal voices.

In-depth interviews	A conversation whereby questions are asked with the aim to obtain information from the respondent. Subjects and criteria can be composed beforehand.	Inform respondent about subjects beforehand. Provide respondents with informed consent and only proceed in case they agree with this.
Mirror meetings	A group meeting of patients facilitated by an independent moderator, with the goal obtain feedback on and information about a certain care product or service.	State clearly who may talk when. Prevent discussion.
Mystery shopping	Mystery patients use innovative products or services to evaluate the limitations of these products or services and to address areas of improvement.	Conduct method unexpectedly and incognito. Repeat for reliable results.
Nominal group technique	A structured process which facilitates the generation, discussion, and ranking of participant ideas.	A maximum of seven participants. Structure the process in four stages (silent generation, round robin, clarification, and voting).
Patient diaries	Diary that is kept by patients (digital or analogue) at the request of the researcher and is usually structured into time, events, persona or units of interest so that it represents the everyday life of the patient and ideas can be generated on the bases of that.	Availability and knowledge of technical equipment in case diary is kept digital. Clearly state purpose of method to the patient.
Patient Journey	A graphical representation of events (both medical and personal) a patient experienced.	Determine whether the facilitator or the patient chooses the scope of the journey before beginning the method.
Personas	Empirically derived user-archetypes that are used to gain a robust understanding of target end users such as patients.	Create a persona on the basis of observations or interviews, so that the persona is most likely to represent the actual (patient) group.
Process mapping	Form of a clinical audit that examines how the patient journey can be managed, using the patient’s perspective to identify problems and suggest improvements.	Provide a facilitator (not substantive involved in the method) who visualises the map so that participants can focus on the content of the meeting. Clearly state that experiences are ‘true’, even though they may differ per patient.
Patients participate in workgroups	Patients are part of work or project group. They can be involved in all stages of innovation; from idea generation to implementation and evaluation.	Clearly state the purpose of the work or project group and make sure every member knows the division of roles. Make sure all members have equal positions (both in voice and payment).
Round-table workshops	Participants (groups with interest in particular service/product) are enabled to make a full contribution to discussions on issues of shared concern and to generate ideas for action.	Pay specific attention to the consensus-part, since relatively wide range of opinions is addressed.
Shadowing	A committed and empathic observer follows a patient or healthcare professional throughout a selected (care) process to view and capture the details of the entire experience from the point of view of the shadowed person.	Clearly state the purpose of the method and make sure this is made public before the method takes place.
Surveys & questionnaires	Method whereby input on specific domains from relevant stakeholders is gathered by asking questions.	Carefully determine and operationalize variables. Give feedback about the results to the respondents.
Users panels	User-feedback about their experience and expectations is used to review products and services.	Panel members are representative for (future) end-users.
Thinking aloud	Participants talk aloud when trying the innovation for the first time. Information derived from this can be used to fine-tune the innovation.	Make sure the test-situation is as realistic as possible. Practice the talking aloud part with the participant beforehand.

8.7 Appendix 7. Results Delphi study – third round

Table 15

Rated usefulness of patient participation methods, per (healthcare) organisation

Method	Field lab (n=1)	Hospital, academic (n=7)	Hospital, general (n=2)	Hospital, top clinical (n=5)	Long-term care (n=2)	Patient org. (n=1)	Research inst. (n=1)	*Avg.*
Comments cards	3.00	3.00	3.00	2.40	2.50	3.00	4.00	*2.99*
Citizens' juries	2.00	2.86	3.00	3.00	3.50	3.00	4.00	*3.05*
DCE	4.00	3.00	3.00	3.20	3.00	3.00	3.00	*3.17*
Mystery shopping	4.00	4.00	3.00	2.80	2.50	3.00	3.00	*3.19*
Roundtable workshops	3.00	3.29	3.00	3.60	3.50	3.00	3.00	*3.20*
Nominal group technique	3.00	3.29	2.50	3.60	4.00	5.00	3.00	*3.48*
Emotional touchpoints	4.00	3.57	3.00	3.40	3.50	4.00	3.00	*3.50*
(Digital) storytelling	4.00	3.86	2.50	3.80	3.50	4.00	3.00	*3.52*
Mirror meetings	4.00	4.14	3.50	3.00	3.50	4.00	3.00	*3.59*
Speak out loud	4.00	3.14	2.00	3.60	4.50	4.00	4.00	*3.61*
Personas	4.00	2.86	4.00	3.40	4.00	4.00	3.00	*3.61*
Dragons' den	5.00	3.57	3.00	3.20	4.00	4.00	3.00	*3.68*
Patient diaries	4.00	3.71	3.00	3.60	3.00	5.00	4.00	*3.76*
Shadowing	3.00	4.43	4.00	3.40	3.50	4.00	5.00	*3.90*
Advisory groups/ Client councils	3.00	4.14	4.50	4.00	5.00	4.00	3.00	*3.95*
Process mapping	4.00	4.00	4.00	4.20	4.00	5.00	3.00	*4.03*
Focus groups	5.00	4.29	4.00	4.00	4.00	3.00	4.00	*4.04*
Patient journey	5.00	4.14	2.50	4.20	4.50	5.00	3.00	*4.05*
Surveys & questionnaires	4.00	3.71	4.50	4.00	3.50	5.00	4.00	*4.10*
Context mapping	5.00	3.43	3.00	3.80	4.50	4.00	5.00	*4.10*
In-depth interviews	5.00	4.57	3.50	3.20	3.50	4.00	5.00	*4.11*
Users' panels	5.00	4.14	3.00	4.00	5.00	5.00	3.00	*4.16*
Brainstorm sessions	5.00	4.00	3.50	4.20	4.50	4.00	4.00	*4.17*
Continuous feedback	4.00	4.00	4.00	3.80	4.50	5.00	4.00	*4.19*
Patients in workgroups	4.00	4.43	4.00	4.60	5.00	5.00	4.00	*4.43*
Avg.	*4.00*	*3.74*	*3.32*	*3.60*	*3.86*	*4.08*	*3.6*	

Table 16

Rated usefulness of patient participation methods, per employment

Method	Advisor (n=2)	Healthcare prof. (n=2)	Manager (n=7)	Project leader (n=5)	Project member (n=1)	Researcher (n=2)	*Avg.*
Comments cards	2.50	3.50	2.43	2.60	3.00	4.50	*3.09*
Citizens' juries	4.00	2.50	3.14	2.40	3.00	3.50	*3.09*
DCE	2.50	3.50	3.29	2.80	3.00	3.50	*3.10*
Roundtable workshops	3.00	4.00	3.43	3.20	3.00	3.00	*3.27*
Personas	3.50	3.00	3.43	3.40	4.00	3.00	*3.39*
Mystery shopping	3.00	4.00	3.00	3.40	3.00	4.00	*3.40*
Emotional touchpoints	3.00	3.50	3.86	3.20	4.00	3.00	*3.43*
Speak out loud	3.00	3.50	3.71	3.00	4.00	3.50	*3.45*

Nominal group technique	3.00	3.00	3.43	3.40	5.00	3.50	*3.55*
(Digital) storytelling	3.00	3.50	3.86	3.60	4.00	3.50	*3.58*
Dragons' den	3.00	4.00	3.71	3.00	4.00	4.00	*3.62*
Mirror meetings	3.00	4.50	3.57	3.60	4.00	3.50	*3.70*
Patient diaries	2.50	4.50	3.71	3.40	5.00	3.50	*3.77*
Context mapping	3.50	3.50	4.14	3.80	4.00	4.00	*3.82*
Patient journey	3.50	3.00	4.71	4.00	5.00	3.00	*3.87*
Focus groups	4.00	4.50	4.00	4.40	3.00	4.00	*3.98*
In-depth interviews	3.50	4.00	3.57	4.60	4.00	4.50	*4.03*
Continuous feedback	4.00	3.50	4.14	3.60	5.00	4.00	*4.04*
Brainstorm sessions	4.50	3.50	4.29	3.80	4.00	4.50	*4.10*
Process mapping	3.50	5.00	4.14	4.00	5.00	3.00	*4.11*
Shadowing	4.00	4.00	3.29	4.40	4.00	5.00	*4.11*
Surveys & questionnaires	4.00	4.50	3.71	4.00	5.00	3.50	*4.12*
Users' panels	3.50	4.50	4.14	4.20	5.00	3.50	*4.14*
Advisory groups/Client councils	5.00	4.00	3.71	4.40	4.00	4.00	*4.19*
Patients participate in workgroups	4.50	4.50	4.43	4.40	5.00	4.50	*4.55*
Avg.	*3.46*	*3.82*	*3.71*	*3.62*	*4.08*	*3.74*	