INTERNSHIP REPORT

Experiential knowledge in health research appraisal

A qualitative study on the added value of patients in their role as a knowledgeable stakeholder

Vera Teunisse

STUDENT NUMBER
2644137

COMMISSIONING PARTY
ZonMw

ECTS + COURSE CODE SPECIALIZATION
30 ECTS + AM_1185

DATE
10-07-2020

VU SUPERVISOR
Dr. C.A.C.M. Pittens

ATHENA SCIENCE SHOP

VU VRIJE UNIVERSITEIT AMSTERDAM

Colophon

Title: Experiential knowledge in health research appraisal
Key words: appraisal, experience, patients, research, health care
Word count:
Author: Vera Teunisse
Commissioning organization: ZonMw
On-site supervisor: Jolanda Huizer, MSc
VU supervisor: Dr. C.A.C.M. Pittens

July 2020
Course code: AM_1185

This internship report was established in cooperation with the Athena Science Shop.

Athena Institute

Faculty of Science
VU University Amsterdam
De Boelelaan 1085
1081 HV Amsterdam
The Netherlands

Table of contents

Summary

Context

The Dutch organization that funds health research and care innovation, ZonMw, emphasizes the importance of patient involvement in health research. To assure the involvement of patients in health research, ZonMw has collaborated with Netherlands Patients Federation for the appraisal of research proposals. A panel of patients and their caregivers and family advise ZonMw by appraising the projects on feasibility, relevance of the research to patients, and patient involvement throughout the research. With their experiential knowledge, panel members can aid to tailor research by giving insights in the needs of patients. ZonMw relies on this experiential knowledge of patients, and wants to gain insights on the expertise of the panel members to assure meaningful involvement. Therefore the aim of this study is to assess the added value of patients in their role as a knowledgeable stakeholder during health research appraisal by assessing the use of experiential knowledge by panel members during these appraisals.

Theoretical background

Teunissen et al. (2013) created a list of patients' issues that could be used during appraisal to share the perspectives of patients in general. The list consists of six criteria, 'relevance', 'quality of life', 'quality of care', 'ethics and safety', 'information & communication', and 'involvement', which all correspond with patients' issues and values.

In this study, the list with criteria can be seen as a tool to indicate which issues are mostly addressed by patients involved during appraisal, and which issues need emphasis in the appraisal and the standardized assessment form, to ensure successful articulation of experiential knowledge during the appraisal. The six criteria can also be regarded as embodying of experiential knowledge of patients during appraisal (Teunissen et al., 2013).

Methods

During this study a qualitative research approach was used to collect data. Thirteen semi-structured interviews were carried out among panel members to access in-depth information about patients' needs, ideas, and perspectives. Respondents were recruited via an email that was sent to them through Netherlands Patients Federation. In the email was described what the content of the study was, what the aim of the interviews was, what was expected from the participants, in what time period the interviews should take place, and how the data would be administered. Among respondents were eleven patients, two were caregivers. Four respondents were male, in contrast to nine respondents being female.

Results

The general feeling of 'being a patient is being an outsider', makes it possible for patients to look through the eyes of patients and to empathize easily. They are able to imagine how a patient would feel under the circumstances mentioned in research proposals, such a being part of a randomized control group instead of the treatment group based on the feeling of being a patient. Respondents' ability to empathize with others allows panel members to address patients' issues of all six criteria with the help of a form. The use of the form contributes to a complete appraisal, and needs little adjustments.

Conclusion

The experience of being a patient has made panel members to empathize easily with other patients, which makes it possible for them to speak on behalf of other patients. The forms that are provided by Netherlands Patients Federation aid to completely address all patients' issues. With the panel members being able to address all patients' issues, the panel members add value to health research appraisal in their role as a knowledgeable stakeholder.

Recommendations

It is recommended that further research is done by Netherlands Patient Federation on different designs for the assessment form. Besides, it is recommended to extend the current research by doing observations of appraisal to gain more direct insight in the application of experiential knowledge in practice, and by interviewing researchers to gain insight in how experiential knowledge is integrated and embedded. Further, it is suggested that panel members receive appropriate training to improve their writing and collaborating skills. Finally, the importance of a reimbursement for panel member is highlighted.

For ZonMw, it is recommended that panel members are provided with an overview of research projects that have been granted financing, to provide them with relevant information of their involvement. In addition, it is suggested to stimulate the collaboration between researchers and patients' advocates to enhance patient information letters and bridge the knowledge gap. Besides, it is suggested that researchers are provided with a detailed description of the term 'involvement', as this is often confused with 'participation'. It is also suggested that researchers are supported by finding the right people to including in clinical trials.

1. Introduction

In the last decades, society has been given a voice in scientific research, which has resulted in a location shift of scientific knowledge into transdisciplinary collaborations (Dornan, 1990; Charlton, 2000; Regeer & Bunders, 2009; Videmšek, 2017; PCORI, 2019). In these transdisciplinary collaboration, the public being involved in different phases throughout research, which range from agenda-setting to policy implementation, to provide new insights (Videmšek, 2017; PCORI, 2019). Within health care, the involvement of the public means that patients become partners of the scientists, as they fulfil an active role during research, and are not solely participating in the research by filling in questionnaires or participating in interviews (Caron-Flinterman, 2005; Renedo & Marston, 2015; Videmšek, 2017; Echeverri & Salomonson, 2017; Jennings, Slade, Bates, Munday & Toney, 2018). By fulfilling the active role, patients can give insights in the needs of patients and the feasibility of patient participation, and thereby they can aid to tailor research with their experiential knowledge.

Experiential knowledge is knowledge that has been generated by patients' implicit, lived experiences and personal insights that enable a patient to cope with individual illness and disability (Caron-Flinterman et al., 2006). Patients with experiential knowledge, experiential experts, can translate their knowledge into explicit needs, ideas, or perspectives (Caron-Flinterman et al., 2006; Blume, 2017; Chugh, 2018), which makes it possible to integrate experiential knowledge in health research (Elberse et al., 2017). The integration of experiential knowledge in health research can contribute to more tailored treatments and strategies, making health research more relevant and useful (van Rooijen, Goedvolk & Houwert, 2013; Lemire, 2015). Besides, the integration of experiential knowledge can lead to improvements in the credibility of results and direct applicability to patients (Domecq et al., 2014; ZonMw, 2020).

Health research can become more relevant and useful as a result of patient involvement during research (Videmšek, 2017; Jennings et al., 2018). In addition, patients can be involved in phases that precede the research, for instance during the appraisal (Teunissen et al., 2013; Abelson et al., 2016; Mason et al., 2020). Here, patients are consulted for their perceptions on the project and its execution with regard to patient participation, providing patients to give insights on their own experiences (Mason et al., 2020, ZonMw, 2020). As a result, it becomes clear whether the outcomes of the research are meaningful to patients, or perceived to be acceptable to patients (Mason et al., 2020). In addition, patients can give suggestions on the execution, to become better adapted to patient needs.

The involvement of patients during appraisal is also applied at ZonMw, the Dutch organization for health research and care innovation (ZonMw, 2020). ZonMw, finances health research projects that show the best prospects of quality and innovation and contribute to research development. ZonMw believes that "patient involvement is an important way to sharpen

research within health care" (ZonMw, 2020), and therefore ZonMw aims to stimulate patient involvement in health research and during grant application appraisal.

ZonMw has collaborated with Netherlands Patients Federation for patient involvement during grant application appraisals (ZonMw, 2020). They have created a panel of patients, their relatives or their care-takers, who are all considered to be experiential experts (ZonMw, 2020; Netherlands Patients Federation, 2020). The panel assesses research projects on feasibility with regard to patient participation in clinical trials, relevance of the research to patients, and patient involvement throughout the research (Netherlands Patients Federation, 2020). The researchers receive the appraisal of their project proposals, which they can consult to make adjustments and to write an extended proposal. The board of ZonMw will decide which applications will and will not be awarded a grant, based on scientific aspects and the assessment of the panel (ZonMw, 2020).

The panel of Netherlands Patients Federation currently uses a standardized form with criteria for research appraisal, which addresses the relevance of research projects to patients, feasibility of clinical trials, and patient involvement, yet it seldomly addresses provision of information, and communication about risks of the participation and compensation for participation for instance (Netherlands Patients Federation, 2020). In addition, it is not clear how the panel members use their own experiential knowledge during the appraisal. Consequently, it is possible that not all issues that matter to patients are included during appraisal, and that the involvement of patients is not of additional value to the appraisal.

Nonetheless, ZonMw relies on the experiential knowledge of panel members during the grant appraisal application to make health research more meaningful for patients, and therefore the aim of this study is to assess the added value of patients in their role as a knowledgeable stakeholder during health research appraisal by assessing the use of experiential knowledge by patients during these appraisals. This can contribute to improvements in patient involvement during grant appraisals.

2. Contextual background

In this chapter, the contextual background of this research will be presented. First, information is provided on the placement of this research: ZonMw. After that, information is provided on the panel of patients. Finally, information is provided on the procedures of grant application appraisals..

2.1 ZonMw

ZonMw is a Dutch organization for health research and care innovation, who has a central role as national funding organization for research projects (ZonMw, 2020). As a funding organization, they enable people to develop new knowledge that can be used both in health policy and health practice. Their funding covers a wide spectrum of projects, ranging from fundamental research to implementation, prevention, and improvements. However, each projects should show societal and scientific relevance (ZonMw, 2020). Therefore, ZonMw collaborates with stakeholders for whom the information of the projects is intended, including citizens and patients.

ZonMw believes that patient involvement aids to tailor health research, and that it assists in "making it more likely that the results of projects will be applied soon and with a bigger success rate" (ZonMw, 2020). ZonMw argues that scientists cannot be solely responsible for implementation of their research outcomes (ZonMw, 2018). Patients should not only be involved during research by giving advice and setting priorities, but also during the conduction of the research and during implementation to guarantee the implementation in health care practice (PCORI, 2019). Therefore, it is necessary for researcher to have a sustainable collaboration with patients.

2.2 Panel

ZonMw emphasizes the importance of patient involvement in health research, and works together with stakeholders to assure the contribution of patients in health research (ZonMw, 2020). The Netherlands Patients Federation is one stakeholder of ZonMw, who provides ZonMw with an advisory panel in grant application appraisals of research projects. This panel consists of (former) patients and their caregivers and family, who are considered to be experience experts.

The panel assesses research projects proposed to ZonMw for feasibility with regard to patient participation, relevance of the research to patients, and patient involvement throughout the research. The experience experts discuss their views on these aspects during appraisal and together they build consensus, which means that they identify a conclusion as their perspectives converge. Based on the conclusion, the panel gives recommendations to the board of ZonMw, who appraises the projects on scientific aspects simultaneously, and to the applicant, who can use the recommendations to make alterations in their research design. The board of ZonMw determines whether research project gets funding (ZonMw, 2020).

2.3 Grant application appraisal

Researchers can submit a project idea to ZonMw for funding (ZonMw, 2020). ZonMw takes care of the appraisal of these applications. Patient relevance is an important part of the appraisal. The panels of the Netherlands Patients Federation are used to assess relevance to the patient. The panel members that assess the projects are randomly assigned, which means they do not necessarily have affinity with the topics of the projects. Each panel member assess the projects individually on paper before they evaluated the projects together as a panel.

The appraisal is based on three aspects embedded in questions: 'is the research relevant from the perspective of the patient group concerned?', 'is the research feasible from the perspective of the patients?', and 'are there patient advocates involved in the design and execution of the research?'. In addition, examples are given with each question for the panel members to know what they should assess. The panel members need to assess all aspects, and grade the aspects collectively 'insufficient', 'mediocre', 'sufficient', 'good' or 'excellent. Subsequently, the panel members are asked to provide an explanation for their grading. After grading the three aspects, panel members are asked to give recommendations to improve from the patient perspective.

The appraisal is forwarded to the programme committees of ZonMw, who decides which projects go to the next round. Here, an extended research proposal is assessed again by the panel. This time, however the appraisal is more extensive as well. Here, panel members are also asked to assess relevance also on whether the results of the research show relevance to patients. Besides, feasibility and patient involvement are addressed under 'design', and panel members are also asked to assess whether the patient advocates involved are being facilitated sufficiently, and whether the research includes proper communication to patients about the research results. Additionally, they are asked to assess the patient information letter when this is present. This time, each question needs to be answered with 'yes' or 'no', and an explanation is asked, before panel members are asked to grade the three aspects 'relevance', 'feasibility', and 'involvement'. Finally, panel members are again asked to give recommendations for improvements.

In addition to the appraisal of the panel, the research proposal is assessed by external reviewers (ZonMw, 2020). These reviewers evaluate the scientific quality of the projects. This appraisal and the evaluation of the panel (rebuttal procedure) are provided to the applicant, who gets the opportunity to respond to the appraisal of the reviewers and the panel. Based on the rebuttal, the evaluations from the panel and the reviewers, and the proposal, the committee of ZonMw makes a final appraisal on the grant application. Besides, the committee determines the priority based on societal relevance and scientific quality, and gives a recommendation to the board of ZonMw. In the end, this board makes the decision for approval or rejection of the research project.

3. Theoretical background

In this chapter, the theoretical background of the research is presented. First, information is provided on the concept of knowledge. Besides, more in-depth information is provided on one recognized type of knowledge: experiential knowledge. In addition, the process of knowledge co-creation is described, including more in-depth information on the different aspects.

3.1 The concept of knowledge

The term knowledge refers to a persons' cognitive contact with reality, in which the person is directly or indirectly related to reality (Zagzebski, 2017). Knowledge can be described by the use of the word 'to know', which include having a special form of competence, be acquainted with something or someone, and recognize something as true (Lehrer, 2018). The word 'to know' means that information is recognized as the correct sense of the word. In order to know the way to a certain place, you must have the correct information on the place. Knowledge can then be described as having the correct information (Lehrer, 2018).

In general, there are two types of knowledge: explicit knowledge and tacit knowledge (Semeon & Garfield, 2019). The main difference between these types of knowledge lies in the possibility to transfer the knowledge (Blume, 2017; Semeon & Garfield, 2019). Explicit knowledge is knowledge that is formalized and codified, which makes it easy to define and to transfer (Semeon & Garfield, 2019). On the contrary, tacit knowledge is largely based on experience, and is context dependent (Semeon & Garfield, 2019). It is considered to be implicit, as people are unaware that they gained it and possess it. As a consequence, it is very hard to define this type of knowledge, and therefore not equipped for transfer.

In the field of patient involvement, however, three types of knowledge are recognized: scientific knowledge, expert knowledge, and experiential knowledge (Pittens, 2013). Here, scientific and expert knowledge are considered explicit knowledge, and experiential knowledge is considered tacit knowledge. Scientific knowledge focusses on objectivity and facts that are obtained through study and observation. Expert knowledge represents scientific knowledge in practice (Pols, 2014), which requires skills and capacities acquainted through training and practice (Schipper, 2012). On the contrary, experiential knowledge is based on experiences, and enables a person to cope with his or her condition after gaining insights based on these experiences (Caron-Flinterman et al., 2005).

3.1.1 Experiential knowledge

In the last decades, experiential knowledge has become more acknowledged, and it is more adopted in scientific research in addition to scientific and expert knowledge (Dornan, 1990; Charlton, 2000; Regeer & Bunders, 2009; Videmšek, 2017; PCORI, 2019). Experiential knowledge

was considered invalid in the past, as it would lack objectivity, verifiability, universality, and rationality (Caron-Flinterman, 2005). It was argued that this knowledge had nothing to contribute to scientific research, as experience with health care does not make a patient an expert in health and clinical research (Pittens, 2013). However, more recently it has been argued that patients' experiences could add value to scientific research nevertheless, through its practical value (Caron-Flinterman, 2005; Pittens, 2013; Blume, 2017; Chugh, 2018). It is therefore that patients are becoming more involved in health research in present-day (Gustavsson, 2016; Elberse et al., 2017; Maccarthy, Guerin, Wilson & Dorris, 2019).

In health research, patients has been distinguished into three different types: lay patients, patient representatives, and professional patient representatives (Pittens, 2013). Each type makes use of experiential knowledge in a different way. Lay patients are able to share their own values and perspectives, and are not familiar with those of other patients, or professionals (Caron-Flinterman, 2005; Pittens 2013). When lay patient become able to share values and perspectives more generally instead of personally, they can become patient representatives (Caron-Flinterman, 2005; Deth et al., 2012). Patient representatives are often part of patient organizations, where they are consulted for their expertise. By sharing and speaking on behalf of others at the policy levels, patient representative can become professional patient representatives.

As stated by Caron-Flinterman (2005), patients' "implicit, lived experiences with their bodies and their illnesses as well as with care and cure" provides patients with "personal insights that enables a patient to cope with individual illness and disability". These insights gives rise to experiential knowledge, which is not transferrable as it is tacit knowledge (Caron-Flinterman, 2005; Deth et al., 2012). To make use of this tacit knowledge to improve research, it has to be made explicit by translating it into explicit demands, ideas, or judgments (Chugh, 2018). Transferrable knowledge makes it possible to develop new knowledge, which could aid to improvements in health research (Tell, Berggren, Brusoni & van de Ven, 2017).

The transfer of experiential knowledge can happen at four different levels: micro, meso, macro, and meta (Tambuyzer et al., 2014, Castro et al., 2018). The micro level comprises of direct care, by using it though interaction to offer emotional, social, or practical support (Tambuyzer et al., 2014). The meso level includes application at the organizational level. Here is can be used to improve health care quality. At the macro level, the use of experiential knowledge can become of aid in health care, and health care policy, by addressing patients' needs and consequently, tailoring treatments and strategies. The highest level, the meta level, comprises of all the other levels as research and education.

3.2 Knowledge co-production

The involvement of different stakeholders in science, for instance patients, can lead to development of new knowledge; a process called knowledge co-production (Pittens, 2013; van der Hel, 2016; Palmer et al., 2018). The term knowledge co-production was originally coined to account for the relationship between science, technology and society (van der Hel, 2016). Knowledge co-production can be presented as a way to enhance science' accountability to society, to ensure implementation of scientific knowledge, and to include the knowledge, perspectives and experiences of other stakeholders into science (van der Hel, 2016; Palmer et al., 2018). As these tacit experiences and insights are not equipped for transfer, this knowledge has to be translated into explicit knowledge (Caron-Flinterman et al., 2006; Chugh, 2018) This translation makes it possible to integrate patients' experiential knowledge in health research, and eventually co-produce knowledge to improve health research (Blume, 2017; Elberse et al., 2017; Tell et al., 2017).

The conversion of tacit knowledge into explicit knowledge is the first of three steps in the process of knowledge co-production: 1) articulation, 2) integration, and 3) embedding (Pittens, 2013). As mentioned earlier, knowledge articulation is necessary for experiential knowledge to be transferred and put into practice (Caron-Flinterman et al., 2006; Blume, 2017; Elberse et al., 2017; Chugh, 2018). In health research, this knowledge is put into practice in dialogue together with scientific knowledge, resulting in 'socially robust knowledge'. This sharing of different perspectives is called knowledge integration, the second step in the process of co-production (Pittens, 2013; Tell et al., 2017; Chugh, 2018). The third step, knowledge embedding comprises of the acceptation and operation of this reliable knowledge (Pittens, 2013). The end result of knowledge co-production is a communicative process and generation of knowledge (Regeer, 2009), which could aid to development of health research and care improvements when applied in this field (Tell et al., 2017).

During grant appraisal, the process of knowledge co-production is important. Panel members generate demands, ideas, or judgments based on their lived experiences. These aspects are brought together with the scientific knowledge of researchers, who often do not possess experiential knowledge of a patient (ZonMw, 2020). The appraisal of research projects aids to produce more feasible and relevant research to patients when it is embedded in the research. The integration of experiential knowledge could then result in more tailored health research (Mason et al., 2020, ZonMw, 2020).

3.2.1 Knowledge articulation

As described above, the conversion of tacit knowledge into explicit knowledge is called knowledge articulation (Pittens, 2013; Semeon & Garfield, 2019). Knowledge articulation is part of

knowledge co-production (Pittens, 2013; Tell, 2018), and is necessary to produce transferrable knowledge (Elberse et al., 2017; Semeon & Garfield, 2019). A person's lived experience and personal insights are often present in people's unconsciousness and therefore not transferrable (Caron-Flinterman, 2005). Articulation results in explicit demands, ideas, or judgments, thought which experiential knowledge becomes transferrable (Chugh, 2018).

Tacit knowledge can be made explicit by means of mechanism, which includes for instance metaphors, dialogue, demonstrations, close observation, or collaborative critical thinking (Chennamaneni et al., 2011; Semeon & Garfield, 2019). In the case of articulating experiences, externalization can occur by empathizing individual's actions, and through personal reflection by giving thought to your experiences and feelings (Semeon & Garfield, 2019). This way, problems and concerns that patients encounter, as well as possible solutions for these problems and concerns, are identified and become explicit. As a consequence, patient involvement adds new knowledge to science after integration, and can then aid to improve research and health care (Gustavsson, 2016; Tell et al., 2017; Semeon & Garfield, 2019).

3.2.2 Knowledge integration

As stated before, knowledge integration refers to the process of sharing different perspectives in dialogue (Pittens, 2013; Tell et al., 2017). During dialogue in health care, experiential knowledge is brought together with scientific knowledge, resulting in 'socially robust knowledge'. This socially robust knowledge is constructed through the process of reflexive learning and through consensus building (Parker & Palmer, 2020). Reflexive learning implies that actors gain insight into other perspectives and underlying assumptions, which can lead to adjustments of their own (Abma & Broerse, 2010; Parker & Palmer, 2020). Consensus building implies that perspectives of individuals are converged and that individuals together identify a conclusion. Consensus building between patients and scientists is needed during grant appraisal to ensure that patient issues are addressed and can be embedded in health research.

3.2.3 Knowledge embedding

Knowledge embedding describes the implementation of knowledge integration, and the result of knowledge co-production (Pittens, 2013). With knowledge implementation, patients acquire a role in decision-making, and a long-term sustainable collaboration between patients, researchers and health professionals is generated. In addition, knowledge embedding could affect health research by making it more meaningful for patients when patients' experiential knowledge is used along the process (Mason et al., 2020). This also account for patient involvement during appraisal, where patients' explain their patient group's needs to scientists, and scientists adapt their research to make it match with patients' needs and make the results more meaningful to patients.

4. Conceptual framework

In this chapter, a conceptual framework is presented that will aid to formulate sub-research questions. Its application and relevance to the study will also be discussed and justified. Finally, the sub-research questions that did emerge from the framework are reported.

4.1 Framework

In this research, a study of Teunissen, Visse, de Boer, and Abma (2013) has been used to assess the added value of patient involvement during appraisal. In the study of Teunissen and colleagues (2013), an inventory of patients' issues and values was performed to identify and to structure a list of appraisal criteria for health research and quality of care by asking patients about their own experiences and on which aspects they focus in a research proposal. The list consist of six criteria: 'relevance', 'quality of life', 'quality of care', 'ethics and safety', 'information & communication', and 'involvement', which are all criteria that patients consider to be important when decisions are made on health research and quality of care. The list can be used generally in health appraisal, as the issues and values of patients are not associated with specific diseases (Teunissen et al., 2013).

4.2 Justification and application

The list with criteria can be seen as a tool to indicate which issues are mostly addressed by patients involved during appraisal, and which issues need emphasis in the appraisal and the standardized assessment form, to ensure successful articulation of experiential knowledge during the appraisal. This also aids to highlight the importance of certain issues to patients, and to sequence the criteria for what is most important to patients. The six criteria can also be regarded as embodying of experiential knowledge of patients during appraisal (Teunissen et al., 2013). The list aids as a tool to discuss the experiences that patients have that enable them to assess a research project on patient issues. Taking into account these aspects, the added value of patients in their role as a knowledgeable stakeholder during grant appraisal will become clear.

The list with appraisal criteria has been developed with the aim to support patients in appraising grant research proposals, by providing patients with a tool to articulate their experiential knowledge on relevant patient issues (Teunissen et al., 2013). By providing scientist with insights on patient issues, a more symmetric power relation between patients and scientists is established, which is essential for knowledge co-production (de Wit et al., 2011; van der Hel, 2016). When a sustainable collaboration between patients and scientists is established, it becomes more feasible that patient's experiential knowledge is successfully integrated within health research (Wildeboer, 2017). As a result, patient involvement could become more successful, and the quality of research could improve when the patients' perspective is properly included (Lord & Gale, 2014; Dent & Pahor, 2015; Gustavsson, 2016; Semeon & Garfield, 2019).

4.3 Appraisal criteria

Teunissen et al. (2013) identified six common criteria that arose from issues that concern patients: 'Relevance', 'Quality of life', 'Quality of care', 'Ethics and Safety', 'Information & Communication', and 'Involvement'. The sequence of the criteria was determined by patients, based on their preference to deal with them (Teunissen et al., 2013). The criteria are listed below and characterized with the related values and issues, of which some are related to more than one criterion. During appraisal, patients want to see these issues to be addressed properly in a research proposal to make the project meaningful and more complete.

The first criterion, 'relevance', concerns issues about inclusion, practical relevance, and the theme choice in research (Teunissen et al., 2013). Patients consider a research to be relevant, when it is expected to be of practical importance by attributing to effective health improvements, mostly for society as a whole, and thus when inclusion if being adressed (Teunissen et al., 2013; Staley & Doherty, 2016). Here, including means that the research is meaningful to all patients, regardless of their gender, age, education, life-style, skills, or culture of instance, or that it aims to be useful for as many patient groups as possible (Teunissen et al., 2013; Rozmovits, Mai, Chambers & Chan, 2018). In addition, it is important to patients that the theme of the research aligns with their patient groups' needs. For instance, research on the cause of an illness can be less important to patients when they would rather see a cure for the itch that comes along with the illness.

'Quality of life' relates to patients' independence, their social participation in life, their quality of life, and respect to their basic values and needs (Teunissen et al., 2013). Examples of these values and needs are: recognition, trust, vulnerability, privacy, support, self-care, and access to facilities and medication (Teunissen et al., 2013). Patients want that the research contributes to improvement of patients' physical, mental, and social quality of life. In addition, practical relevance to patients is also important to patients, where the research results should attribute to effective health improvements, or improvements of care (Teunissen et al., 2013; Staley & Doherty, 2016).

'Quality of care' relates again to the inclusion of patients, which is also an issue related to the criterion 'relevance' (Teunissen et al., 2013). Additionally, 'quality of care' relates to issues on care environment. Patients want to see that a research contributes to improvement of care, and that it reflects perception of a diverse group of patients. In addition, it is important for patient that the research contributes to care improvements that aid for mental support, and for good social interactions with family and friends. Besides, a research should contribute to a more quick and adequate diagnosis according to the patients (Teunisse et al., 2011).

The fourth criterion, 'ethics and safety' relates to issues regarding protection of patients against harm and damage, to freedom of choice, and to respect for fundamental needs (Teunissen et al., 2013). Additionally, proper medical care, dignity, social security, fear and pain avoidance,

compensation of costs, and respect to patients values are among related issues that should be considered in a research (Teunissen et al., 2013; Dagron et al., 2020). For patients, it is important that their social status does not become at stake, and that they feel respected. For this, it is necessary that fear and pain are being avoided at all times as well during participation of trials and by receiving medical care, which is also considered to be a human right (Dagron et al., 2020). It is important to patients that a research is conform regulations, codes, and laws, and that the efforts of patient participation is acceptable and least of a burden to patients.

The criterion 'information and communication' relates to issues about provision of information in a correct, complete, and informed consent way (Teunissen et al., 2013). Patients that participate in clinical trials should be made aware of potential risks of participation, and the results of performed procedures should be shared with patients to make them feel respected according to patients. Furthermore, this criterion relates to issues regarding contact with caretakers, in which attitude, empathy, and language use are of importance (Teunissen et al., 2013; Schoenthaler, Knafl, Fiscella & Ogedegbe, 2017). These aspects all aid to create a feeling of respect towards patients, which makes them feel empowered as well (Esmail, Moore & Rein, 2015). Besides, it aids to create clarity for patients when the caretakers talk to them with appropriate language.

The sixth and last criterion describes the precondition 'involvement' of patient advocates throughout the research (Teunissen et al., 2013). Here, patients want that a research makes use of the experiential knowledge of patients by involving them in different phases throughout the research and by consulting them for their perceptions. The issues that relate to this criterion regard equivalency, education, independent voice, advocacy, right to say, empowerment, conditions for patient representation, and a knowledgeable (Teunissen et al., 2013; Esmail, Moore & Rein, 2015). Furthermore, recognition, patients being informed, and theme choice in research are issues that relate to this criterion in addition to other criteria (Teunissen et al., 2013). While being involved, patients believe that the patient advocates need to be equal to scientists, are given a feeling of empowered, and that they have a right to say, independently of experts (Esmail, Moore & Rein, 2015). Finally, patients think it is important that the values and needs of the patient group have been inventoried for the project.

4.4 Research questions

The objective of this research is to assess the added value of patients in their role as a knowledgeable stakeholder during grant appraisal by assessing the use of experiential knowledge by patients during these appraisals. Following this objective, and the framework, the next sub-questions arose:

1. What experiential knowledge do panel member have and how do they used this knowledge during appraisal?
2. What criteria are appraised by panel members of Netherlands Patients Federation during grant appraisal?
3. What criteria matter most to panel members of Netherlands Patients Federation and why do they matter most?

In addition, ZonMw and Netherlands Patients Federation would like to learn how to improve the current appraisal forms, which has leaded to the following sub-question:

4. What attitudes do panel members have towards the current assessment forms and towards the use of these forms during appraisal?

5. Methodology

In this chapter, the methods of this research are described. First, the scientific approach is discussed, followed by methods. In addition, the research population, and the recruitment of the research population are discussed. Subsequently, the data collection approach is presented, as well as the approach for data analysis.. Finally, the ethical concerns discussed.

5.1 Approach

The strategy to collect data in this research was via a qualitative research approach, which include interviews with a small group of respondents (Gray, 2013). These interview have given access to in-depth information about patients' needs, preferences, ideas or opinions, and patients experiences. Moreover, a qualitative research design is flexible, and the design has been accustomed easily to the context of the research. Finally, the approach has provided understanding of complex problems as multiple perspectives were obtained (Gray, 2013).

5.2 Research population

To gain insights in the experiential expertise of Netherlands Patients Federation's panel members, interviews were carried out among panel members who have participated in the appraisal of research projects. All panel members are (former) patients (74%), relatives of patients (6%), or caregivers (20%), and are therefore considered to have experiential knowledge in health care (Netherlands Patient Federation, 2020).

Amongst the panel members, 72% is female, and only 28% is male (Netherlands Patient Federation, 2020). The age of panel members ranges from 21-75 years, where approximately 50% of the panel members is 60 years or older, and only 3% is younger than 25. In addition, about half of the panel members is acquainted with scientific methods as a result of their education, whereas the other half is not scientifically educated.

Most of the panel members have been carrying out appraisals for 2-5 years (41%), although many panel member have been doing this for more than 5 years (37%) in contrast to 22% of the members who are relatively new to the panel (<2 years of experience)(Netherlands Patient Federation, 2020). Besides, about 55% of the panel members is, or has been, a member of a patient organization.

5.2.1 Recruitment

Respondents were approached via an email that was sent to them through Netherlands Patients Federation. The approach of respondents through Netherlands Patients Federation aimed to crease security and comfort, which could facilitate participation. Respondents are selected based

on their gender, age, and medical condition to ensure diversity amongst respondents. This diversity is needed to ensure representation of as many patient groups possible.

In the email was described what the aim of the research was, what the content of the interviews was, what was expected from the respondents in advance and during the interview, in what time period the interviews should take place, and how the data would be administered. The email also contained contact details of the researcher to plan an interview and ask for further questions. It was emphasized in the email that the data collected would be handled with discretion and that the respondents would remain anonymously, although the data would be accessible for everyone who would want access. All respondents had to agree upon these conditions before interviewing.

5.3 Data collection

5.3.1 Interview design

The interview-design of this research was semi-structured and in Dutch as all respondents were Dutch. Via interviews, patients' lived experiences with health care practice were being uncovered and underlying values of respondents were unraveled. This was firstly done by asking respondents about their illness or disease, or their relation to health care in different ways, and their prognoses regarding this. These anecdotes did provide insight in the first experiences of respondents with health care, and how respondents do make use of their experiential knowledge during appraisal.

Secondly, respondents were asked for their reasons to join the panel of Netherlands Patients Federation, to introduce the topic of patient issues. Besides, respondents were asked for their perception on their added value by asking if they feel heard as a panel member. In addition, respondents were asked about their perception on the current approach of appraisal and about their experiences of working together for instance. This did provide ZonMw and Netherlands Patients Federation with insights in respondents perceptions on the current approach.

Finally, respondents were asked to describe what a proper research proposal would resemble in their opinion, to gain insights in the patient issues that matter to respondents. Respondents were asked for arguments and examples that demonstrate why certain criteria are important to them, which in turn displayed issues that matter to the panel members and respondents lived experiences with health care practice. Furthermore, patients were asked how they believed their lived experiences would aid to their appraisal.

Overall, the interview guide did aim for respondents to mention issues and values that regard them personally and that regard patients in general. Besides, it aimed for respondents to express their feelings on their added value, and it aimed to obtain insight on the use of experiences in the appraisal.

5.3.2 Justification of interview design

The purpose of a semi-structured guide format was to direct the conversation according to a number of preplanned topics, but also to allow for probing if it was desirable for the respondents to elaborate on their answers (Gray, 2013). The respondents were given the freedom to supply additional information, including any relevant topics which were not anticipated during the interview (Gray, 2013). A set of example questions had been added to each topic within the interview guide and could have been called upon at the discretion of the interviewer.

A semi-structured guide format did ensure topics to be uniformly discussed throughout all interviews (Verschuren & Doornewaard, 2014). In addition, reliability was increased as the topic list helps to prepare for the interviews assuring that the interview covers all aspects that are relevant for the study. A topic list did allow for flexibility as well, in contrast to a predetermined list of questions. However, example questions were written down to prevent the conversation to be interrupted.

In addition, a semi-structured guide format did allow for a two-way communication (Verschuren & Doornewaard, 2014). This two-way communication did contribute to get new insights in addition to the confirmation of hypotheses. Instead of putting the focus on the answers, the underlying reasons for answers had been disclosed. In this study it was important to get these insights as experiential knowledge might not always have been articulated yet by panel members.

Finally, a semi-structured guide format did allow for personalized questions. The opportunity of personalizing questions was crucial in this study, since this study aimed to get insight in personal experiences that differ among the research population. A topic list did ensure that all aspects are covered, but also allowed for individual application.

5.3.3 Procedures

All thirteen interviews were executed via telephone or via Skype/Hangouts by the same interviewer in the period of April 6 2020 until May 8 2020, and lasted for about 30 minutes. All interviews did start with small talk to get to know each other and to provide participants comfort and a feeling of trust, which was important considering the personal nature of the interviews.

After this short personal introduction, the information that was sent via email was again discussed with respondents to make sure all relevant information did reach the respondents. In addition, informed consent for tape-recording was requested from the interviewee. If informed consent was granted, the interview was tape-recorded and transcribed for further data-analysis. After transcribing the interviews, the tape recordings were deleted. Anonymity and discretion of personal details and the data was ensured by the interviewer throughout the research.

5.4 Data analysis

The data gathered in this study was analyzed using a theoretical thematic analysis. The purpose of thematic analysis was to identify, analyse and interpret patterns of meaning (Gray, 2013). The theoretical aspect in this method was the use of a codebook that had been developed based on the data and the conceptual framework used in this research. In order to retrieve as much information as possible, both deductive and inductive coding strategies were applied to avert the possibility to miss valuable information, if concepts were not covered by conceptual framework. Finally, the data was analyzed with the aid of qualitative analysis software ATLAS.ti 8.4.

The analysis consisted of six steps: 1) familiarization, 2) generating initial codes, 3) generating themes, 4) reviewing themes, 5) defining and naming themes, and 6) produce the report (Castleberry & Nolen, 2018). Firstly, the audio files were transcribed, and the transcripts were read thoroughly to get familiar with the data. Secondly, a codebook was generated based on the data and the conceptual framework, and the data was coded. Thirdly, the codes were grouped in themes to gain insight in the data. In the fourth step, the themes were reviewed, and alterations were made if needed. In the fifth step, the themes were defined and named. Finally, the data related to the labels was placed into the context of the conceptual framework, which has been reported in the result section and discussed of this report.

5.5 Validity and reliability

The objectivity and credibility of the obtained data was assured by validation and reliability (Gray, 2013). Validation of data refers to the extend the findings can be generalized to other social settings; reliability refers to the extent the data can be replicated (Verschuren & Doorewaard, 2014). Validation and reliability was assured by following systematic procedures during the analysis of these interviews and all interviews were carried out and analyzed by the same interviewer. Besides, usage of a coding guide did allow for standardization of analysis. In addition, a member check had been done by sending a summary of the findings to the participants for verification, to avoid oversimplifications or misunderstandings and to increase validity and credibility.

5.6 Ethical considerations

According to Gray (2013), there are several ethical issues that must be accounted for during research. During data collection, potential harm for respondents was minimised. In addition, it was made clear that there would be no repercussions for refusal of participation before or after the interview. All participants did voluntarily take part in the research and were informed and well prepared before the interviews to avoid ethical dilemmas regarding informed consent and risk assessment. For this, the participant was asked to give informed consent on tape (*see*

Appendix B). On short notice of the interview, the informed consent form was sent to the participants in advance.

Privacy was ensured to all participants by making note that personal details would not be published or become accessible for anyone, with exception of the interviewer. Confidentiality was thereby also ensured to participants. However, data should be open to anyone who wants to have access (Vrije Universiteit Amsterdam, 2020), although the researcher maintains ownership of the data until further notice. Regardless of open access of data, data has been handled with discretion.

6. Results

This chapter shows the findings of this study. Firstly, an overview of the research population and respondents is given. Subsequently, a comprehensive description is given on the results that are found. Each subheading is based on the sub questions mentioned chapter 4.

6.1 Research population

In total, thirteen interviews were conducted with respondents who had been selected to ensure diversity. The interviews had a range of duration between 24 and 57 minutes, with 35 minutes on average. Table 1 shows an overview of the respondents, and their experience solely. To secure anonymity, information on gender or age is not provided in the table.

Amongst the respondents 31% was male and 69% was female, with their age ranging from 21 to 63 years. Respondents had mostly been active as a panel member for years, although some respondents were relatively new members (less than two years). 11 out of 13 respondents were patients, two were caregiver. Amongst patients, 91% had a chronical disease, from which about 73% did have a physical disease, whereas 27% did have a developmental disorder. One respondent did have an acute disease.

Table 1. An overview of respondents and their experience with health care.

Respondent	Experience
Respondent 1	Multiple conditions
Respondent 2	Caregiver
Respondent 3	Multiple conditions
Respondent 4	Physical impairment
Respondent 5	Stroke
Respondent 6	Chronic fatigue syndrome
Respondent 7	Hormonal disorder
Respondent 8	Caregiver
Respondent 9	Physical impairment
Respondent 10	Autism spectrum disorder
Respondent 11	Diabetic
Respondent 12	Autism spectrum disorder
Respondent 13	Cancer

6.2 Experiences

The majority of the respondents explains that their overall experience of being a patient is most important during appraisal. As stated by respondent 4:

> *"Being a patient often means being made an outsider." (respondent 4)*

This experience is acknowledge by other respondents as well; these respondents mention that the general experiences of being a patient aids for them to empathize with other patients. The experience makes it possible for them to look through the eyes of patients with different conditions from theirs. As a consequence of this experience, patients are able to imagine how a patient would feel under the circumstances that are mentioned in research proposals, such a being part of a randomized control group instead of the treatment group. One respondent recalls:

> *"When we are doing the appraisal, we do not always presume what the researchers say for truth. It is true that you will be included in one group or the other [during a clinical trial], but I can imagine you would rather be part of that one group [the treatment group], than the other [the control group]." (respondent 7)*

Another respondents recalls:

> *"Initially, you think about the consequences of the research when it results in something beneficial. You imagine the happiness of patients. The more patients are happy with the results, the more relevant the research becomes." (respondent 1)*

Respondents acknowledge that this overall experience is mostly important during appraisal, as they believe that their individual experiences could only help them in specific cases, where the research concerns their personal medical condition. In addition, they stress that they have to take some distancing from their own experiences now and then, and by doing this, they create a more general point of view, instead of a personal one. Respondent 2 explains:

> *"When it concerns the panel members, I think it is important that people do not solely think from their own experiences, but that they are also able to think more abstractly and be critical." (respondent 2)*

This objective point of view gives them the feeling that they are able to represent the patient population more correctly, and not focusing on their own, personal desires that do not relate to their illness or disease. Looking at proposal from a more objective point of view, also allows patients to look at proposals with multiple points of views. Panel members believe that being a patient solely, and having experience, is not sufficient to attribute to health research: panel members should be able to empathize with others, and be able to think critically, and step aside from their personal circumstances.

Some respondents mention that they believe it is important for panel member to not only be able to speak on behalf of others, but also to be able to critically reflect on proposals and to be able to thoroughly read scientific papers to give recommendations adequately, they need to be capable of understanding science. Respondents have explained that being able to think at this level together, makes it easier for them to work together on their recommendations.

Respondents also mention that sharing individual experiences with other panel members during the appraisal is nevertheless important, as it provides them with more specific insights. In addition, it helps them to create a personal opinion about the matter when they have trouble doing so.

"Sometimes I do not know how to look at it [the proposal]. While talking with the other panel members [during appraisal], you can help each other to look at things in a certain way, by sharing your knowledge on or experiences with the matter. You do not have experience with everything, but with the three of you, you can make it." (respondent 7)

Nevertheless, individual experiences are also used during appraisal. Most respondents reflect on situations by imagining how they would feel under the circumstance taking into consideration their own ordeals. This is illustrated by a quote of respondent 5:

"People were discussing epidurals after a stroke, and they could not imagine how this would be an issue for patients. I started thinking about my own situation, almost fifteen years ago. I thought an injection for the CT scan was already incredibly thrilling and troublesome. How could they think it would not be an issue for patients, three days after having a stroke?" (respondent 5)

Respondent 9 also made the following statement about how personal experience is of aid during appraisal:

> *"Sometimes, you know from your own experiences that the targeted patient group is not able to deal with the burden. A researcher does not always know what the impact of the clinical trial is on the patients, while the burden can be very heavy." (respondent 9)*

Nonetheless, some of the respondents had felt that their experiential knowledge had not been recognized in the past. Mostly, this did concern the diagnosis or treatment of their illness or disease, which had not always been an easy road for the respondents. One of the respondents specifically mentions they felt that doctors considered patient to have no knowledge about medicines and their use.

> *"My whole life, I have the feeling that doctors think that patients cannot treat themselves. They are unable to assess a situation, and to take action adequately. Therefore, they need us." (respondent 1)*

However, the patient recall to have enough experiences with the use of the medicine and was confident enough to use it without any professional help. In fact, the respondent mentions that twenty years later, his way of using the medicine, was recognized to be indeed a way to treat the disease. Despite this, the respondent mentions that it has created scepticism towards doctors' knowledge in practice, which provided them with the insight that scientists only work with what they have, and that they do need the patient perspective in practice.

6.3 Attitude

Many respondents have mentioned that they would like to have more interaction with the researchers, and have direct conversations with them. They believe that this would improve the integration of their experiential knowledge.

> *"We do not have direct contact with researchers, and I think that is okay. On the contrary, we are trying to communicate with researchers [by doing the appraisal], and I believe that it would be worth it to have contact with researchers now and then." (respondent 4)*

However, these respondents did acknowledge that this would take much more time than the current assessment, which is mostly not feasible for them. Besides, respondents feel that the current assessment through forms and written recommendations is sufficient enough to provide scientists with the required information and patient perspective.

In addition, respondents do not see the need of adjusting the forms by expanding the questions on the form, or by adding new questions. Again, they believe that this would only take up more time, which would result in less thorough assessment. Besides, the respondents believe that the patient issues are being addressed properly and completely with the current forms and the current questions. This way, asking panel members to assess less projects while making the assessment forms more extensive, would not improve the quality of the appraisal.

Regardless, respondents do see the added value of having contact with researchers once in a while. Besides, some respondents think that it would be better if the assessment forms are directed send to the researchers, which does not happen according to their observations:

"I would rather have the forms being send to the researchers as a whole. Now, I do not see that happening. Based on the reactions they give, you can see that they are not provided with the everything comment we have written for them." (respondent 1)

This opinion shows that panel members are not familiar with the way their appraisal is processed, and that they want to get more insight on this.

During the appraisal of research projects, the different forms that are being used by panel members appear overall to be of value with regard to patient issues. The respondents of this research acknowledge the usefulness of the different forms used during appraisal to account for all aspects that need to be addressed to make the projects most meaningful and complete. One of the respondents mentioned, however, that the forms standardization of the forms is not always helpful.

"Sometimes, a new subject arises from the research. On the standardized from there is no room to address these subjects. Besides, there is too much steering, and then you can't go in depth on the matter." (respondent 2)

The design of the forms is overall fine according to respondents, as they are equipped in a way that explanations can be given properly. However, the extended form appears to be a bit more complicated, and the grading system is not suitable according to respondents. There are seven

questions that need to be answered, however, grading is done on two aspects that each include multiple of these questions. For instance, design needs to be graded collectively based on four questions, so an average is given, which might give the wrong idea to the researcher. Besides, this detailed assessment feels like repetition to some respondents.

"It was much more detailed (and it does not add that much), which makes it even more complicated for us as we have to give an explanation for all answers again and again. I am glad already if I am able to say why patient involvement is accurate or not." (respondent 8)

"Sometimes, there is too much repetition. Why do we need to give an argumentation again after only two questions?" (respondent 6)

Another respondents explains:

"I would rather have less questions to answer, to make it much more workable. Especially when we have not been able to prepare properly due to time management." (respondent 13)

Nonetheless, some respondents preferred the extended form as it requests less grading and focusses more on the clarification for their recommendations.

The grading for relevance also appeared to be unsuitable to respondents, as they would rather grade studies relatively to each other with regard to relevance. Especially as grading relevance is not easy because almost every study is relevant for the group of patients that it accounts for.

"The grading is very weird, as one [option] is negative, and the others are positive." (respondent 6)

"'How relevant is this research?', it always is. It is only relative. A researcher wouldn't write a proposal on something irrelevant. (…) You could make a distinction between thing that are more relevant than others, by assigning a certain 'weight' to all aspects. That way, you could

see which aspects [have the most weight and] are the most relevant." (respondent 1)

Two of the respondents mention that one criterion is missing among appraisal: "inclusion". This inclusion concerns the diversity amongst participants in studies, something that is often not described well in the research proposals. Respondents feel that this aspect deserves to have its own criteria, as they believe that it is important that all people are represented in the studies. In the current forms, they feel this aspect does not receive as much attention as it should. Besides, panel members explain that they often see that inclusion is not done properly, and patients that are included in research are not always the right ones.

"Often, you see that patients that participate in trials are very actively [in an organization for instance], and mostly educated people. This is, of course, not very representative for the average Dutch person" (respondent 11).

Despite this criticism, respondents stated that the forms did provide the possibility for clarification , and aid to structure the appraisal, which was often satisfactory to panel members. With the use of the form, panel members believe that they are able to address all relevant issues, and are able to provide clear recommendations that will help researchers to improve their researchers to make it more meaningful to patients, and more complete. Overall, panel members appeared to be positive about the use of the form, although the design of the four could use some attention.

Furthermore, some respondents did mention that they had the feeling that they were taken more seriously with time by scientists. They have seen that their recommendations were received by scientists, as they saw during the second appraisal round on extended research proposals that alterations were made based on their recommendations. This gives them a positive feeling of empowerment, and this enhanced their willingness to keep participating in appraisal.

6.4 Criteria

During appraisal three criteria being assessed by using an assessment form: relevance, feasibility, and patient involvement. However, while talking to the respondents, it became clear that these three criteria together include patient issues that are related to all six criteria mentioned by Teunissen et al. (2013): relevance, quality of life, quality of care, ethics and safety, information and

communication, and involvement. By using the standardized assessment form, panel member should be able to address all patient issues that do concern them.

In the next few sections, each criterion mentioned by Teunissen et al. (2013) will be addressed individually in sections. Issues that were mentioned by respondents will be discussed in the section of its related criteria, and the underlying values will be addressed as well. This will give an overview of all the issues that are addressed during appraisal, and which ones are not and need more emphasis to ensure successful articulation of experiential knowledge during the appraisal.

6.4.1 Relevance

During assessment, respondents reported to look at two things that concern the criterion 'relevance': practical relevance and inclusion. Respondents think that a research becomes more relevant when it is of practical relevance, which means that it would attribute to effective health improvements. The attribution to effective health improvements of a research has been considered important by respondents multiple times. The underlying value of this is that patients would like to see development new medicines or treatments that would aid to live the best life possible, also by creating independency for patients.

> *"You mostly think about the fact that your disease is not lethal, but chronic, and you will not get better. In that case, you want your life, with the disease, to be as easy as possible." (respondent 1)*

Besides, a research was considered relevant when inclusion of participants would be addressed. Here patients value that the implications of a research could be beneficial for as many different patient groups possible, and when it is useful for all patients, regardless of their gender, age, education, culture, or skills for instance. Only two out of thirteen respondents mention this inclusion to be important for consideration. One of the respondents mentioned that they were missing a subheading on the appraisal form. They considered inclusion to be as important as practical relevance, and think that it would need individual attention on the assessment forms.

The majority of respondents acknowledge practical relevance of research projects to be of great importance. One of the respondents noted, however, that the assessment of this is difficult: panel members are not always familiar with the progress on certain medicines or treatments when it regards another disease or illness than their own. This way, they feel that they do not possess the knowledge to assess the relevance of studies about these medicines and treatments.

The respondent explained that in this case, the panel members would advise the researcher to adjust their proposal by giving a clear overview of the progress concerning the treatment.

"Sometimes I think that a research has a good theme, and I think it is very relevant. (…) But it is very hard to assess when you do not know the progress on a certain disease, maybe the knowledge is there already at another university for instance. That way, the research might not be that relevant." (respondent 8)

6.4.2 Quality of life

During assessment, respondents reported to look at three things that concern the criterion 'quality of life': respect to their basic values and needs, social participation, and independence.

Respect to their basic values and needs has mostly been mentioned by respondents. Although none of the respondents did specifically mention trust to be assessed, some did mention indirectly that is was important. They believe that trust is the foundation for good appraisal. As panel members, they have to believe what a researcher writes, and they believe that the researcher will live up to their promises during the execution of the research. This shows that panel member do consider this issue, yet it also shows that many respondents take it for granted.

According to respondents, the most important aspect of a research are the benefits of the research for patients. Respondents do assess a research often firstly based on this: will the results be meaningful to patient, will it make them happy. Respondents did assess this aspects on the question about relevance, where respondents felt a study to be useful only when patients could gain directly from the study when it had been successfully finished.

"As a patient, you are constantly busy with thinking about new developments that could improve the quality of your life." (respondent 1)

In addition, respondents mentioned that they think it is important that a research does show how the research aids to patients independence. They believe that patients would prefer a new treatment or disease that would increase their self-care. Respondents mentioned that they believe participation in society to be important as well, regardless of the disease or illness, and believe that a research should show prospect on that as well.

Many respondents think that privacy is one aspect of least concern. They believe that it is irrelevant, when you look at the benefits of violating privacy. However, some respondents are able to imagine situations where it would be preferred to respects patients privacy, and therefore they

do assess a research on whether it shows respects for patients' privacy, regardless of their own opinion.

6.4.3 Quality of care

During assessment, respondents reported to look at two things that concern the criterion 'quality of care': inclusion, support, independent voice, and care environment. Inclusion has already been mention in the first subheading, relevance, and will not be explained further. In addition to the issue inclusion, one of the respondents did mention the issue support. This respondent stated that the need for support by friends and family, for them personally, was not amongst concerns.

> *"Personally, I do not want any support of family and friends. This has to do with the way I was raised: I want to be able to take care of myself."(respondent 1)*

Nevertheless, the respondent explains that they do understand that other people might want support while receiving care, and therefore do assess on this aspect.

Besides, respondents did mention that it is important to them, that patient could have an independent voice. They state that a proper research should contribute to increasing this voice, by giving patients options for treatments and medicines. Respondents therefore do assess on this matter as well, as they do think it is important that patients can receive the care they want.

Finally, respondents do think that relevant researches do need to show prospects on improvements in care and the care-environment. This also relates to making it more easy to treat patients, and by creating treatments that are less of a burden to patients. These aspects are considered by respondents when they do assess the relevance of a research.

6.4.4 Ethics and safety

During assessment, respondents reported to look at things that concern the criterion 'ethics and safety': inclusion, compensation of costs, fear and pain avoidance, privacy, and informed consent. Inclusion is again one of the issues that relate to the criteria that is discussed in this section. It is not discussed any further here.

Some of the respondents think that covering the expenses of participants is important for participants to feel taken seriously. This feeling could increase the motivation of patients to participant, and to keep participating in studies that are time consuming. One respondent mentions that it is also important for a researcher to show that they have thought about the losing interest of patients to keep participating.

In turn, avoidance of fear and pain for patients, something that could hamper the executing of the research had been considered by respondents during appraisal. Respondents did mention that a research would be considered feasible when there were no unnecessary strains for patients, and when it does show that they have chosen for the least objectionable way to execute the trail. In addition, a reimbursement for patients, and patients' values being respected were amongst issues mentioned by respondents that they do assess. These aspects would aid to increase motivation of participants, something that was considered fundamental for long-term studies. In addition, respondents mention that living up to made promises makes them feel respected. Respondent 3, stated:

"Participation regards your own body. You have provided researchers with personal information, and I do not want gifts, but I do want them to provide me with information if they did promise me to do that. It makes you feel taken seriously." (respondent 3)

Further, several respondents stated that the aspect 'privacy' was of little importance. One respondent mentions that privacy will be guaranteed and never be used against participants; the benefits are greater than the drawbacks. Another respondent acknowledges that privacy is not amongst concerns, although it would become an issue if it is used against them. Respondent 1, stated:

"I often receive an email from the pharmacy to pick up my medicines, yet I cannot see which medicines this concerns, due to privacy concerns. Sometimes I do have a stockpile of certain medicines and I do not need new ones, now I have to go to the store to find out." (respondent 1)

Finally, one issue that is being appraised by many respondents is provision of complete and correct information. This will be discussed in detail in the next section.

6.4.5 Information and communication

During assessment, respondents reported to look at two things that concern the criterion 'information and communication': clear communication, and provision of information.

Overall, the respondents believe that good communication between patients and scientists to be important, and with that, they believe that a research should show prospect on provision of information about the benefits and risks of patient participation. The patient information letters therefore receive much criticism from the panel members when this lacks clear information.

Especially the risks and physical and mental burden of participation should be clear to patients in advance, something that is also considered to be an ethical issue.

In addition, respondents acknowledge the issue of receiving information about the results of studies patients do participate. They emphasize the importance of providing this information to participants, as they consider positive results to be the motivation for patients to participate in the first place. Besides, providing participants with the results would give them a feeling of being respected and valued. Therefore, they do assess a research on whether a research does show good prospect on this, to ensure that patient are aware of all the consequences of the research, and their participation.

6.4.6 Involvement

Respondents emphasized the importance of showing prospect of patient involvement in proposed studies. They did state that it was important for participants to gain knowledge from their involvement directly. By showing the interest of patient involvement, researchers show that they do see the added value of experiential knowledge, which would give patients a feeling of recognition:

> *"When you want patients to participate in your research, you take them seriously, and you show that the aim of your research is to create a better treatment for patients for instance, not to get your PhD." (respondent 11)*

One respondent mentions that they felt no need to make recommendations on involvement when a researcher shows no interest for it at all.

Respondents acknowledged the importance of involvement by explaining that it would aid to enrich research and make it more relevant and achievable. They also mention that the researcher personally could improve their skills as a result of patient involvement, especially regarding making their future studies more tailored to patients' needs. Respondent 13, stated:

> *R 13: "I would rather see that they argue why patient involvement cannot be accomplished yet; certain projects would score better than when they try to come up with reasons why it should be happening while saying that it is actually not possible right now." (respondent 13)*

Therefore, respondents mention patient involvement to be one of the first thing they look at. Respondents did mention that it was important for them that a research shows how they would involve patients, how they would treat them, and that do acknowledge patients as their equals.

7. Discussion

In this chapter, a reflection is given on the results of this research and a comparison with existing literature is given. Besides, the conceptual model used in this study is being reflected upon, followed by the strengths and limitations of this model. Finally, suggestions for further research are made and a sound conclusion is drawn.

7.1 Main findings

The aim of this study was to assess the added value of patients in their role as a knowledgeable stakeholder during grant appraisal by assessing the use of experiential knowledge by patients during these appraisals, which could contribute to improvements in patient involvement during grant appraisals. To assess the added value of patients' experiential knowledge during appraisal, this study used the work of Teunissen et al. (2013) as a framework. Data was gathered via semi-structured interviews to find answers to the sub questions that arose from the framework and theoretical background. The results are discussed in the sections below, which will aid to answer the sub-questions, and consequently the main research question.

7.1.1 Experiences

Patients assess projects by emphasizing and by looking through the eyes of patients with the disease or illness it regards. For empathizing with others, patients do rely on their own experiences unconsciously. The experiences of being a patient have affected their point view according to respondents, which makes it easier for them to empathize with other patients and to speak on behalf of them (Korevaar and Droës, 2011). That way, their experiences serves as a reference point for envisioning the situation of other patients, an approach that is often used by panel members of Netherlands Patients Federation.

These results align with literature on experiential knowledge, embodied knowledge, or knowledge from within (Castro et al., 2018). Experiential knowledge is knowledge from our unconsciousness, as it is learned through daily experiences. It can be put into practice, although it is very hard to describe due to its implicit characterization (Burda et al. 2016; Utschakowski 2017; Castro et al., 2018). By putting the experiences into action, it becomes a source for problem solving and support (Castro et al., 2018).

Sacristán et al. (2016) emphasized the importance of getting insights in the experiences of patients. The experiences of patients are believed to point out basic values of patients, and insights on this can help to address them. In turn, researchers can become aware of the pitfalls in their research design, and can make improvement to enhance the relevance of the research for patients.

The shows that the involvement of patients becomes of added value for research to become more meaningful to patients, and to improve.

7.1.2 Attitude

Panel members feel that they could address all patients' issues with help of the appraisal forms that are provide by Netherlands Patients Federation. They do not see the urge to make adjustments in the forms, of by setting up dialogues with researchers, as it would not enhance their appraisal. In fact, they believe that adjusting the forms, by adding statements, would only take up more time. This could result in motivation loss, and in turn, to a poorly formulated appraisal.

It has been proven that motivation relies on effort and outcome (Schunk et al., 2020). This means that whenever a person feels that the effort of acting exceeds the outcome of the action, they will lose motivation. It is therefore important that the effort op panel member will be compensated by the outcome of their actions, in this case the application of their recommendations and suggestions. In this case it means that panel members see that their experiential knowledge is integrated and embedded in science, and that the patient perspective is indeed of use to make health research more meaningful to patients when it is integrated and embedded in health research.

7.1.3 Criteria

The study showed that panel members of Netherlands Patients Federation during appraisal address patient issues that relate to six criteria: relevance, quality of life, quality of care, information and communication, and involvement. The appraisal of these criteria is in line with the framework of Teunissen et al. (2013). Panel members are capable of addressing general patients' issues, although with the help of appraisal forms provided by Netherlands Patients Federation. Patients mention that they think that 'quality of life' is most important to consider during appraisal, as they "want to live the best life possible" (respondent 13). The study of Teunissen et al. (2013) previously highlighted the importance of fundamental human values that are grouped under the criterion 'quality of life'. These fundamental human values needs to be secured, before other aspects as quality of care, and involvement can be addressed (Teunissen, 2014).

A study of Sacristán et al. (2016) also shows that the list of criteria can be applied to address patient issues in different settings. Sacristán et al. explain that patient involvement in health research can improve health care, and they name several examples that align with the abovementioned criteria. Firstly, most research projects are solely focused on basic science, and

they do not take into account specific needs of patients. Patients can help to enhance the relevance of health research by being involved in various steps. Next, it has been mentioned that patients with diabetes showed more interest for clinical trials that could enhance their quality of life. This has become clear by involving patients in the research design. In addition, it was mentioned that patients see patient involvement as a human right, and that all patients should be able to become involved, not only those who's doctor is an investigator. Besides, the study showed that patients would want to receive information about trails, including results, and about new technologies. This information can be passed along with associates, or it can help to make free, informed choices. It was also mentioned that the informed consent documents were often not clear and to the point about basic aspects, something that is also considered to be a right for patients. It is believed that when patients are aware of all the risks and benefits, their participation can aid to generate useful information for future patients in turn (Sacristán et al, 2016). This shows that by addressing patient issues according to the appraisal tool of Teunissen et al. (2013), the involvement of patients can become useful for scientists to make health research more meaningful to patients in general.

A study of Le Lain et al. (2017) showed the list of criteria to be of use in safeguarding the needs of elderly as well. Here, the appraisal tool is used for patient-centered review of documents and to create an online discussion tool. It has resulted in interactive discussions between members regarding topics like execution of the clinical study, enrolment strategies, patient information and informed consent process, ethical considerations, dissemination strategies, dedicated informative Web texts, and health technology assessment (Le Lain et al., 2017).

A study by Makkar et al. (2018) showed similar results to these of Sacristán et al. The study aimed to get insight in the perceptions of patients about the care they received. During the study, patients were asked to put things into perspective on several aspects that concern patients. Among these aspects were: information and education, coordination of care, physical comfort, emotional support, respect for patient preference, involvement of family and friends, continuity and transition, and overall impression; which are all aspects that are similar to the six criteria mentioned by Teunisse et al (2013). Patients were overall happy about their treatment, yet they want to be involved in their own treatment-related decision-making, and communication with the treatment team needed to be improved. This shows the importance of patient involvement during appraisal, as during this phase the desire to be involved and the desire for good communication could be addressed, and subsequently embedded in the research design. This could result in less negative feedback from patients, and thus patient involvement could be of added value to improve health care and make it more meaningful.

These findings show that the appraisal forms of Netherlands Patients Federation, which address all six criteria, are of practical use for patients in their appraisal, and that it is of use to

make patient involvement more workable and effective in appraisal. It shows that with these forms, patients have become aware of their patient groups' issues and can accomplish their appraisal completely and structured, which makes the appraisal effective. In the end, this could aid to more meaningful health research to patients.

7.2 Strengths and limitations

7.2.1 Strengths

An evaluation of this study shows several strengths. The first strength is the semi-structured interview guide that provided in-depth information about issues that concern respondents and issues that arose from their experiences as a patient. This in-depth information had aid to structure a list of issues that matter to panel members in general, which could not have been carried out without the insights.

In addition, a strength of this study regards the validity and reliability. These aspects have been assured in this study by following systematic procedures during the analysis of the interviews, as all interviews were analyzed by the one person and with the same codebook. The use of this codebook allows for standardization of analysis.

Furthermore, the enthusiasm of respondents could be considered a strength as well. Respondents were very fond of participating in a research on the appraisal, and the number of potential respondents did exceed the number of respondents that was aimed for. This shows that the subject of this research matters to them. Consequently, this did results in extensive, and very personal stories that aid to build report.

7.2.2 Limitations

A limitation of this study relates to the diversity within the group of respondents. Amongst the people that had replied on the email that was sent to recruit respondents, not all patient groups were present. This has resulted in under representation of certain patient groups. For instance, relatives where not represented in this research, although they were present in the pool of panel members (6.5%); most respondents did have a chronic disease (91%); and people with mental illness were not included.

Furthermore, the approach of carrying out interview via telephone or Skype could have affected the interaction between respondents and interviewer. The absence of face-to-face contact could have created a less comfortable situation for the respondents, although in the case of some respondents this could have been a positive experience, as it also creates distance between people.

In addition, the lack of observations of carried out appraisals can be considered a limitation as well. The obtained information on the use of patients' experiences did solely rely on

respondents' awareness of it. Observations of actual appraisals could result in new findings, that respondents are not aware of. Besides, the absence of observations has the effect that no conclusion can be drawn on the collective experiential knowledge of the panel, and exclusively on the individual experiential knowledge of panel members and their perception on how collective knowledge is established.

7.3 Conclusion

The panel members of Netherlands Patients Federation make use of their experience of being a patient, which might even have changed their point of view towards patients' values and issues. Being a patient makes it easy for panel members to empathize with other patients, even if these patients have a disease or illness that was not related to their own. This empathy helps panel members to make recommendations in favor of the targeted patient groups. The experiences that patients have had, made them aware of struggles, objections, and strains that patients encounter in general. This awareness is part of the experiential knowledge that solely patients acquire, which researchers often do not.

All different aspects that have previously been mentioned by other patients to be essential for grant appraisal approval are successfully being appraised, with support of the standardized assessment forms that are provided to panel members prior to the appraisal. Panel members mainly focus on the relevance of the research to patients' needs, and how it can improve their quality of life. The involvement of patients during appraisal can be considered to be of added value to research projects by making it more meaningful to patients and more complete, regardless of the experience of panel members with health care. This value is added by providing the real-life context and by providing the missing perspective in health research, when experiential knowledge is integrated and embedded in research. Nonetheless, patient involvement is often not included properly in research designs, and thus action in required to enhance patient involvement in health research.

8. Recommendations

In this final chapter, recommendations are made for future studies. Besides, recommendations are made for Netherlands Patients Federation, and for the commissioner (ZonMw), based on the results.

8.1 Further research

Although this study shows that the form provided by Netherlands Patients Federation aids to support appraisal, panel members stress that the assessment form is not always suitable and workable. It is suggested that Netherlands Patients Federation will do an extensive study on the design of the forms that are currently used during appraisal. This study will provide insights in adaptations that might enhance the appraisal of research projects by making the assessment uncomplicated for panel members.

In addition, it is suggested that triangulation of the data is carried out in the future. In this future research, panel members could be observed during appraisal, which would provide insight on the group process of the panel when they try to reach consensus. This study could then focus on the subconsciousness of panel members, as this current study has been focusing more on the awareness of respondents. The results from practice will reflect the importance of the issues for patients more collectively, and thus independently of illness or disease.

Besides, further research should also focus on the integration and embedding of experiential knowledge during appraisal. Some of the respondents did mention that they had the idea that their recommendations had led to alterations in research proposals, however, this does not confirm knowledge integration. To draw a sound conclusion on the actual added value of experiential knowledge during appraisal, it is important to know how this knowledge is integrated and embedded in health research.

Finally, it is suggested that research is done on techniques to enhance patient participation in clinical trials. It has been mentioned before, that inclusion is often not addressed properly according to panel members, and that not always the right people are involved in clinical trials. This is a concern amongst panel members, as they see the importance of including the right people to make sure the results of clinical trials are of use to as many patients as possible. It seems that there is lack of knowledge about the inclusion of patients, and therefore knowledge should be gathered on this matter to increase meaningful participation of patients during clinical trials.

8.2 Recommendations for Netherlands Patients Federation

It is recommended that the appraisal of health care research continues in the same way as it does currently. Respondents have spoken very fondly about the approach, especially with regard to the group meetings. However, it has been stressed multiple times by respondents that it is often very

hard to find consensus, and to formulate valuable propositions. Respondents sometimes have generated their own manners that do not strike with others, and some respondents appear to lack proper writing skills. It is therefore proposed that Netherlands Patients Federation aims to educate their panel members on their collaboration and writing skills.

Further, many respondents have emphasized the necessity of appreciation of their work. With this appreciation they are mainly talking about reimbursement. Some respondents see their appraisal as primary source of income, and they do value this. Without the reimbursement, respondents would not consider to continue with the work. This also account for some respondents who do not see their involvement as primary source of income. According to the findings in this study, it is important to compensate participants to give them the feeling of empowerment. It is therefore recommended that Netherlands Patients Federation aims for a secured allowance for their panel members.

In addition, the Netherlands Patients Federation is recommended to keep the diversity amongst patients as high as possible. This diversity accounts for age, gender, medical condition, education, and cultural background for instance. As a result of a higher diversity, it is ensured that the group of panel members is representing as many patient groups as possible, and with as many different point of views that can result from personal experiences with illness and disease.

Finally, it is also recommended to train the panel member to become professional patient representatives, which enables them to speak on behalf of other patients and then share the collective knowledge. This way, insights can be gained on the collective experiential knowledge of the panel, and not exclusively on the individual experiential knowledge of panel members and their perception on how collective knowledge is established.

8.3 Recommendations for ZonMw

Many respondents have emphasized the necessity of appreciation of their work. It has been mentioned that they do not see any results of their work, and they would like to have knowledge of projects that have been granted. According to the findings in this study, it is important to provide participants with valuable information, such as the findings of a study. It is therefore recommended that ZonMw provides panel members consequently with an overview of research projects that have been granted.

In addition, some of the respondents had the feeling that their appraisal was of less value to ZonMw than they had expected. They argue that their voice has been heard more often in the last years, yet they do not always have the feeling that their knowledge is in balance with scientific knowledge. They feel that their work is of less significance, something that does not completely

align with the mission and vision of ZonMw. It is therefore recommended that ZonMw will look into measures to increase the feeling of empowerment of panel members.

Further, respondents have also highlighted the quality of patient information letters that are provided by researchers. The overall quality of the letters appears to be low with regard to patients' issues. The main reason for this, is because of the different 'languages' that researchers and patients speak. It is therefore recommended that patient information letters will be written with the help of patients advocates, to enhance their quality and to bridge the language gap.

Respondents mentioned the misuse of the term "involvement" in research proposals. They feel that researchers often do not understand the meaning of involvement, and often confuse it with "inclusion". Respondents did stress that it might be helpful to provide researchers with useful information about involvement. This would not only take away some of the work for panel members, it can in general result is a better understanding of the term "involvement". With this, is it also important to provide researchers with tips on how to improve involvement: to make sure that they include the right patients and patient organizations, who contribute to enhance meaningful research by providing the patient perspective properly.

Furthermore, it is recommended that the panel is widely deployed at ZonMw. The panel members do provide insight in patient issues well, and with the use of the assessment forms, their experiential knowledge can become of use in other projects of ZonMw as well. This mainly concerns the fact that the panel members consider relevance and quality of life to be most important for them and other patients, which shows that living with the disease or illness is more important than the disease or illness on itself. This is a perspective that is important for other programs of ZonMw (ZonMw, 2020), and thus the deployment of the panel can also be of use these projects.

Finally, it was described by Abma et al. (2013) that researchers would become more motivated to collaborate with patients when they were shown the added value of their involvement. Elberse, de Boer, and Broerse (2017) showed that by making this explicit on a larger scale, it could motivate researchers to start experiments in collaboration with patients. To further motivate researchers to involve patients, it is recommended to make the added value of patient involvement explicitly known to researchers. It is believed that all stakeholders involved may benefit from a greater awareness of the way in which patients' experiential knowledge can add value to the appraisal process (Staley & Doherty, 2016).

References

Abelson, J., Wagner, F., DeJean, D., Boesveld, S., Gauvin, F. P., Bean, S., ... & Giacomini, M. (2016). Public and patient involvement in health technology assessment: a framework for action. *International journal of technology assessment in health care, 32*(4), 256-264.

Abma, T. A., & Broerse, J. E. (2010). Patient participation as dialogue: setting research agendas. *Health Expectations, 13*(2), 160-173.

Abma, T.A., Broerse, J.E., Elberse, J.E., & de Wit, M.P. (2013). Towards Structural Patient Participation in Health Research the Dutch Network of Patient Research Partners in Rheumatic Research.

Berglas, S., Jutai, L., MacKean, G., & Weeks, L. (2016). Patients' perspectives can be integrated in health technology assessments: an exploratory analysis of CADTH Common Drug Review. *Research Involvement and Engagement, 2*(1), 21.

Blume, S. (2017). In search of experiential knowledge. *Innovation: The European Journal of Social Science Research, 30*(1), 91–103.

Bombard, Y., Baker, G. R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., ... & Pomey, M. P. (2018). Engaging patients to improve quality of care: a systematic review. *Implementation Science, 13*(1), 98.

Burda, M. H., van den Akker, M., van der Horst, F., Lemmens, P., & Knottnerus, J. A. (2016). Collecting and validating experiential expertise is doable but poses methodological challenges. *Journal of Clinical Epidemiology, 72*, 10-15.

Charlton, J. I. (2000). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.

Caron-Flinterman, J.F. (2005). A new voice in science: patient participation in decision-making on biomedical research.

Caron-Flinterman, J. F., Broerse, J. E., Teerling, J., Van Alst, M. L., Klaasen, S., Swart, L. E., & Bunders, J. F. (2006). Stakeholder participation in health research agenda setting: the case of asthma and COPD research in the Netherlands. *Science and public policy*, *33*(4), 291-304.

Castleberry, A., & Nolen, A. (2018). Thematic analysis of qualitative research data: Is it as easy as it sounds?. *Currents in Pharmacy Teaching and Learning, 10*(6), 807-815.

Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2019). Patients' experiential knowledge and expertise in health care: A hybrid concept analysis. *Social Theory & Health, 17*(3), 307-330.

Chennamaneni, A., & Teng, J. T. (2011). An Integrated Framework for Effective Tacit Knowledge Transfer. In *AMCIS.*

Chugh, R. (2018). Tacit Knowledge Transfer in Australian Universities: Exploring the Barriers and Enablers. In *MATEC Web of Conferences (Vol. 210*, p. 04054). EDP Sciences.

Dagron, S., Chakhaia, T., González-Angulo, L., Hermanns, S., Skrahina, A., & Wallace, A. E. M. (2020). Access to experimental medicines for TB: ethical and human rights considerations. *The International Journal of Tuberculosis and Lung Disease, 24*(5), 38-43.

Dent, M., & Pahor, M. (2015). Patient involvement in Europe–a comparative framework. *Journal of Health Organization and Management.*

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Abu Dabrh, A. M., & Murad, M. H. (2014). Patient engagement in research: A systematic review. *BMC Health Services Research, 14*(1), 89.

Dornan, C. (1990). Some problems in conceptualizing the issue of "science and the media". *Critical Studies in Media Communication*, *7*(1), 48-71.

Echeverri, P., & Salomonson, N. (2017). Embodied value co-creation: A turn-taking perspective on service encounter interactions*. Journal of Creating Value, 3*(1), 33-49.

Elberse, J. E., de Boer, W. I., & Broerse, J. E. (2017). Toward a needs-oriented health research system: Involving patients in health research. In *Toward Sustainable Transitions in Healthcare Systems*, 235-258. Routledge.

Esmail, L., Moore, E., & Rein, A. (2015). Evaluating patient and stakeholder engagement in research: moving from theory to practice. *Journal of comparative effectiveness research, 4*(2), 133-145.

Gray, D. E. (2013). *Doing research in the real world.* Sage.

Gustavsson, S. (2016). *Patient involvement in quality improvement.* Chalmers University of Technology.

van der Hel, S. (2016). New science for global sustainability? The institutionalisation of knowledge co-production in Future Earth. *Environmental Science & Policy, 61*, 165-175.

Jennings, H., Slade, M., Bates, P., Munday, E., & Toney, R. (2018). Best practice framework for Patient and Public Involvement (PPI) in collaborative data analysis of qualitative mental health research: methodology development and refinement. *BMC psychiatry, 18*(1), 213.

Korevaar, L., & J. Droës. (2011). Handboek rehabilitatie voor zorg en welzijn. *Handbook rehabilitation for care and well-being*. Bussum: Coutinho.

Lehrer, K. (2018). *Theory of knowledge.* Routledge.

Le Lain, R., Ignaszewski, C., Klingmann, I., Cesario, A., de Boer, W. I., & SPRINTT Consortium. (2017). SPRINTT and the involvement of stakeholders: strategy and structure. *Aging clinical and experimental research, 29*(1), 65-67.

Lemire, F. (2015). Patient and public involvement. *Canadian Family Physician, 61*(4), 384-384.

Lord, L., & Gale, N. (2014). Subjective experience or objective process. *Journal of health organization and management.*

Maccarthy, J., Guerin, S., Wilson, A. G., & Dorris, E. R. (2019). Facilitating public and patient involvement in basic and preclinical health research. *PloS one, 14*(5).

Makkar, N., Jain, K., Siddharth, V., & Sarkar, S. (2019). Patient Involvement in Decision-Making: An Important Parameter for Better Patient Experience—An Observational Study (STROBE Compliant). *Journal of patient experience, 6(3),* 231-237.

Mason, R. J., Searle, K. M., Bombard, Y., Rahmadian, A., Chambers, A., Mai, H., ... & Jerzak, K. J. (2020). Evaluation of the impact of patient involvement in health technology assessments: A scoping review. *International Journal of Technology Assessment in Health Care,* 1-7.

Netherlands Patients Federation. (2020). (Information gathered through consultation of the panel's coordinator)

Palmer, V. J., Weavell, W., Callander, R., Piper, D., Richard, L., Maher, L., ... & Iedema, R. (2019). The Participatory Zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Medical Humanities, 45*(3), 247-257.

Parker, S., Racz, M., & Palmer, P. (2020). Reflexive learning and performative failure. *Management Learning.*

Patient-Centered Outcomes Research Institute (PCORI). (2019). Better Research through Involvement.

Pittens, C. A. C. M. (2013). Knowledge co-production in health research, policy and care practice.

Pols, J. (2014). Knowing patients: turning patient knowledge into science. *Science, Technology, & Human Values, 39*(1), 73-97.

Renedo, A., & Marston, C. (2015). Spaces for citizen involvement in healthcare: an ethnographic study. *Sociology 49*, 488-504.

Regeer, B. J. (2009). Making the invisible visible. *Analysing the development of strategies and changes in knowledge production to deal with persistent problems in sustainable development.*

Regeer, B. J., & Bunders, J. F. (2009). Knowledge co-creation: Interaction between science and society. *A Transdisciplinary Approach to Complex Societal Issues. Den Haag: Advisory Council for Research on Spatial Planning, Nature and the Environment/Consultative Committee of Sector Councils in the Netherlands [RMNO/COS].*

van Rooijen, M., Goedvolk, R., & Houwert, T. (2013). A vision for the Dutch health care system in 2040: towards a sustainable, high-quality health care system*. World Economic Forum,* McKinsey & Company.

Rozmovits, L., Mai, H., Chambers, A., & Chan, K. (2018). What does meaningful look like? A qualitative study of patient engagement at the pan-Canadian Oncology Drug Review: perspectives of reviewers and payers. *Journal of health services research & policy, 23*(2), 72-79.

Sacristán, J. A., Aguarón, A., Avendaño-Solá, C., Garrido, P., Carrión, J., Gutiérrez, A., ... & Flores, A. (2016). Patient involvement in clinical research: why, when, and how. *Patient preference and adherence, 10*, 631.

Schipper, K. (2012). Patient participation & Knowledge.

Schunk, D. H., & DiBenedetto, M. K. (2020). Motivation and social cognitive theory. *Contemporary Educational Psychology, 60*, 101832.

Schoenthaler, A., Knafl, G. J., Fiscella, K., & Ogedegbe, G. (2017). Addressing the social needs of hypertensive patients: the role of patient–provider communication as a predictor of medication adherence. *Circulation: Cardiovascular Quality and Outcomes, 10*(9), e003659.

Semeon, G., & Garfield, M. (2019). Framework for Externalization of Tacit Knowledge in Participatory Agricultural Research in Ethiopia: The Case of Farmers Research Group (FRG). In *Proceedings of the 52nd Hawaii International Conference on System Sciences.*

Silverman, D. (Ed.). (2016). *Qualitative research.* Sage.

Staley, K., & Doherty, C. (2016). It's not evidence, it's insight: bringing patients' perspectives into health technology appraisal at NICE. *Research Involvement and Engagement, 2*(1), 1-12.

Tambuyzer, E., Pieters, G., & Van Audenhove, C. (2014). Patient involvement in mental health care: one size does not fit all. *Health Expectations, 17*(1), 138-150.

Tell, F., Berggren, C., Brusoni, S., & Van de Ven, A. H. (Eds.). (2017). *Managing knowledge integration across boundaries.* Oxford University Press.

Tell, F. (2018). Knowledge articulation. In: *Augier M., Teece D.J. (eds) The Palgrave Encyclopedia of Strategic Management.* Palgrave Macmillan, London

Teunissen, G. J. (2014). Values and criteria of people with a chronic illness or disability (Dissertation). Retrieved from Athena Institute Amsterdam.

Teunissen, T., Visse, M., de Boer, P., & Abma, T. A. (2011). Patient issues in health research and quality of care: an inventory and data synthesis. Health Expectations, 16(4), 308-322.

Teunissen, G. J., Visse, M. A., de Boer, W. I., & Abma, T. A. (2013). Structuring patient advocates' appraisal and evaluation of health research and quality of care*. Journal of Participatory Medicine, 5,* e16.

Utschakowski, J. (2017). *Foundations and consequences of experiential knowledge.*

Verschuren, P., Doorewaard, H., (2014). *Designing a research project (Vol. 3).* The Hague: Eleven International Publishing.

Videmšek, P. (2017). Expert by experience research as grounding for social work education*. Social Work Education, 36*(2), 172-187.

Wildeboer, J. A. (2017). Collaboration between researchers and patients in scientific research (Master's thesis). Retrieved from internal drive of ZonMw.

de Wit, M. P., Berlo, S. E., Aanerud, G. J., Aletaha, D., Bijlsma, J. W., Croucher, L., ... & Jongkees, M. (2011). European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. *Annals of the rheumatic diseases, 70*(5), 722-726.

Zagzebski, L. (2017). What is knowledge?. *The Blackwell guide to epistemology,* 92-116.

ZonMw. (2018). External Evaluation of the programme Efficiency Studies 2006-2017.

ZonMw. (2020). Over ZonMw. Den Haag. Retrieved 24 June 2020, from: https://www.zonmw.nl/nl/over-zonmw/

Appendix I: Interview guide

INTRODUCTION

" Hallo, u spreekt met Vera. Ik bel u zoals afgesproken voor het interview over uw deelname aan het beoordelen van subsidieaanvragen. Nogmaals bedankt dat u wilt deelnemen. Voordat we beginnen wil ik graag nog wat praktische zaken met u bespreken.

Momenteel loop ik stage bij ZonMw. Tijdens mijn stage doe ik onderzoek naar de ervaringsdeskundigheid van panelleden. Het doel van dit interview is inzicht krijgen in hoe ervaringsdeskundigen gebruik maken van hun ervaringen, en daarmee kennis, tijdens het beoordelen van subsidieaanvragen. Ik zal u dan ook vragen naar uw persoonlijke omstandigheden, naar wat u ervaringsdeskundige maakt. Ik begrijp dat dit erg persoonlijk is, en ik wil u dan ook aangeven dat uw gegevens met uiterste discretie behandeld zullen worden, en enkel voor mij in te zien zijn. Uw antwoorden zal ik echter wel gebruiken om mijn onderzoek op te bouwen, en omdat mijn onderzoek voor ieder in te zien moet zijn, zullen uw antwoorden dat ook zijn. Uiteraard zullen uw antwoorden hier anoniem worden behandeld. Hiervoor is het ook van belang dat het interview wordt opgenomen, waarna deze getranscribeerd wordt en vervolgens wordt vernietigd. Ik zal u zo dadelijk vragen aan te geven of u toestemming geeft.

Uw deelname aan dit onderzoek is vrijwillig. U bent vrij om te allen tijde af te zien van uw deelname, ook als u achteraf besluit dat uw antwoorden niet mogen worden gebruikt voor het onderzoek. Als u deel wilt nemen aan dit onderzoek wordt er gevraagd om dit voorafgaand aan het interview aan te geven. De interviewer zal u hier nader om vragen. Ook na het geven van uw toestemming bent u vrij om zich terug te trekken zonder opgaaf van reden. Wanneer u zich terugtrekt uit dit onderzoek zijn er verder geen consequenties en zal de onderzoeker u dit ook niet verwijten. Als u zich terugtrekt uit het onderzoek voordat alle data verzameld is, zal uw data vernietigd worden.

Als u geen vragen heeft wil ik graag beginnen met het interview."

"Geeft u toestemming om het interview op te nemen?"

TOPIC GUIDE

Introductie	Omschrijving project Discretie en anonimiteit Vrijwillige deelname Toestemming opname
Over jezelf	Patiënt? Ziekte/aandoening? Hoe lang? Ervaringen diagnose? Obstakels?
Panel	Hoe bij panel terecht gekomen? Hoe lang? Toegevoegde waarde?
Beoordeling	Hoe ervaart u het? Stem gehoord? Hoe werken in groepje? Juiste aanpak? Training nodig? Welke aspecten maken een goed onderzoeksvoorstel? Eigen ervaringen meenemen?
Criteria (bij vragen over huidige beoordeling niet aanbod gekomen? Alsnog vragen!)	Belangrijkste criteria Worden ze allemaal meegenomen? - Relevantie Nut, toegevoegde waarde, diversiteit - Communicatie en informatie Gevaren, resultaten, taal - Ethiek en veiligheid Keuze vrijheid, bescherming, kosten, respect voor normen en waarden van patiënt, geen belasting - Kwaliteit van leven Privacy, toegang tot medicatie, vertrouwen - Kwaliteit van zorg Verbeterde zorg, support familie - Inclusie Stem, samenwerking Allemaal even belangrijk? Welke belangrijker? Waarom?
Afsluiting	Iets toe te voegen? Member check Bedankt

Appendix II: Informed Consent

ONDERZOEKSPROCEDURES & DISCRETIE

Het is belangrijk dat u begrijpt dat dit interview wordt opgenomen en dat de antwoorden uit dit interview later zullen worden geanalyseerd om het bovenstaande doel te behalen. Het interview zal ongeveer 35 minuten duren. Voor dit onderzoek zullen uw antwoorden volledig anoniem worden behandeld, en het is van belang dat hiervoor toestemming wordt verleend. Bij vermelding van quotes en antwoorden zal niet uw volledige naam worden genoemd, maar zal gebruik worden gemaakt van een pseudoniem. Uw antwoorden zullen dus wel worden gebruikt, en voor iedereen in te zien zijn.

VRIJWILLIGE DEELNAME

Uw deelname aan dit onderzoek is vrijwillig. U bent vrij om te allen tijde af te zien van uw deelname, ook als u achteraf besluit dat uw antwoorden niet mogen worden gebruikt voor het onderzoek. Als u deel wilt nemen aan dit onderzoek wordt er gevraagd om dit voorafgaand aan het interview aan te geven. De interviewer zal u hier nader om vragen. Ook na het geven van uw toestemming bent u vrij om zich terug te trekken zonder opgaaf van reden. Wanneer u zich terugtrekt uit dit onderzoek zijn er verder geen consequenties en zal de onderzoeker u dit ook niet verwijten. Als u zich terugtrekt uit het onderzoek voordat alle data verzameld is, zal uw data vernietigd worden.

Appendix III: Gantt chart

Task\Week	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**
Research design																					
Write: Introduction																					
Write: Theoretical and conceptual																					
Write: Methods																					
Data Management Plan																					
Turn in Research Design																					
Interviews																					
Transcribe																					
Analysis																					
Write: Results																					
Write: Discussion and conclusion																					
Write: Recommendations																					
Poster (design)																					
Presentation (preparation)																					
Write: Summary																					
Turn in Research Report																					

Appendix IV: Data Management Plan

0. GENERAL INFORMATION

Your contact details

Name: Vera Teunisse
Address: Cambridgelaan 305, Utrecht
Telephone: +31630278843
Email: v.teunisse@student.vu.nl
University: Vrije Universiteit Amsterdam

Please list the partner organisations involved in this project and indicate which organisation has the lead

Vrije Universiteit Amsterdam had the highest lead as this research is part of an education program. However, ZonMw funds the research and also has a high leading role. The research is conducted under their responsibility. Netherlands Patient Federation provides necessary information and subjects.

Consulted data management expert

-

1. DATA DESCRIPTION

Please specify the origin of the data: will new data be collected or produced and/or will existing data be re-used? If you re-use data, what is their source?

New data will be collected in this research

How will you collect/access the data?

The data will be collected through semi-structured in-depth interviews that are carried out via telephone or Skype

Describe your data assets at each stage during the research process. In which format is the data at this stage? Also indicate a rough estimation of the volume of the data assets.

Raw data

Data description: audio files of interviews

Format: mp3 or mp4

Estimated volume: 4GB

Processed data

Data description: Transcripts of interviews

Format: .docx

Estimated volume: 4GB

Analyzed data

Data description: Codebook in Atlas.ti

Format: atlas.ti

Estimated volume: 4GB

Research documentation

Data description: Research rapport and presentation

Format: .pdf

Estimated volume: 8GB

2. LEGAL AND ETHICAL REQUIREMENTS

Are there any ethical issues that should be addressed by an ethical review board?

No

Will you use animals for experimental or scientific purposes in your research project?

No

Please list the applicable Codes of Conduct for your research project

Honesty, Scrupulousness, Transparency, Independence, Responsibility

What other legislation is applicable to your research project? Please describe.

This research falls within an international collaboration, in which data ownership is divided among partner organizations (ZonMw and Netherlands Patient Federation)

3. STORAGE AND BACK-UP DURING THE RESEARCH PROCESS

What is the security level needed for your project?

Privacy: High

Availability: Medium

Integrity: Medium

Confidentiality: High

What measures will you take to secure and protect data during the research process? Please describe, for your data assets, how you will ensure data security and who has authorization to access the asset.

Raw data (Audio files)

Security measures: Anonymous stored on a secured location SURFdrive and deleted after transcribing is completed.

Access: Vera Teunisse

Processed data (Transcripts)

Security measures: Anonymous stored on a secured location SURFdrive

Access: Vera Teunisse

Analysed data (Codebooks)

Security measures: Anonymous stored on a secured location SURFdrive

Access: Vera Teunisse

Research documentation (Research Rapport and poster)

Security measures: Stored on a password secured laptop and on secured server of ZonMw

Access: ZonMw, Vera Teunisse; anyone can be given access to the files if requested

Is it necessary to transfer the (physical or digital) data assets to other locations or research partners? If yes, please describe how you secure the file transfer.

-

Please describe, for your data assets, where and how you will store and back them up during the research process.

Raw data

Storage: Secured SURFdrive location

Back-up: Secured harddrive of ZonMw

Processed data

Storage: Secured SURFdrive location

Back-up: Secured harddrive of ZonMw

Analysed data

Storage: Secured SURFdrive location

Back-up: Secured harddrive of ZonMw

Research documentation

Storage: Own secured laptop.

Back-up: Secured SURFdrive location, secured harddrive of ZonMw

4. DATA SHARING AND LONG-TERM PRESERVATION

In which digital repository (or data archive) will you archive your data? Please provide a name and link.

Data will be archived on Darkstor

What is the persistent identifier (e.g. DOI-code) that refers to the dataset?

To be allocated

In which online catalogue or web portal will you register your data assets? Please provide a description and a link.

-

Are there restrictions to data sharing? If yes, please specify the reasons and list the data assets you do not wish to share publicly.

The data is condidential and should not be shared publicly

When will you share the data (e.g. immediately after completion of the project, or after an embargo period)? If not immediately, please specify the reasons.

The data will be shared immediately after completion of the project with ZonMw and VU Amsterdam

Please indicate the license and/ or terms of use under which you share your data.

-

For how long will the data be available in the archive/ repository?

The data will be available for five years at VU Amsterdam, and until further notice for ZonMw

Will the research publication resulting from this research project be openly accessible?

The publication of this project will openly be accessible

5. DOCUMENTATION AND DATA QUALITY

How will you document your data?

All data will be documented as FileName_Month-Day

All data will be stored in folders named ProjectName

Submitted documents will be documented as FileName_Version_Number

Will you follow a specific metadata standard? If yes, please provide a name and link. If there are no standards in your discipline, describe what metadata will be created and how.

Version number; Date of creation (YYYY-MM-DD); Name of creator; Description of content; Name of research team/department associated with the data; Publication date; Project number.

Will you use standard vocabulary for all data types present in your dataset? If not, will you provide mapping to more commonly used ontologies (naming conventions)?

Standard vocabulary will be used for all data types in the dataset

What methods or software tools are needed to access and use your data?

No tools or methods are required. Request for access will only be granted to individuals who are directly involved with either organization of this research

Will you take measures to ensure data quality? Please describe these, if applicable.

By following systematic procedures during the analysis of the interviews. One person will be carrying out the interviews and analyze them. In addition, a member check will be done and a coding guide will be used

6. DATA MANAGEMENT RESPONSIBILITIES AND RESOURCES

Who will be responsible for management of the data assets after completion of the project (e.g. the project lead/ dedicated data manager/ department head)?

ZonMw will be responsible for management of the data assets after completion of the project

What resources (for example financial and time) will be dedicated to research data management? Please estimate their cost.

ZonMw has its own storage location and no resources will be dedicated to this.