Promoting Quality of Life Monitoring and Communication between Healthcare Professionals and Lung Cancer Patients Treated with Immunotherapy in ZGT

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PREFACE

In front of you lies the thesis “Promoting Quality of Life monitoring and communication between Healthcare professionals and lung cancer patients treated with immunotherapy in Ziekenhuisgroep Twente hospitals”. I have written this thesis as part of my graduation from the Health Sciences study program at University of Twente and on behalf of the Ziekenhuisgroep Twente (ZGT) hospitals. This study was conducted from September 2019 up to April 2020 and contributes to the improvement of quality of life monitoring of lung cancer patients and the patient-doctor communication.

During the research paper writing process, I have experienced good moments and sometimes bad moments. All clichés around the writing process of a graduation assignment seemed to be true. The last months I had to rely on the skills that I already had and the skills that I still had to learn. Overall, it was a very educational period in which I managed to develop myself and succeeded to finish my thesis.

I would like to thank my supervisors, Miriam Vollenbroek, Annemieke Witteveen, Josien Timmerman and Jeske Staal-van den Brekel for your guidance and support during this process. Your valuable feedback made me want to get the best out of myself. I also wish to thank all the respondents. Without their cooperation I would not have been able to conduct this analysis.

I would also like to express my gratitude towards the other colleagues at the ZGT hospitals, especially Erna Haverkate, for the great cooperation. Together we have often been able to discuss my research. I would also want to thank my parents, sister and significant other. Your advice and encouraging words have helped me a great deal. Interviewing patients with a heavy accent would have been a lot harder if I had not grown up in Groningen. Last but not least, I want to thank my fellow researcher Lauren Kerkhof for your endless support and for being my partner in crime. It was a blessing to end my student life working with you.

I hope you will enjoy reading this paper!

Ester de Groot

Enschede, 28th of March 2020

ABSTRACT

Background: In the Netherlands more than thirteen thousand patients are diagnoses with lung cancer each year. Most cases include non-small cell lung cancer (NSCLC). Immune checkpoint blockade treatments provide oncologists new treatment options to improve survival of NSCLC patients. Despite the improvements of the acquired knowledge base on immunotherapy, not much is known about the impact on patients' health related quality of life (HRQoL). A Patient Reported Outcome Measures (PROM) could provide more insight in the HRQoL of patients. Existing literature shows that PROMs have a positive impact on patient-doctor communication, e.g. improved symptom discussion, increased awareness of patients' QoL and a stimulated patient-centred approach. To achieve these PROM advantages, sustainable implementation of an ePROM in clinical practice is essential. This study provides more information regarding the requirements in terms of content and implementation of an (electronic) PROM with the current care routines.

Methodology: This study conducted a mixed method study design including questionnaires and interviews. The Perceived Efficacy in Patient-Doctor Interactions (PEPPI-5) scale was used to analyse the perceived issue-addressing skills of patients. After comparison of seven existing QoL measurement tool, respondents indicated their preference in QoL-items which they would like to discuss during consultation. The five most frequently mentioned items per domain were included in the questionnaire. Next, the Cognitive-Social Health Information Processing model (C-SHIP) and the Consolidated Framework for Implementation Research (CFIR) were used to create semi-structured interviews conducted with primary involved health care professionals (HCPs) and NSCLC patients to gain more in-depth information in the indicated preferences. The interviews were coded and analysed inductively.

Results: Six HCPs (of which three lung physicians and three lung nurses) and ten patients were included. Based on the results of the PEPPI-5 questionnaire, patients indicated a strong confidence towards addressing (health)issues (4.4 - 4.6 out of 5 points). Although the QoL domain Physical wellbeing was preferred as most important item to discuss during patient-doctor conversations according to all respondent groups, there was a great variety in further specific QoL items. The most frequent selected items by patients included “Energy and fatigue”, “Social energy/desire for interacting” (N=7) and "Anxiety / fear", "Stress / worries", "Loss of control" and "Social acceptance" (N=6). All these corresponded to the top-3 indicated by nurses. None of the top-3 items indicated by patients corresponded with the top-3 indicated by physicians. Most of the patients (N=7) mentioned an aversion with health monitoring but stated that they would like to use a PROM if the physician

recommended using it. HCPs see the added value of using a PROM in clinical practice, provided that clear protocols related to data interpretation and data integration prior to PROM usage are conducted.

Conclusion: Encouraged by the outcomes of this study and the existing literature, it is recommended to implement an ePROM tool in the care path of NSCLC patients. This study found that due to the great variety in importance of specific QoL items, personalisation of the PROM tool to each individual patient should be required. Short use of a PROM in clinical practice could change the patients' negative attitude towards monitoring their own health. Further research should be focused on thresholds for PROM data interpretation and how to act on this data. Furthermore, research implications should be aimed on executing a PROM tool pilot in order to receive more insight in the attitude towards PROM tool usage in clinical practice.

CONTENTS

1. INTRODUCTION

In the Netherlands over thirteen thousand patients were diagnosed with lung cancer in 2017 [1]. Lung cancer can be roughly categorised into non-small cell lung cancer (NSCLC), which represents 75-85% of the cases [2], and small cell lung cancer (SCLC) [3]. Usually symptoms appear until the disease is at an advanced stage, which results in late detection [4-7]. This leads to a mortality of over ten thousand patients, putting NSCLC as leading cause of deadliest cancer types [8]. Due to the poor prognosis of advanced-stage lung cancer, treatment is often palliative [8-10]. Immune checkpoint blockade is one of the latest treatment options to prolong survival of NSCLC patients [11]. Still, response rates are below 20%, since only patients with specific cancer features (PD-L1 expression) qualify for receiving this therapy [8, 12, 13]. However, when immunotherapy is successful, the treatment can lead to enhanced survival and less experienced side effect burden [7]. Due to the poor prognosis of NSCLC, extension of survival together with the preservation of a patient's wellbeing is an essential goal of treatment.

Despite the improvements of the acquired knowledge base on immunotherapy, not much is known about the impact on the patients' quality of life, and physical and psychosocial wellbeing [14-18]. Side effects of the treatment are similar to the symptoms of the activation of the immune system, but the appearance and impact of these side effects are not always predictable [18-20]. This interferes with the decision making regarding the optimal treatment strategy such as treatment scheme, supportive interventions or even (dis)continuation of treatment. To improve decision making, more insight in the impact of immunotherapy on daily functioning and quality of life (QoL) is necessary. This desired insight could be obtained using Patient Reported Outcome Measures (PROM). PROMs consist of health status assessments and measures of, e.g. health-related quality of life (HRQoL), symptom reporting, treatment satisfaction, economic impact, and instruments for assessing specific dimensions of patient experience, such as depression and anxiety [21]. Nowadays, cancer clinical trials aim for routinely inclusion of patient reported outcomes to further illustrate the tolerability of new cancer therapies. With use of PROMs an overall view of the experienced treatment impact could be received.

The value of engaging PROMs has been frequently investigated in the past years. These studies show the advantages of measuring self-reported outcomes, such as increased patient satisfaction and improved health outcomes and HRQoL [22-24]. Additionally, a considerable amount of literature has been published on the influence of PROMs on communication between patients and doctors [25-37], including an increase in the discussion of symptoms and (emotional) wellbeing [28, 31-35, 37], an increase in the awareness of patients' HRQoL [29, 30, 36], and improvements in serving a patient-centred approach [31, 33]. So, using a PROM in the care path of NSCLC patients can stimulate patients as well as physicians to draw more attention to the broader definition of HRQoL, and not solely to the

experienced clinical symptoms. However, these advantages can only be realised if healthcare professionals understand the value of using patient reported outcomes in clinical practice and start utilising the information in their daily work [38].

To achieve these PROM advantages, sustainable implementation of an electronical PROM (ePROM) in clinical practice is essential. Various factors can impact successful implementation of an innovation, e.g. perceived usefulness of the innovation, available financial resources and leadership support [36, 39]. The implementation of an ePROM tool in clinical care requires considerable planning and resources at the outset [36]. Additionally, careful coordination and communication with healthcare professionals (HCPs) and patients are essential for adoption of an intervention [40, 41]. To combine all these aspects, the Practical, Robust Implementation and Sustainable Model (PRISM) was produced by Feldstein et al. [42]. This framework consists of four domains, being, (1) intervention, (2) external environment, (3) infrastructure for usage spread, and (4) recipients. Before the process of an ePROM tool adoption in current care processes can start, the barriers and/or facilitators for the implementation of innovations must be identified. Therefore, the purpose of this study was to gain more insight in the requirements regarding content and fit of an ePROM with the current care routines. This was done by exploring the topics with the highest importance according to patients and HCPs for good medical communication. After this, the expected influence of a PROM tool on consultations was explored. Additionally, needs were collected regarding a well-fit implementation of an ePROM in daily (clinical) routines. The primary aim of this research was to answer the following question:

What are the requirements regarding content and compatibility with current care processes of an ePROM to promote QoL monitoring and communication between NSCLC patients treated with immunotherapy and HCPs in ZGT?

This study aims to answer the following sub-questions:

1) What items of HRQoL should be measured according to NSCLC patients in order to gain better insight into the topics to be addressed during patient-physician consultations?
2) What items of QoL are most important to be measured according to HCPs in order to gain better insight in the QoL of NSCLC patients?
3) What is the current self-reported capability and confidence of NSCLC patients regarding communicating health issues with their healthcare professional?
4) What are the expectations of NSCLC patients and healthcare professionals related to the added value of a PROM in clinical processes when PROs are measured?
5) What are the barriers and facilitators according to patients and healthcare professionals in order to achieve a successful implementation of an ePROM tool in current care processes?

2. THEORETICAL FRAMEWORK

Good communication between patients and HCPs together with patient-participation in decision-making are likely to result in better care outcomes. Street and Millay [43] stated that patient participation in medical consultations could be defined as the amount of influence that patients have on the interaction and the health-care provider's beliefs and behaviour. Patients asking questions, expressing concerns and stating preferences are examples of patient participation. Nowadays, the participation of patients during consultation could be improved, especially of older patients [44-46]. Consultations are not always adapted to the patients' needs, as the average consultation has a standard content of what is often discussed with the patient [47]. HCPs would like to see more assertiveness of patients, in order to receive more insight in the patient's goals and needs, as these may vary over time [48].

Patient reported outcome measures (PROMs) catch a patient's health status directly from the patient to provide knowledge about symptom burden and health-related quality of life (HRQoL) [49]. Therefore, PROMs are suitable for paying more attention to the patient's needs. The urge for PROMs in the care path of NSCLC patients is therefore increasing [50, 51]. To receive more insight in the daily HRQoL of patients and to improve patient-doctor communication based on this knowledge, more information regarding patients' and HCPs' communication needs and PROM use preferences should be gained. In this study the preferences concerning HRQoL items to discuss were determined first, in order to receive more insight in the needs of patients regarding discussing their health status. Next, the impact of these preferences on the patient-doctor communication was assessed. Finally, the attitude towards the implementation of a PROM in current care processes was investigated. In this chapter, theoretical frameworks of the three-fold approach is discussed in the subcategories: (1) (HR)QoL, (2) Communication and (3) Implementation.

2.1 HEALTH RELATED QUALITY OF LIFE (HRQOL)

Measurements of health and the effects of health care should not only include a signal of changes in the appearance and intensity of diseases impact, but also contain an estimation of the patient's wellbeing [52]. By measuring the improvement in the QoL related to health care, both key aspects are taken into account. In a study of Cella et al (2010), QoL represented the gap between one's actual functional level and one's ideal standard [53]. The World Health Organization defined QoL as: "the perception that an individual has about their place in their own existence, in the context of culture and their value system in which they live and on relation to their objectives, their expectations, their norms,

their concerns, etc." [52]. Therefore, QoL is patient-specific and depends on the individual's opinion regarding the goals and needs in life.

In the past few years, there is a growth in literature about the health-related QoL (HRQoL). HRQoL in is multidimensional and can be divided into multiple disciplines or components, including physical wellbeing, functional wellbeing, emotional wellbeing, social wellbeing and psychological wellbeing [53, 54]. Some of these components are related to one or more components. Cella (1995) defined HRQOL as "the extent to which one's usual or expected physical, emotional, and social wellbeing is affected by a medical condition and/or its treatment" [55]. Despite the broad view of HRQoL, its concept has been criticised for its agreement regarding its definition [56]. Definitions of HRQoL concepts depend on the patient's needs and consideration of the priorities of each individual [57]. This should be considered when analysing QoL instrument results.

(HR)QoL of patients can be assessed using QoL instruments, often in the form of questionnaires. Each instrument has its own focus (e.g. general, cancer-specific, tumour-specific), and has its benefits and limitations [58]. The *International Society for Quality of Life Research* have come up with a User's Guide which provided a practical aid in implementing patient reported outcomes in clinical practice [59]. This guide distinguishes six application types of PROM tools, being (1) Screening tools, (2) Monitoring tools, (3) Patient-centred care, (4) Decision aids, (5) Facilitating multidisciplinary team communications, and (6) Evaluating quality of care. Before choosing the instrument, it is important to know the purpose of the patient reported outcomes that will be collected. In this study, the primary goal is to use a PROM to improve patient-doctor communication, which means that the four first-mentioned applications could be useful. The selected tool should be adapted in order to achieve information about the patient's needs.

2.2 COMMUNICATION

Greenhalgh et al. (2005) presented a theory-driven approach to reproduce the evaluations of the feedback of patients' HRQoL measures to HCPs within clinical practice [26] (Figure 1). This framework shows the relationships between the intervention, in this example an electronic PROM tool, and its expected outcomes [26]. The framework consists of a bundle of PROM hypotheses that were mentioned in a study of Higginson and Carr (2001) [37]. This framework was chosen, since it clearly displays the connections between the various possible PROM outcomes. The outcomes mentioned in the framework of Greenhalgh et al. [26] were adapted in this study to check whether these applications are recognised as requiring outcomes by patients and HCPs when an ePROM is implemented.

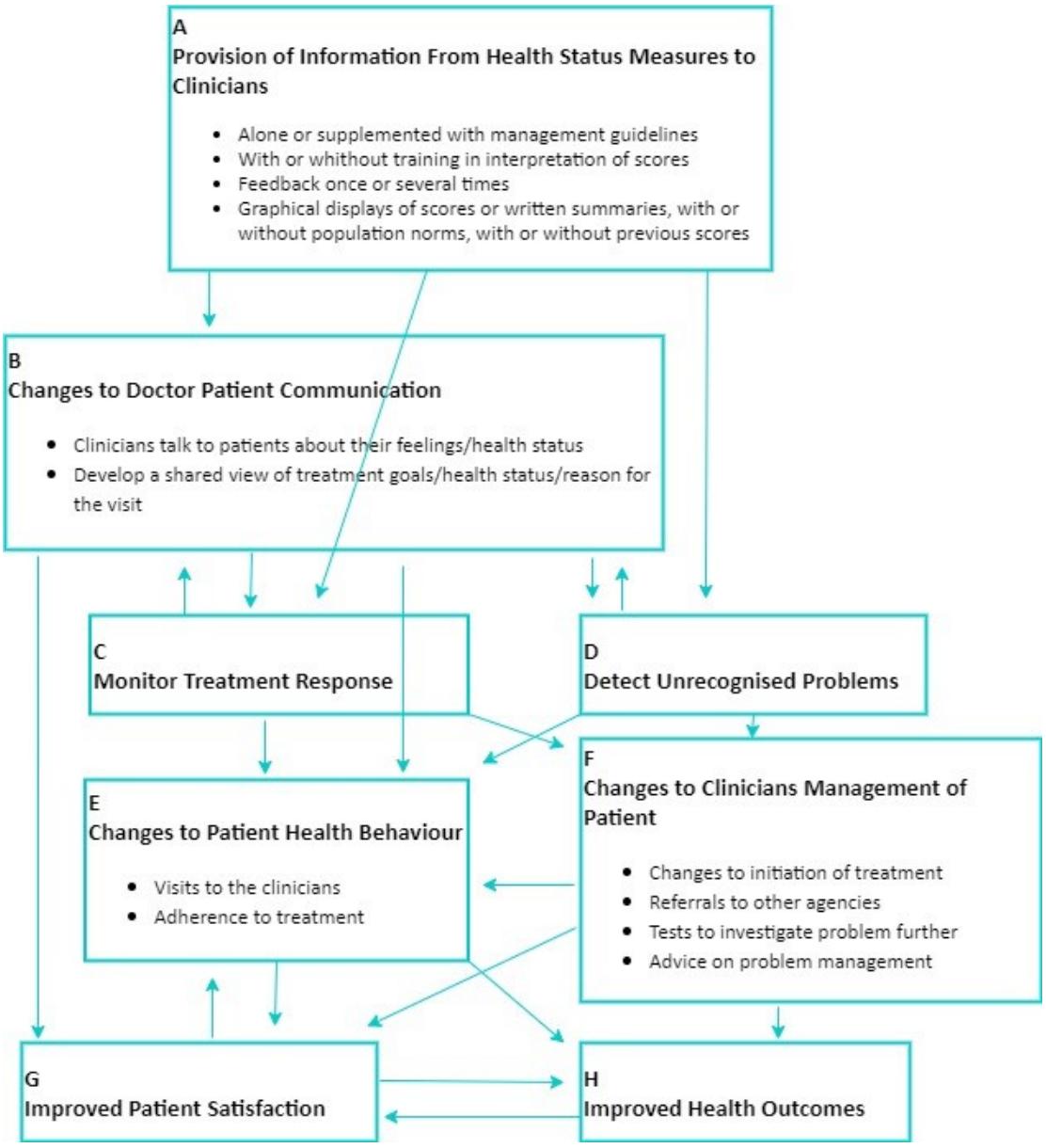

Figure 1: Bundled PROM outcomes and hypotheses in the framework of Greenhalgh et al. [26]

In order to answer a PROM item, respondents must take into account both the subject matter of the question and the meaning of the subject matter implied by the question [60]. Respondents have their own perception of that item to understand the relation between that item and their own lives. Based on the patient's subjective interpretation of the item, the final results could give them insight in the impact the disease/symptoms have on their functioning and HRQoL [61]. The way people process information about health expectations depends on their strategies for encoding or understanding health information i.e. illness status and adverse events. Psychological processes have an important role in the patient's behaviour when performing health behaviour, such as processing health-related information, or taking health-related decisions [62]. Patient-doctor communication can be perceived as a certain health-related behaviour, which should be analysed to understand the attitude of patients beforehand of and during a consultation. The Cognitive-Social Health Information Processing model

(C-SHIP) can be used to analyse and quantify this aspect [62]. An important component of the C-SHIP model is a set of cognitive-affective units and the structure and dynamic processes through which these units interact to generate a specific behaviour [62]. This component concerns the mental representations of the person's: (1) health relevant encodings; (2) health beliefs and expectancies; (3) affects (emotions); (4) health goals and values; and (5) self-regulatory competencies and skills [62, 63]. These terms are further explained in Appendix 1A. The cognitive-affective units were used for coding the interviews, to gain more insight in the mental processes of patients. By interviewing NSCLC patients, the appearance of these units in daily life will be made visible to help understand what drives the patient to perform certain communication behaviour.

This study highlighted the 'self-efficacy' part of the C-SHIP model. The C-SHIP model focusses mainly on the role of self-regulated competencies and skills. Self-efficacy and self-regulation have long been recognized as an important determinant for patient-doctor communication [64-66]. The patient's belief that he or she is able to perform the required behaviour for a specific situation is an important factor for maintaining difficult health-related behaviour. It has been shown that expectations about self-efficacy predicted the effective performance of difficult tasks, in particular when the possible outcome is extremely important for that patient [67]. Therefore the validated questionnaire "Perceived Efficacy in Patient-Doctor Interactions (PEPPI-5)" [68] was added to this study. The PEPPI-5 shows the extent in which patients trust and consider themselves capable to communicate health problems and for HCPs to act on this information. To achieve good patient participation in patient-physician communication enough self-efficacy and confidence of patients is essential. By asking about this confidence, an indication could be made whether patients think that the current patient-physician communication is inviting to discuss everything or that this communication deserves more improvement. The applications of an ePROM could be adapted to the personal needs of patients.

2.3 IMPLEMENTATION

PROMs are part of a health information system (HIS). Implementation of HIS is not a simple straightforward process [69]. The significance of technical, social and organisational attention is important in confirming that innovations are useful and usable, but that they also have a supporting role in the current (clinical) processes [70]. Adoption and implementation of HIS are not the same thing [71]. Because a HIS has been adopted, does not directly mean that it is, or will be used (or used in the way it was intended). Successful implementation may relate to a long process, containing planning, designing, and piloting [70, 72]. Despite the advantages of measuring HRQoL, PROMs, and in particular those measuring HRQoL, are not yet implemented often in today's clinical practice [26, 37, 73]. Many

studies so far have focussed on the importance of including patient characteristics in innovation implementation [42]. Patients' needs and resources must be acknowledged to implementation that aims to improve patient outcomes [74]. To understand why PROM outcomes are rarely used in clinical practice, more attention needs to be drawn to defining which factors lead to a successful implementation. This study assessed these influencing factors to gain more insight in barriers and facilitators regarding to PROM implementation in the current (clinical) care processes of the outpatient lung department of ZGT.

One recognised barrier to progress in improving program implementation is the lack of an extensive, prescriptive, and practical model to help organisations understand what implementation elements need to be considered and addressed and how success can be measured. The Practical, Robust Implementation and Sustainability Model, in short PRISM, is a model that helps to combine the key features for successful intervention design, predictors of implementation and usage spread and applicable outcome measures [42]. It recognises the important role of the patient's perspective when care processes are changed, since patients fulfil a key role in PROM usage. Essential implementation elements that this model includes, are (1) *Intervention (consisting of Organisational Perspective and Patient Perspective),* (2) *External environment*, (3) *Implementation and Sustainability Infrastructure*, and (4) *Recipients* (Figure 2) [42]. These elements consist of factors that affect the ability of implement changes in work processes and behaviour. The descriptions of these factors are displayed in Appendix 1B. This study mainly focussed on the PRISM elements *Intervention, Implementation and Sustainability*

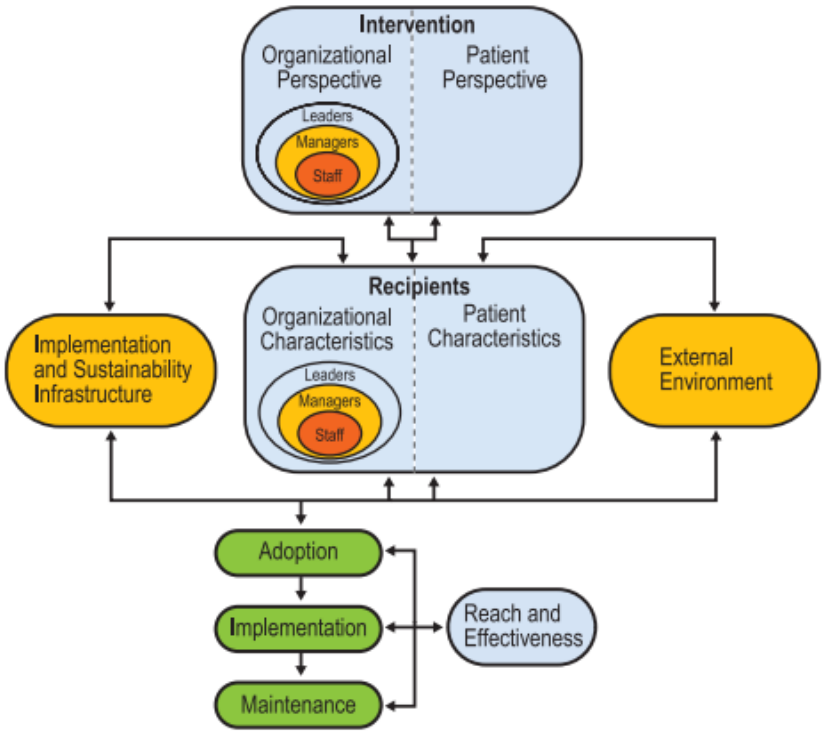

Figure 2: The Practical, Robust, Implementation and Sustainability Model [41]

Intervention, Implementation and Sustainability Data analysis and synthesis were organised around these PRISM elements to provide insight in the general acceptance of an ePROM in current care processes according to HCPs and NSCLC patients. The element *External Environment* was left out of consideration, because this study focussed in particular on the first exploration of the added value of PROM usage and the readiness of the lung department of ZGT to make changes in clinical practice.

Because the PRISM represents the implementation elements focussed on end users and patient-centeredness, another model or framework needs to be used to translate the above-mentioned elements into practice. Therefore, the Consolidated Framework for Implementation Research (CFIR) was applied (Figure 3) [75-77]. Researchers can select the constructs of the framework that are most relevant for their particular study setting to, as for this research, guide diagnostic assessment of implementation context. By a combination of the four components, being (1) intervention, (2) inner setting and (3) outer setting, (4) process, with a more flexible element describing individual's characteristics and attitude towards the intervention, this framework can be used in various settings [77]. The first mentioned component is related to features of the intervention implemented in a particular organisation. The outer setting generally includes the economic, political and social context in which an organization consists. Features of structural, political and cultural contexts through which the implementation process will proceed are included in the inner setting [78]. The fourth domain is the implementation process itself. The last crucial domain is the individuals involved with the intervention and/or implementation process. This framework was chosen above other existing implementation frameworks, because this framework connects well to the PRISM framework domains. In the current study the outer setting was left out of consideration, because the focus was on exploring the readiness and attitude of the lung department towards using an ePROM in clinical practice. The CFIR provided consistent classifications, terminology, and definitions on which the results of the study can be built. The CFIR was used to help composing and coding the ePROM implementation section of the interviews [75, 76].

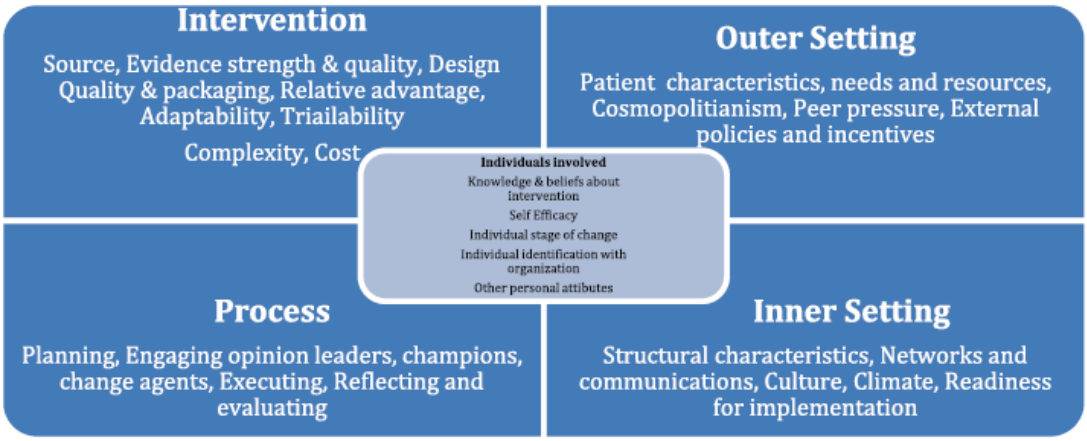

Figure 3: Consolidated Framework for Implementation Research (CFIR) [75]

3. METHODOLOGY

3.1 STUDY DESIGN

A mixed method consisting of questionnaires and interviews was used. The study consisted of two parts (Table 1). The first part of the study focussed on receiving insight in the topics of HRQoL that are essential to discuss during consultation, according to patients and HCPs. Besides, patients were asked to indicate their capability and confidence regarding communicating their health issues with an HCP. This information was gained by questionnaires. The second part investigated the rationale behind the preferences of the patients and HCPs. Additionally, the practical changes of patient-physician encounters were explored to enable to discuss the preferred topics of QoL. This was collected by interviews.

Table 1: Summary of setting, subjects, study procedure and data-collection

Part	Focus	Participants	How	Theoretical base
1	• Important QoL items to be addressed during consultation (sub-questions 1, 2) • Self-reported capability/confidence communicating health issues (sub-question 3, only for patients)	• Patients • HCPs	• Questionnaires	• EQ-5D [79], SF-12 [80], Stark QoL [81], WHOQOL-BREF [82], DASS-21 [83], PRO-CTCAE [85, 86] and FACT-L [87] • PEPPI-5 [68]
2	• Rationale behind choices and expectations regarding use of PROs • Expectations and requirements for using ePROM tool (sub-questions 4, 5)	• Patients • HCPs	• Interviews	• C-SHIP [62] • CFIR [75, 76]

3.2 SETTING AND SUBJECTS

This study was conducted at the outpatient clinic of lung diseases of ZiekenhuisGroep Twente (ZGT), located in Almelo and Hengelo, the Netherlands, between December 2019 and February 2020. The study was approved by the local ethical review board of ZGT.

Patient sample:

Eligible subjects were Dutch speaking adults aged 18 years or older, diagnosed with NSCLC and scheduled for immunotherapy (monotherapy) in first or second line.

Inclusion criteria:

- Patients, aged 18 years or older, diagnosed with NSCLC;
- Treatment with immunotherapy (monotherapy) in first or second line is planned, or first treatment is in progress, in ZGT;
- Competent in reading, writing and understanding the Dutch language.

Exclusion criteria:

- Diagnosis SCLC;
- Adjuvant treatment;
- Emotional or cognitive instability (as determined by the physician or nurse).

HCP sample:

Inclusion criteria:

- Physicians and nurses specialised in lung oncology;
- Working with patients receiving immunotherapy;
- Employed in ZGT.

Exclusion criteria:

- Not available during study period.

3.3 STUDY PROCEDURE

Patients

All eligible patients were approached and informed by their medical physician or nurse for participating in the study during regular consultations during a six week period. An information letter and informed consent was handed out to the patients to inform them about the research objective and content

(Appendix 2). The patients had three participation choices: (1) immediate participation, (2) delayed participation (another appointment was planned) and (3) no participation. When a patient wanted to participate, an appointment was scheduled on a day that the patient should already be in the hospital for an appointment with an HCP. If the patient did not have to be in the hospital in the subsequent three weeks, the primary investigator asked the patient if the interview could take place at the patient's home. When the patient chose for the second option, the HCP asked permission to pass a telephone number to the researcher for contacting the patient. The patient was then given 2-7 days to consider whether he or she wanted to participate in the study. After this period, the researcher contacted the patient by telephone to ask whether the patient would like to participate in the study. When the patient agreed to participate, an appointment was scheduled in the same manner as described above.

Healthcare professionals

All six HCPs specialised in lung cancer (three physicians and three nurses) were approached to participate in the study. An email was sent, containing a description of the study. When no reply was received, the HCPs were asked face-to-face whether they would like to participate. After approval was granted, an appointment for conducting the questionnaire and interview was planned.

3.4 DATA-COLLECTION

QUESTIONNAIRE DEVELOPMENT:

Patients

A questionnaire was conducted to gain information about the patients' preferences and included three parts (Appendix 3, Dutch):

- Part 1: Demographic outcomes: including sex, age, education, time passed since diagnosis, treatment type and amount of completed immunotherapy cycles
- Part 2: PEPPI-5 questionnaire
- Part 3: Essential QoL items to be discussed in HCP encounters by selecting and ranking those items.

In Part 1, demographic features were asked to check whether the sample was a representation of the nationwide NSCLC patient group.

Part 2 of the questionnaire consisted of the short 5-item version of the validated Perceived Efficacy in Patient-Doctor Interactions (PEPPI-5) scale [68] to explore the self-efficacy of patients regarding discussing health issues. The questions focused on:

a. Knowing which questions to ask;
b. Being able to get an HCP to answer all their questions;
c. Making the most of a visit to an HCP;
d. Being able to have an HCP take your most important health complaint seriously;
e. Being able to get an HCP to do something about your most important health problem.

Part 3 of the questionnaire consisted of QoL domains and associated items. To compile a list of QoL items, seven existing validated QoL measurement tools and questionnaires were compared to each other, including the EQ-5D [79], SF-12 [80], Stark QoL [81], WHOQOL-BREF [82], DASS-21 [83], PRO-CTCAE [85, 86] and FACT-L [87]. Overlapping items were removed. Five domains were selected, being physical wellbeing, functional wellbeing, emotional wellbeing, social wellbeing and psychological wellbeing. Per domain the five most frequently mentioned items were selected, so that the number of items was evenly distributed over the domains. When a domain was under-represented in the validated QoL questionnaires, the items were supplemented with items mentioned in the study of Pietersma et al. [88] and the systematic review of McCaffrey et al. [89]. The final items within the domains are presented in Appendix 4.

Healthcare professionals

The questionnaire for HCPs (Appendix 5, Dutch) consisted of two parts:

Part 1: Demographic outcomes: including sex, age, profession, time working in this profession

Part 2: Essential QoL items to be discussed in patient encounters by selecting and ranking those items (same items as mentioned in the patient's questionnaire).

INTERVIEW SCHEME DEVELOPMENT

The content of the semi-structured interviews was classified in three different categories, being (1) (HR)-QoL, (2) Communication and (3) Implementation. For patients an interview scheme was used to explore the rationale behind the choices addressed in the questionnaires and to receive more insight in the requirements for an ePROM tool (Appendix 6). For HCPs the interview was, next to the rationale behind the HRQoL item preferences, mainly focused on functional and organisational barriers and facilitators when implementing an ePROM (time, administration, etc.) as well as communication behaviour (mindset, etc.) (Appendix 7). The implementation section of this interview scheme was based on the CFIR [75-77].

PROCEDURE QUESTIONNAIRE AND INTERVIEW

For HCPs the questionnaire and interview were conducted face-to-face in a consulting room in the outpatient clinic for lung diseases. For patients this was also the common practice, but if preferred the

interview could take place at home. Furthermore, the patients had the opportunity to bring a family member or other loved one with them during the interview.

In the questionnaire, patients were asked to indicate how confident they were to achieve certain goals regarding communicating with the physician or nurse using a 5-point Likert scale (1 = not at all confident, to 5 = completely confident) by using the PEPPI-5 [68].

In the last part of the questionnaires (Appendix 3 and 4) an overview of the collected items of HRQoL was given. Respondents (both patients and HCPs) had to indicate which QoL items were most important to discuss during patient-doctor conversations. Respondents had the opportunity to add an item if one was not already included in the list. Of the 25 given items (plus potential added items), respondents had to select the ten most important items to discuss during consultation and rank these from 1 (most important) to 10 (least important) to identify urgency of addressing these. After filling in the questionnaire, the interview was conducted.

3.5 DATA-ANALYSIS

QUESTIONNAIRES

To explore the patient's and HCP's preference regarding the QoL items to be discussed during consultation the average ranking was calculated using the following formula:

$$\frac{x1w1 + x2w2 + x3w3 + \cdots}{Total\ response\ count}$$

where:

w = weight of ranked position

x = response count for answer choice

The answer choice with the lowest average ranking was defined as the most preferred choice (so 1 as most preferred or urgent and 10 as least preferred or urgent). To complete an entire average, the rankings of items that were not selected by the respondents were set on 11, in order to avoid misinterpretations of the mean ranking:

Patients: To calculate the mean ranking the result had to be divided by 10 (total response count);

Lung physicians: To calculate the mean ranking the result had to be divided by 3;

Lung nurses: To calculate the mean ranking the result had to be divided by 3.

Example: When an item was selected by three out of ten patients, and ranked with a 2, a 5 and a 7, the calculation of the mean ranking was executed as follows:

Mean ranking = (2+5+7+(7*11))/10 = 9.1

A value of 11 was chosen, because this was outside the number of items that had to be ranked by the respondents. The range between which a mean ranking could lie was 1 – 11 (in which 1 was indicated most important and 11 was indicated least important). The lowest ranking possible was 1 (when all ten respondents ranked that item as most important). When an item was not selected once, no mean ranking was shown (the result would be 11). Microsoft Excel (Office 365) was used for analysing the ranking questions. A further analysis of the preferred choices was done in the analysis of the interviews. Of the PEPPI-5 scores a mean per patient per question and a mean per question over the whole patient sample was calculated.

INTERVIEWS

The responses of the interviews were audio-recorded and transcribed verbatim by the researcher, using Amberscript. First, all the transcripts were read by the primary investigator. A code list was partly based on the existing CFIR codebook [90] and the definitions of the elements mentioned in the C-SHIP model [62, 63]. After this, the interviews were coded using the software Atlas.ti. The codes from the CFIR and C-SHIP model were supplemented with codes that were not included in the two models, i.e. codes for describing patient-doctor communication and the requirements the tool should met. This was done by open-coding. Thirdly, together with a fellow researcher this code list was discussed to compose a code book consisting of codes and corresponding definitions. This was done by co-coding three transcripts (two for physician group and two for patient group) to check the codes and its definitions. The agreement percentages were calculated to show the degree of similarity between the encoded transcripts. The final codebook can be found in Appendix 8.

The results of the questionnaires and interviews were ultimately structured based on the following subcategories with corresponding models and frameworks:

1. (HR)-QoL;
    a. Important QoL items to be discussed during conversations
2. Communication
    a. Reported communication skills
        i. *PEPPI-5 [68]*
    b. Addressed QoL items during current consultations
    c. Impact PROM tool on communication
        i. Codes from C-SHIP [62, 63],
        ii. Analysis based on framework of Greenhalgh et al. [26]
3. Implementation
        i. Existing codes from CFIR [75, 76],
        ii. Analysis and structure based on PRISM [42]

4. RESULTS

4.1 RESEARCH SAMPLE

PATIENTS

The patient sample consisted of ten NSCLC patients treated solely with immunotherapy. Out of these participants seven were male. Only one patient had an age of less than 56 years; the majority was older than 65 years (N=6). The majority of the participants was lower and average educated, with education levels ranging from primary school to secondary vocational education (primary school (N=1), lower vocational education (N=1), secondary general secondary education (N=3) and secondary vocational education (N=4). One participant received a university education. Most patients received their diagnosis lung cancer more than one year ago (N=7). Five patients received one to six treatment cycles and five patients received over seven treatment cycles. There were no drop-outs during the sessions. In Appendix 9A all patient characteristics can be found.

HEALTHCARE PROFESSIONALS

The participating healthcare professionals consisted of all invited healthcare professionals (N=6), of which three physicians and three nurses. Out of these six respondents, four were female. All three physicians and nurses had an age higher than 46 years old and all had more than ten years of experience in their current profession. There were no drop-outs during the sessions. In Appendix 9B all HCP characteristics can be found.

4.2 (HEALTH RELATED) QUALITY OF LIFE

4.2.1. IMPORTANT QOL ITEMS

Table 2 shows a summary of the most selected items and highest mean rankings per respondent group. The items which were rated to be important by the patients closely matched the items mentioned by the lung nurses, when focussing on the frequency of selected items: all three items that are most selected by the lung nurses are also mentioned by the patients (“Energy and fatigue”, “Social energy/desire for interacting” and “Anxiety/fear”). The top three of patients’ most selected items does not match any item that is in the top three of lung physicians’ most selected items. In Appendix 9C, an overview of the frequencies and mean rankings per QoL item and per respondent group is displayed.

Table 2: Summary of most selected items (frequency) and highest mean rankings per respondent group

Respondent group		1st Item(s)	2nd Item(s)	3rd Item(s)
Patients	**Frequencies**	Energy and Fatigue (N=7)	Social energy /desire for interaction (N=7)	• Anxiety / fear (N=6) • Stress / worries (N=6) • Loss of control (N=6) • Social acceptance (N=6)
	Mean ranking	▪ Energy and fatigue (6.6) ▪ Anxiety/fear (6.6)	Social energy/ desire for interaction (6.8)	Side effects of treatment (6.9)
Lung physicians	**Frequencies**	Pain and discomfort (N=3)	Side effects of the treatment (N=3)	Washing / selfcare (N=3)
	Mean ranking	Side effects of treatment (2.0)	Pain and discomfort (2.7)	Energy and fatigue (6.0)
Lung nurses	**Frequencies**	Energy and fatigue (N=3)	Anxiety / fear (N=3)	Social energy / desire for interaction (N=3)
	Mean ranking	Energy and fatigue (2.0)	Anxiety/fear (4.3)	Side effects of treatment (4.7)

Frequency: Patients: 0 = lowest frequency, 10 = highest frequency.
HCPs: 0 = lowest frequency, 3 = highest frequency.
Ranking: Patients: 1 = highest ranking, 11 = lowest ranking.
HCPs: 1 = highest ranking, 11 = lowest ranking.

The selected QoL items per domain per respondent group are shown in Figure 4. Emotional wellbeing is indicated as most important domain according to patients, based on the frequency of selected items within that domain. For the HCPs, the items within the domain Physical wellbeing were most frequently selected.

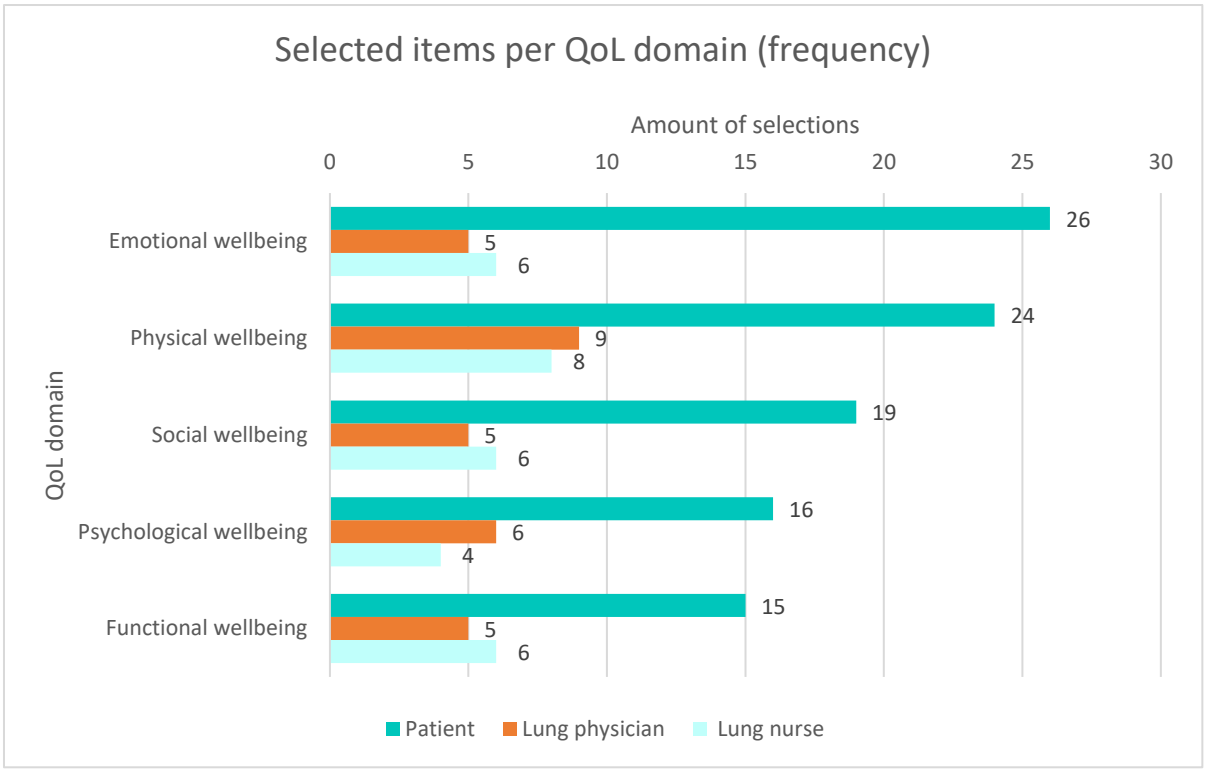

*Figure 4: Sum of selected Health Related Quality of Life items per domain per respondent group, sorted by patients from high to low. Total points to divide per respondent group over five domains: patients = 100, lung physicians = 30, lung nurses = 30 (number of respondents * number of selected items)*

HCPs perceived physical wellbeing as most important topic. The HCPs mentioned to have chosen this topic because it is a key factor in the decision to continuation of treatment. When there are too many side effects or adverse events, patients need to think about whether they would like to proceed with the treatment, or whether it is better to postpone the next treatment course, or even to quit the treatment.

> *"Because the physical wellbeing is of course one of the points that you need to see whether the next cure of immunotherapy can be prescribed. So that is what you need as a benchmark. And I understand very well that patients will probably come up with a different ranking, but at the moment I think: What do you need? In the follow-up with immunotherapy, how can you deregister the next cure? For that you need to know the physical condition of the patient. Because immunotherapy can do a lot with your physical condition." (HCP3, nurse).*

Three out of six HCPs stated that if a patient is physically fine, the other items will be covered in the consultation. Those HCPs stated that other items, like emotional wellbeing and functional wellbeing, are influenced by the patient's physical wellbeing. Therefore, most attention is focussed on the physical wellbeing.

Patients selected most items out of the Emotional wellbeing domain. HCPs indicated that this is due to the 'rollercoaster effect', dealing with many emotions in a short time period. Most patients stated that, mainly in the first stages after the diagnosis, emotions were the most intense. After a while, the most intense emotions slowly faded into the background, but the burden of the disease always plays a role. One patient stated:

> *"When you are treated, then you are confronted with it, but if you are not treated you can also be confronted with it and I think that is a bit unpleasant" (Patient3)*

4.3 COMMUNICATION

4.3.1 REPORTED COMMUNICATION SKILLS

Based on the results of the PEPPI-5 questionnaire, patients indicated a strong confidence towards addressing (health) issues. Of a maximum score of 5 points, the average mean per question ranged from 4.4 - 4.6. In Appendix 9D, the scores per respondent per question can be seen. Six out of ten patients rated the highest score for confidence concerning patient-doctor communication for all questions. During the interviews, all patients indicated that they were satisfied with the conversation with the doctor and that they did not need anything to improve the conversations. Eight out of ten patients stated that they do not prepare the consultations with HCPs by thinking of questions beforehand. The other two patients kept a daily dairy or prepare a note with questions and/or health features before entering the consultation.

This lack of preparation prior to consultation has also been noticed by the HCPs. They stated that participation of patients during consultations may have to be improved. HCPs, in specific physicians, indicated that patients do not always prepare the consultation, which leads to one sided information transfer (only HCP to patient). One physician stated:

> *"You really have to insist that the patient prepares himself well to even think about which medication, the medical history, what actually bothers the patient. How long have I been suffering? What do I actually want on the agenda? Yes, the latter in particular is one thing we are missing now." (HCP1, physician)*

4.3.2 ADDRESSED QOL ITEMS IN CURRENT CONVERSATIONS

During the interviews with patients, majority of patients (N=7) indicated that they did not discuss the items that were selected by the patients with their HCP in current conversations. These same patients

also stated that discussing the selected items were not important enough to discuss or that problems experienced with these items were irrelevant:

> *Researcher: "Do these items really come up for discussion during the consultation?"*
> *Respondent: "No, no. I'm not bothered by anything so ..."*
> *Researcher:" No, so then that does not have to be discussed?"*
> *Respondent: "No."*
> *Researcher: "What is often discussed during the interview?"*
> *Respondent: "How it's going, how you feel."*
> *(Patient8)*

HCPs indicated that the selected physical items by the HCPs always came up for discussion. However, most HCPs indicated that the remaining selected items by the HCPs were not being addressed during consultations, due to time restrictions. As a result, not every HCP is always satisfied after speaking with a patient (three out of six). However, five out of six HCPs stated that when a patient wanted to address an item that does not belong to the physical wellbeing domain, this is always possible and always allowed. One HCP explained which advice is given to a patient when he or she brings up an item out of a domain other than the physical wellbeing domain. When a patient brings up an item himself…

> *"Then that could be discussed in more detail, but then I also say clearly that within the oncology treatment, there are also supporting disciplines, in which certain guidance in certain domains clearly does not belong to the doctor's duties, except for the signalling role." (HCP 3, physician)*

As mentioned before, the item Sexuality/intimacy was rarely discussed. Some HCPs stated that there is still a taboo on this subject. Other HCPs stated that sexuality is not often an issue, since the average NSCLC patient is in the age where sexuality does not play a big role in their lives anymore. HCPs acknowledge that patients also never bring up this item themselves. This was confirmed by the patients, as none of the patients selected this item in the questionnaire. In three interviews the item has been discussed shortly: two patients mentioned that sexuality was not integrated in their lives anymore and the other patient indicated that for sex you need two people, and that she lives alone.

HCPs were not unanimous about covering each domain of QoL during current patient-doctor conversations. Most of the HCPs stated that not all items of QoL were addressed during consultation, because there was not enough time. HCPs state that patients did not always bring up conversation

topics by themselves. HPCs believe that NSCLC patients are not always capable of indicating what is wrong with their health or emotional status (recall bias).

> *"[…] And that is basically in all domains, although I realize .... That is of course the important part, that when I ask a patient, he very often goes back to the last days and not to the last weeks. You often have the time interval in between. Certainly, if you receive certain immunotherapy, nowadays once every six weeks, then very often you no longer know what happened in the beginning. Or if you do not show any emotion, then he may have been very upset about the therapy and at the moment that they are with you again, they want to proceed [the therapy] so badly, that they do not know that piece anymore ... and they do not even deliberately do that. They just don't think about it anymore. While if you did report it, you could do something about it to prevent things. So that is an important part." (HCP1, physician)*

Furthermore, the input for the conversation is highly depended on the openness of a patient. HCPs stated that a patient often only gives health information when a specific question is asked by the HCP. Patients do not often bring up conversation subjects by themselves, which often leads to one-sided conversations.

> *"I didn't really get through that, so if you are not open to a conversation as a patient, it can sometimes be difficult to discuss all those points. Then you are already happy that he indicates that he's fine. Or he gets it." (HCP4, nurse)*

Patients also may lie about their health status. They may pretend to be finer than they really are and can be afraid that the treatment plan would be changed if he or she reports that the treatment causes side effects or he or she does not feel any improvements related to their health status:

> *"Patients do not always report everything, because they know exactly why they are sitting at my table, namely, to get that next cure or to get that next treatment. And when they say: "I feel actually so bad, I need help from my partner to wash myself" and then it is kept behind […], to get that next cure anyway." (HCP 1, physician)*
>
> *"And that sometimes makes it difficult to set up adequate treatment if we start looking purely at targets." (HCP5, physician)*

Four patients confirmed this latter statement. They indicate that the most important information that they would like to discuss during consultation, is the permission to prescribe the next immunotherapy cure:

"We come here, if you have to go to the lung physician, to get permission for the immunotherapy. See, that's my goal for me to come here." (Patient4)

These four patients indicated that discussing the results from blood samples and scans is important for knowing whether the therapy could be proceeded:

"When I hear from the doctor or from the nurse: the blood values are good, and you can proceed the therapy, then it is uh ... then I don't think much about it anymore." (Patient7)

4.3.3 IMPACT OF PROM TOOL ON PATIENT-DOCTOR COMMUNICATION

Healthcare professionals

The different HCPs state three kinds of advantages of the implementation of an ePROM in the current care path of NSCLC patients treated with immunotherapy related to the patient-doctor communication.

First, the HCPs receive more insight in the health status of patients. Most of the HCPs (four out of six) stated that when patients would fill in a monitoring tool, the insight in the daily QoL of patients would enhance, treatment plans could be adapted, and consultations could be used more efficiently. One HCP explained this as follows:

"You only get better communication, and if you get better communication you can draw up better treatment plans, you can better come to an agreement with each other, you get more satisfied patients. […] And in the end, it takes less time. Sometimes people say: this leads to more talking, but that is not true. My office hours never last longer than planned. It just depends on how you do it." (HPC1, physician)

Second, patients would be able to gain more insight in their own health status. Having more insight in their own health status could encourage patients to be more active and assertive during conversations. One HCP made this clear by the following quote:

"I think that insight is important anyway, that it gives people the chance to think about it. And it is just important, and also in our conversations… I find it particularly important to discuss those things in terms of pain complaints, or in terms of mental complaints, that you are planting a kind of seed, which you can later refer back to, uh ... reap the benefits." (HCP6, nurse)

Finally, patients could become better prepared before entering consultation. When the patient is more conscious about his or her own health status, patients could enter the consultation more prepared. Doing preliminary work could lead to better knowledge about what should be discussed during consultations. This means that a patient could suggest by him of herself what should be discussed and what not. HCPs would be more reassured that everything that the patient wants to talk about has come by during the conversation. One HCP stated:

> *"It would be nice if by the patient ... uhm ... would deliver [medical information] in a structured way, say, on a kind of questionnaire, where you .... before he comes to your clinic, so that you can screen through it." (HCP5, physician)*

Two HCPs stated that there could be a disadvantage of having more insight in the QoL of patients. There could be the possibility that 'overtreatment' could arise, so that too much help could be provided to the patient, even though he or she does not need it that much. The other reason that was mentioned was that it could be too heavy for patients to always monitor their health status and focus on possible health complaints. But this varies per patient.

> *"It could also be too much for the patients, too deep. The patient could think: 'I feel good. I'm fine with it. I don't have to share more information'." (HCP2, nurse)*

Patients

Most patients see disadvantages in using a PROM tool (N=7). The reasons mentioned for this were:

1. *It causes concern (N=2)*

> *"Then you can worry, I think. If you don't know it, you don't have to worry." (Patient6)*

2. *It takes too much work (N=2);*

> *"Advantages? Not for myself, only disadvantages. I have to think about it extra. But it benefits you, the hospital." (Patient2)*

3. *It does not change the situation (N=3)*

> *"It doesn't change anything. It is the way it is, and what they can do about it, well, they are busy with that, And, and, yes... Nothing else can be done about it." (Patient5)*

Of the seven patients that would not like to monitor their health status to gain more insight in their own health status, five patients would keep track of their health if the physician would ask them to do so.

Three out of ten patients would see advantages of health monitoring, related to receiving more insight in their health status:

1. *When using a PROM, patients could improve their communication*

Patients that experience difficulties with discussing or addressing (health) issues could refer to the tool when describing their health status.

> *Researcher: "And in what way would that improve something for you?" Respondent: "Well, then the communication from me to him gets better." (Patient9)*

2. *Having more insight in your health status could take away some worries or doubts.*

The tool could help in describing to the physician what the issue is and what the patient is uncertain about.

> *"I think it can just take away some anxiety, that you ... if you already had a certain fear, because of pain or something, and more research would be done on that... And it shows that nothing is wrong, or even is wrong, but that it becomes clear what is going on ... that is better than if you keep walking around with uncertainty." (Patient10)*

3. *When having more insight in health status, patients could make targeted health improvements.*

Patients could take targeted steps to improve their health or lifestyle. One patient explained this as follows:

> *Researcher: "Would it be nice for you to gain more insight in your daily health?" Respondent: "Yes, because then I can work on it. Because I want to get a little fitter again. Get some more energy. Then I can see how ... how I can spread the energy over a day." (Patient9)*

4.4 IMPLEMENTATION

Participating patients experienced difficulties with mentioning requirements for the ePROM, because they did not prefer the use of a PROM in daily living, except when the physician would recommend the patient to use it. Furthermore, most of the patients did not have a specific idea of how the tool would be used and how it should look like. The PRISM elements *Intervention, Implementation and Sustainability Infrastructure,* and *Recipients* are used to structure the results regarding implementation.

Intervention

Entry for a conversation and involving loved ones

The tool should be an entry for the conversation between patients and HCP. With this tool, health information of a patient should be seen instantly. According to three out of six HCP, a patient should only fill in the tool a couple of days before the appointment and not every day or every week. Involving relatives of the patient is a very important item for four out of six HCP. They state that family members and other loved ones are often invited to participate in the conversation with the HCP. However, is often made clear that the patient is the focal point. One HPC explicitly stated that once the monitoring tool is in use, the patient needs to fill it in together with someone who knows the patient very well.

> *"There must be a condition that there are also questions to which the patient's environment must answer ... does the partner think so too or does ... do the children think so too? So that you do something with it. That everyone has the same, or at least a little, the same idea about the issue. But if there are very different insights ... well look, those insights may continue to be different, that's not the point, but that people are aware of that. Then I can respond more easily to that." (HCP5, physician)*

Eight out of ten patients stated that they always bring a loved one when visiting the hospital. Three out of ten patients indicated explicitly that they would use the PROM together with a family member, when the PROM concerns a questionnaire.

Compact, easy and user friendliness (for both patients and HCPs)

This requirement was explicitly mentioned by five out of six HCPs. Nurses often focused mainly on the interest of patients, while physicians often focused mainly on their own interest.

First, two HCPs stated that patients should benefit from using the tool. If patients were asked to be more involved in conversations by monitoring their health, he or she should see better results in the

conversation and should be more satisfied with the outcomes. Moreover, three out of five HCPs mentioned that the tool should be easy to use, and that it should not take a lot of time to fill in the details of a patient's health status. Also, the tool should not be too hard to understand, or too long, because then patients would not fill in the tool. One HCP described how the appointments were currently scheduled for NSCLC patients and how a monitoring tool could affect a patient's life:

> *"It must be conceivable for people, it should not take up too much time, because people are already very busy. Especially people with immunotherapy who receive the treatment every two weeks, they are already busy with taking blood samples for two or three days for two weeks. Sometimes there is another CT out there. Then they have an appointment with the doctor and then they have the immunotherapy that they have to receive and if they also have to fill it in every time ... So, there must be ... I think that if the load is very low and that patients also receive an explanation… and also that they have better insight, that it can also be an added value. Then I think people are willing to fill in. But it should not be a lengthy questionnaire, then patients would quit easily." (HCP6, nurse)*

Two nurses stated that the tool should not be 'black and white': patients should be able to use a scale to indicate what their health status is in a specific domain instead of only choosing between two options. Nowadays, the 'Lastmeter' is used for patients to give an overview of their health status. Two nurses were not that fond of the 'Lastmeter', because patients could only check 'yes' or 'no'. This should be considered in the development of the tool. Two patients also mentioned the difficulty of choosing between only two answer options when they filled in the 'Lastmeter' (*Patient7 and Patient10*).

Three HCPs mentioned that the chosen language should fit with the cognitive and health intelligence of the patient population. When a PROM tool is too difficult to fill in, patients will not be motivated to use the tool to monitor their health. One HCP stated explicitly that it should not be possible to misinterpret the words used in the tool. The HCP explained it as follows:

> *"We may have a different idea with a question, or concept, or a word, so that's the difficult thing with this kind of tools. You have to use very clear words that you think are universal." (HCP5, physician)*

Easy viewing and interpreting of results monitoring tool (preferably in HiX)

All six HCPs mentioned that the results of the monitoring tool should be displayed in such way that the HCP could have a quick overview of the most essential and outstanding values that the patient mentioned. It is important that guidelines are prepared for making these decisions in order to guarantee equal quality of care spread over the different HCPs. When the researcher asked what information of a patient would be important to see in HiX, the opinions were divided. Two HCPs stated explicitly that only a summery or graphics should be displayed, so that only 'alarming' factors would show up. None of the HCPs thought that 'pop-ups' would be helpful, because these would disappear between other pop-ups in HiX or would be too triggering (distracting) but highlighting adverse events in the electronic patient file would be acceptable. HCPs stated that they prefer to see the health status of patients before consultation, and not weekly or monthly. One HCP stated that especially side effects should be highlighted in the electronic patient file, to alarm the HCP. One HCP was very clear in stating this requirement:

> *"Yes, I think the IT anyway, that it will be linked to HiX, that you will not get separate lists on Excel or so. And that with a touch of a button, it is all clear, that you can get something out of it a little easier. I think that it is just important to include HiX in it to link it to the file you have." (HCP6, nurse)*

Providing user instruction prior to PROM implementation

Providing information to both the patients and the HCPs is very important. Two HCPs foresaw troubles regarding the intended use of a PROM by patients. They stated that patients should be informed about how to use the tool and what the health information will be used for. HCP4 indicated that it must be clear that the main goal of using the monitoring tool is to improve the communication between patients and HCPs and that patients can bring up every QoL item during conversation, but that the HCP cannot help solving every problem (i.e. financial problems). Patients need to understand the goal of monitoring their HRQoL and should be reassured that the information that is filled in will be used to eventually improve patient care. One HCP explained it by using an example:

> *"People connect consequences to pop ups. Because if you notice that you have a lot of stomach pain and the pop up is only read 4 days afterwards and the patient thought it was seen on the day itself…, but then again, you can get big mistakes. That, of course, is something that you have to include in the preparation, of how do I provide coverage to what we get from information. That we inform the patient well." (HCP1, physician)*

ePROM vs. paper-based PROM

During the interviews the patients that were in favour of using a monitoring tool when an HCP would suggest using the PROM, they were asked whether they would prefer a paper-based or digital monitoring tool to keep track of their health or lifestyle. Of the six patients, four patients preferred a digital tool and two patients preferred a paper-based tool.

Recipients

Skills regarding interpreting and acting on data

When patients would fill in the tool and the data was sent to the HCP, the HCP should know what the data means and what he or she should do with it. I.e., when a patient fills in that out of five, she has a pain value of three, should the HCP act on it or is this a normal value and should the HCP leave it for this time? So, it should be clear what the values mean and what the next steps should be.

> *"You should outline a whole follow-on path: What do we do, should we then refer you to that or that or that? So, you will have to roll out an action plan." (HCP4, physician)*

Patients' self-regulatory competences and skills

HCP were worried about the self-regulatory competence and skills of the patients when implementing a monitoring tool in the current care process. Being conscious about your own health status and knowing what to detect, requires a high level of literacy, as stated by HCP5. Not all NSCLC patients will be able to screen their own health, even with the use of a tool. Low-literate patients and patients with low cognition could be experience barriers when using the tool. It is important that the HCPs take this into account when using the information of the tool. One physician explained this as follows:

> *"It is about making the effort and the results. Look, and if people are just low-literate, cognitively not too strong, then it is a lot of trouble. And, well, certainly the older generation still has the tradition, like, 'Well, doctor, tell me what to do'." (HCP5, physician)*

Expected impact of PROM use on consultation time

Two out of six HCPs (one physician and one nurse) were worried about extension of a consultation time if a monitoring tool would be implemented. When patients gain more insight in their QoL, the possibility of patients to bring up "every little complaint" will arise. Two HCPs mentioned that there are not enough HCPs to discuss the results with the patients, to transfer the data to HiX, etc.

"Time is a very important factor. That is actually one of the most important factors. I think it is very important that a patient functions well in all domains, but if I have to spend one hour per patient on it as a doctor, that is simply not possible. In particular, being able to see quickly and act on it is important." (HCP4, physician)

Involvement HCPs in PROM design and implementation process

HCPs should be informed about the usage of the tool as well. Providing information about this process change was equally essential for HCPs as for patients. It is important that each HCP of the department is involved in the implementation and that everyone sees the added value of using the PROM. Implementation should be done carefully and deliberately. One nurse drew an example from the past of which she learned the following:

"Everyone must be informed: this is implemented, this is expected of you and this is how it looks. I think that's important. I've had a few times… something was implemented and then I thought like huuuuuh. I didn't know anything about that. That is annoying. You have to discuss it well beforehand. You have to let everyone go in the same direction, with everyone pointing in the same direction and then you also have to ensure that everyone goes along. So, everyone has to get involved too. Inform everyone: This we want to implement, and we want that for that and that reason. What do we want to achieve with it? Then we start. Make sure it is ready, then we start, beginning then and then. You must be very clear on that. You should not just say: well this is it and we will start with it. That is a shame, because people have invested so much energy in it." (HCP4, nurse)

Implementation and Sustainability Infrastructure

Inviting implementation climate

Multiple HCPs (three out of six) have stated that: if the need for change is big enough, employees of the lung department are open to change. It will take time to get used to usage of the tool, but the HCPs state that overall this will not be a major barrier. One HCP stated that one of the reasons that changes in previous care processes were relatively easy, is because every HCP has the same mindset. Another HCP stated that "the extent to which the lung department is open to changes depend on the effort that implementing that change costs."

"We want to implement improvements, these are always changes. So, if something entails an improvement for our method of working, for our personal well-

being, or for the patient, so just in that order, then we are always positive about it. When you change things, then you always have to look first at the one who's first bothered by it, because in this case that is the doctor. Do I benefit from it? Well, and we welcome all the changes, improvements that we benefit from. If something gives a small improvement to the patient but a huge effort for our system, then I think we should take another look at how we are going to handle that. That has to do with how much effort it costs and how much it yields in the order of the lung physician and then the patient." (HCP5, physician)

Compatibility PROM in current care processes

Two HCPs have stated that the time that stands for a consultation is sufficient when implementing the ePROM. HCPs do not think that the layout of the conversation would change very much after implementing the monitoring tool. The medical part of the consultation will not change, but the HCP receives more insight in whether patients could be referred to other accompanying bodies. All HCPs think the tool could be a good addition to the existing consultations. Instead of asking the patient what is bothering him or her, the patient could address this issue by him or herself.

"That fits perfectly [in the current care process], because we just know that we sometimes fail during our consultation. It's just that you have to convert your mindset. And uh ... in the end you are going to win, because I think that you get more sustainable care by taking such good care of the patient and therefore may also start to treat less often or stop the treatment earlier." (HCP1, physician)

However, two HCP (one physician and one nurse) have stated that the lung nurses should play a greater role in the conversation with the patient, so lung nurses should be seeing more NSCLC patients than they do in the current care path. They should be the first filter for the information that has been provided by the patient, so that the physician only sees the screened information that is relevant for him or her. Nurses could then refer the patient earlier to another HCP, like a physiotherapist or social worker. That same nurse foresees problems based on time and appointment scheduling. It was explained as follows:

"But someone will have to inform the patient that it exists, provide such information. They will have to look at the results and the potential problems that can be expected or the problems that actually exist will also have to be addressed. So, if you implement such a tool, you have to have time to do something about the consequences and I don't know about the time available…" (HCP4, nurse)

But, again, she also stated that when someone comes up with a good plan to implement the tool and it improves the quality of care for the patient, every team member will be willing to participate in the change process.

Changing leaders

Four out of six HCPs stated that for the implementation of the monitoring tool "fast-adapters" or "go-getters" are needed. In other words, team members that are easily used to the new care processes could convince others to use it. All four HCPs thought that these go-getters were present in the lung department. One HCP stated:

> *"Yes, yes, you do have the permanent go-getters. There are always the same people who come up with new things. The sceptics, well, they also go along…" (HCP1, physician)*

5. DISCUSSION

The aim of this study was to explore the requirements regarding content and compatibility with current care processes of an ePROM to promote QoL monitoring and communication between NSCLC patients treated with immunotherapy and HCPs in ZGT. To achieve this goal, more insight into the desired HRQoL items to be discussed during patient-physician conversations, according to NSCLC patients treated with immunotherapy and HCPs, was gained using questionnaires. Patients indicated that mainly the HRQoL items "Energy and fatigue", "Anxiety/fear" and Social energy/desire for interaction", were most important to discuss with their HCP, based on both selection frequency and ranking. Lung nurses also demonstrated a great importance of the items "Energy and fatigue" and "Anxiety/fear", but also of "Side effects of the treatment". Lung physicians, on the other hand, expressed a preference regarding the physical HRQoL items, being "Pain and discomfort", and "Side effects of the treatment".

In the second part of the study the current self-reported capability and confidence of patients regarding communicating health issues with their HCP was indicated. Patients showed a high self-efficacy regarding indicating health issues during consultation. HCPs, on the other hand, mentioned that patients do not often bring up health concerns. This may be due to lack of consultation preparation and health illiteracy.

Finally, to obtain more insight in the chance of success of PROM implementation in current care processes of NSCLC patients, the expectations and barriers and facilitators mentioned by NSCLC patients and HCPs regarding the added value of a PROM in clinical processes were collected. Many of the participating patients did not see an added value of using a PROM. Barriers that they foresaw were the causation of concern, the amount of extra work and the fact that it does not change the situation of being sick. Only four patients mentioned advantages of PROM use, being improvement of communication towards HCPs, removing some worries or doubts and enabling targeted health improvements. HCPs also mentioned three advantages of using PROMs in clinical practice, namely to receive more insight in the health status of patients, to enable patients to gain more insight in their own health status and to offer more knowledge to patients in order to become more prepared before entering consultation. Outside of the advantages, HCPs indicated a few expected barriers for PROM use, being a shortage of consultation time, lack of skills regarding interpreting and acting on data and the lack of patients' self-regulatory competences and skills. Indicated existing facilitators, according to HCPs, are an inviting implementation climate, compatibility of a PROM in current care processes and the presence of changing leaders in the department. To achieve a successful PROM implementation, requirements were mentioned by the HCPs, being the provision of user instruction prior to

implementation, involvement of HCPs in PROM design and implementation process and the usage of the PROM as conversation entry with patients.

Contrary to the researcher's expectations, the expectations of patients for using a PROM in clinical practice were negative. Most of the participating lung cancer patients did not have any interest in monitoring their health status to gain more insight in their own QoL. Patients in the current study indicated that they were highly satisfied with the care that is currently provided and that a PROM would not be experienced as an added value in current care processes. The negativity in the current study towards health monitoring of the patients could have been caused by the invalid method in which the questions were asked during the interviews regarding the need for health monitoring. The benefits of a PROM were not explained prior to the interview in order to avoid bias caused by the explanation. However, the patients indicated that when the physician would suggest or recommend monitoring health issues, they would cooperate for scientific purposes or to improve the care.

Other factors that could play a role in the negative attitude towards health monitoring are cultural differences and the age of the participating patients, as this study was conducted in a specific area of the Netherlands (east of the Netherlands) and most patients were above 65 years old. In a study of Callahan et al. (2000) where satisfaction of older patients was researched, results show that older patients reported a greater satisfaction regarding the provided care than younger patients, as younger patients experience an emphasis of physicians on being assertive during consultation [91]. Since older people do not experience the pressure, they may be less inclined to have all of their health needs identified and addressed, which could have serious implications for quality of care [91, 92]. In a different study of Haug et al. [93], elderly patients pointed out that they have a desire for the physician to take control of the appointment. Older patients tend to be more accepting towards physician advice and are less likely to doubt the professional authority [93]. Participating patients of the current study mentioned that monitoring their own health would change the current care, and changes in the current processes could only worsen the care. This attitude towards health monitoring expectancies contradicts the advantages of health monitoring mentioned in existing literature. In a study focussed on an online application (*BijKanker*) [94], the results showed that 85% of the respondents thought it was useful to monitor side-effects of the cancer treatment and that they were moderately positive about regularly reporting their side-effect burden. Three-quarters of the respondents used the gained information for communication purposes. A study of Cranen et al. (2011) stated that brief use of an eHealth tool (e.g. in pilot form) can change the patient's attitude regarding the use of eHealth from negative to positive [95]. As patients do not have prior experience with the ePROM tool, providing

patients a safe way to test the tool can increase the creation of a precise attitude and user needs. This will eventually enlarge the patient's acceptance of the ePROM tool [95].

To encounter the attitude towards using a PROM tool in daily care processes, a pilot containing working with a PROM should be implemented in which patients as well as HCPs could experience the benefits and disadvantages for the quality of care. According to Cranen [95], this could change the negative attitude of patients towards health monitoring. Considering the advantages of PROM use and the patients' willingness to change care processes in order to improve quality of care, implementing and integrating a PROM tool in daily care processes should be realised to be sure what the opinion is regarding PROM acceptance once it is used. To achieve an acceptance of the PROM users, a small step-to-step plan for implementation of the PROM tool pilot in clinical practice is displayed in Appendix 10.

5.1 CONSULTATION AND PROM CONTENT

All HCPs have indicated that the QoL domain "Physical wellbeing" is most important to address during consultation with a NSCLC patient. Especially the QoL items "Side effects of the treatment" and "Pain and discomfort" were rated as most important according to physicians and "Energy and fatigue" according to nurses. The reason for this preference is that physicians base their treatment decisions in terms of starting or continuing the immunotherapy on physical features of the patient, as the presence of side effects of the treatment or symptom burden is an essential item of QoL for deciding that the treatment should be discontinued. Also, HCPs stated that physical complaints can cause barriers in other QoL domains, i.e. stimulating depression or being unable to perform daily activities. When physical items cause complaints that affect other QoL domains, these must be solved first to improve QoL, according to the HCPs. Existing literature confirms the focus of the HCPs on the physical wellbeing domain [96].

The results of the current study show that patients selected the physical domain and emotional domain as most important. Nonetheless, patients stated that the corresponding selected items are not specifically necessary to be discussed with the physician. Many patients mentioned that the lung physician should focus solely on providing medical information during consultation and that the other health related topics could best be discussed with an additional specialised HCP from another field or a lung nurse. This finding was also reported in other studies [47, 97-99]. Reason for this is that patients think that nurses have more time to discuss other aspects of QoL, outside of the physical domain. This is consistent with the existing literature that stated that patients often select medical topics rather than psychosocial and practical topics for patient-doctor conversations when using consultation preparation tools [100, 101]. When focusing on the HCPs' perspective, the study of Gough and Dalgeish

(1991) demonstrated that nurses generally give greater importance to the overall HRQoL than physicians [102], which is in accordance with the results of the current study. Jansen et al. (2020) showed that concerns in general are less discussed in consultations than medical information [103]. Despite the clear division of HCP roles in outpatient care, it is recommended that the chief physician, often being the lung physician, should be updated about the patient's health status in order to be able to make the right care decisions. PROMs provide a valuable patient information foundation, on which those decisions should be based. Also, PROMs could ensure the desire of HCPs to receive more insight in the patient's HRQoL and to improve patient assertiveness during consultation [26, 28, 30]. In order to achieve the desired communication outcomes, according to the participating HCPs and as mentioned in the framework of Greenhalgh et al. [26] as "Changes to doctor patient communication, Monitor treatment response, Detect unrecognised problems, Changes to patient health behaviour and Changes to clinicians management of patient", three conditions must be met: (1) *Patients want to talk about their health status with HCPs*, (2) *HCPs feel it is appropriate to discuss HRQoL issues with patients*, and (3) *HCPs see HRQoL information as sufficiently important to prompt changes to the management of their patients* [26]. To be able to meet these criteria, HCPs in the current research mentioned that when PROMs are implemented in clinical practice, lung nurses should play an enlarged role in the discussions of the PROM outcomes with patients. In this way, nurses can already filter the HRQoL that has been raised, so that physicians only need to be aware of the most important or striking results. So, based on these results and the existing literature, nurses should play an essential part in discussing HRQoL with patients when a PROM is used in clinical practice. Patients should be comfortable to address every issue related to QoL in order to increase the opportunity to receive the right care when desired by the patient. The tool should be used as a triage tool prior to the consultation: the tool should contain lists consisting of conversation topics categorised by subject, in order to provide conversational ideas.

Although patients indicated that on average physical and emotional wellbeing are most important to discuss with an HCP, the results of the present study show that there is a great variety between the specific needs of patients, both in frequencies and rankings of the items (only three out of six most frequent selected items by patients were also ranked the highest). Therefore, it is not possible to generate a list of fixed QoL items to be discussed, because each patient is unique and has its own needs and burdens. This variability in patients' personal needs and monitoring preferences match those mentioned in other literature [104, 105]. Because of this variety, a personalised monitoring tool should be considered. Furthermore, in another study it was recommended that monitoring tools may be more readily adopted if they are developed as tools for personalised, longitudinal self-investigation that help users learn about the conditions and variables that impact their health on different domains [105].

Therefore, it should be possible for patients to indicate which QoL domains they would like to discuss with the HCP prior to a consultation. As individualised monitoring tools could lead to difficulties in administering and scoring the results, there may be opportunities to combine the personalised lists with short, standardised measures that include screening questions. Respondents of a study by Linn et al. [99] suggested that a list with discussable categories could be shown prior to a consultation to facilitate their concern expression and retrieve tailored information for the specific concerns they are experiencing. Patients could choose which of the categories are important to discuss and so they would not be confronted with problems or feelings they do not experience. When a patient does not want to select any of the categories, this is also possible. Addressing concerns during consultation could help lung physicians and nurses referring patients to specialised HCPs instead of providing solely medical information based on test results.

5.2 ACCEPTANCE AND COMPATIBILITY OF A PROM TOOL

The interviews have shown that the involved HCPs have a positive intention to use a PROM tool in clinical practice, provided that certain requirements are met. The culture in the outpatient lung clinic is generally accessible for implementing innovations in care processes. However, three barriers were mentioned for implementing a monitoring tool, being the fear of exceeded consultation time due to PROM discussion, the health illiteracy of patients and having trouble with interpreting PROM data. Existing literature confirms that the workload associated with the collection and analysing patient data was identified as a compelling obstacle to clinical use of PROMs [106-108]. Additionally, including patients in decision-making is often linked to time as a barrier [109]. Nonetheless, existing studies have pointed out that when PROMs were implemented and used in health processes, the workload could be reduced, since PROMS may help HCPs focus attention on their patients' most urgent problems [76, 110-112]. Other studies have suggested additional barriers including the lack of clear guidelines on the data collection process and how to correctly analyse and interpret the data [106, 113, 114].

In the current study, HCPs mentioned the urge for automatic QoL information transfer between the PROM and the electronic patient files, to create a quick and clear overview of the provided QoL information by the patient. Nowadays, most of the paper-based PROM tools are replaced by electronic-based systems. Compared to paper-based PROMs, ePROM systems can lead to more accurate and complete data, controlling of data entry errors, less administrative burden, high respondent acceptance, reduced sample size requirements, and potential cost savings [21, 36, 115, 116] and allow healthcare professionals to be informed early about patients' transitions and adverse events [20, 117]. The five out of six patients who were asked about PROM usage expressed a clear

preference over a digital PROM (ePROM) instead of a paper-based prom. On the other hand, existing literature has shown that older, less educated and chronically ill patients have lower eHealth literacy than younger, healthy and more educated individuals [118, 119]. When an ePROM is chosen over a paper-based PROM, providing a training on how to use the PROM for patients (and relatives) should therefore be considered.

The patient sample in the current research consisted mainly of older, lower educated individuals. The common low health literacy of NSCLC patients is mentioned as a concern by HCPs for using the tool. Low health literacy is a feature that mainly occurs in low socio-economic populations [120]. A cross sectional study pointed out that health literacy varies for the competences of accessing, understanding, assessment and utilisation of information in the domains of health care, disease prevention and health improvement [121]. Patient support to achieve shared decision-making requires high levels of health literacy, especially in the functional and communicative fields. As shown in a study about the relationship between health literacy and question-asking behaviour, people with lower health literacy ask fewer and less in-depth questions [122]. Besides, the amount of questions asked during consultations decrease as the age of patients increase [123]. Implementation of PROMs can be used to screen for low levels of health knowledge, align information accordingly and improve patient involvement in healthcare decision making [120].

One striking subject that is mentioned by the HCPs, is the importance of consultation preparation of patients. Nowadays, HCPs depend on the skills and courage of patients to address the topics they would like to talk about during consultation. This has also been emphasised in other studies [124, 125]. In a study comparable to the current study, the purpose was to determine whether providing patient specific QoL information to lung HCPs prior to a clinic appointment would change the degree to which specific QoL issues identified by the patient were addressed during the consultation [126]. After providing the HCPs a training how to discuss these QoL issues, significantly more QoL items were discussed during clinic consultation, compared with patients that had a conversation with an untrained physician. So, a screening tool, like an ePROM, could be effective in increasing detection of QoL problems during the clinic appointment and resulted in a trend towards more concerns being charted and marginally more actions being taken related to these concerns. By implementing PROMs in clinical practice, patients could be more involved during conversations.

During the interviews it was pointed out that the HCPs would like to be involved when changes were to be implemented in the current care processes. Existing literature confirms this need. In a study about training clinicians in how to use PROMs in routine clinical practice it was stated that the HCPs should be involved in the choice of PROs and graphic presentations [127]. However, involving HCPs in

the implementation plan alone is not sufficient to achieve a successful implementation [128], [129]. Getting used to working with the monitoring tool in clinical routines could be facilitated by offering trainings to the HCPs. Other studies concluded that appropriate training was necessary to effectively engage in the process. They specifically proposed that a lack of training for dealing with difficult situations and effectively using the information created inevitable obstacles. Group training was recommended in order to stimulate exchange of knowledge and experiences. When organising a training, an essential element should consist of a case from practice, which allows HCPs to learn how to refer to the monitoring data and how to act on this. This procedure addresses the key obstacles identified by a systematic review of the experiences of professionals with patient reported outcomes, namely valuing, understanding the data, and using it to make changes to patient care [127, 130]. Despite the value of providing training to reduce the lack of knowledge about outcome measure, other barriers could raise, e.g. limited resources and the low priority given to outcome measures [131]. A large amount of research from health psychology has shown that increasing knowledge is necessary but not sufficient to change behaviour [132]. A clear protocol containing guidelines on what PROM outcomes mean for treatment decisions and how to act on thresholds that indicate alarming scores is essential for HCPs for knowing when and what action needs to be taken. As long as this is not set up, implementation of a PROM in clinical practice may probably fail.

5.3 STRENGTHS AND LIMITATIONS

A mixed methods design was chosen for this study. This was an appropriate design, as the different designs together offered rich data. The interviews were a suitable addition to the questionnaires, in order to receive more in-depth information about conversation preferences. However, coding of the interviews was done by a single researcher, which could have led to subjective interpretation of the results. Notwithstanding, two of the transcribed interviews were coded a second time by a fellow researcher and resulted in a high agreement percentage. The HCPs sample of six respondents and patient sample of ten respondents offered enough substantive saturation of the results. The participating patients were a representative sample of nationwide NSCLC patients, as the majority of lung cancer patients is male and most patients receive their diagnoses between the age of 60-74 [3].

Another strength of this study is the relevance of the subject. ZGT strives to improve care processes and quality of care for patients in several care areas. One project that is currently running is called '*3 good questions*' [133], which has also been emphasised in existing literature [134]. This project encourages patients to ask good questions during a conversation with the doctor. The final goals of this project are to involve patients in decision-making and to improve conversations between patients

and doctors, because, as quoted: "*Better care starts with a good conversation*" [133]. The campaign "*3 good questions*" is an initiative of the Dutch patient federation and the federation of medical specialists [135]. ZGT also became a partner in 2019. The current study is therefore a good addition to achieving the goals of ZGT to improve patient-doctor communication. The results can be used in future research for designing innovations to improve shared decision-making and patient-centred care.

The current study also contained some limitations. No information was provided to the patients how PROMs could be used in the care process. This may have been an invalid procedure of receiving insight in the patient's willingness to monitor their health status. An improved way of learning what the actual attitude is regarding health monitoring would be to ask out several scenarios how PROM usage could be integrated in the care process. Furthermore, it is not entirely certain that no socially acceptable answers were given by HCPs as well as patients during the interviews. Even though the information letter and informed consent clearly indicated confidentiality.

A second limitation that occurred during the study was related to the C-SHIP model. The codes that were used for analysing the interviews appeared not to be relevant to the final conclusions of the study. The codes only gained insight in emotional effects of the disease in daily life and patients' self-regulated competences and skills, but those were found to have no influence on the ultimate research goal. In retrospect, the elements of the C-SHIP model did not have to be added to the codebook.

Additionally, the QoL items mentioned in the questionnaire were susceptible to multiple interpretations. This was related to the created list of items composed of various QoL questionnaires. This led to a list that was not validated but was only based on validated questionnaires. It is possible that the results are affected by misinterpretations of the respondents. Some of the items could have been placed under multiple QoL domains, causing some possible misunderstanding among respondents.

Due to part of the research method being based in qualitative practice, the results of the current study cannot be generalized over other cancer type patients and cancer staffs; they reflect the specific setting and characteristics of the sample and are inevitably shaped by the priorities and perspectives of the researcher.

5.4 RECOMMENDATIONS FOR FURTHER RESEARCH

The current study shows some requirements which a PROM should meet when it is to be used in clinical processes. Before a pilot could be started, a few factors should be considered first. Because of the

great variance of existing PROM possibilities, decisions should be made about whether an existing PROM should be implemented in current care processes or that a new PROM must be conducted. The Netherlands Comprehensive Cancer Organisation (IKNL) are currently working on a symptom measuring tool, called the SYMPRO-lung [136]. Using a digital application, lung cancer patients can indicate whether and how much they suffer from specific health-related complaints [137]. The existing SYMPRO-lung questionnaire could be used as PROM. Although, currently the SYMPRO-lung is mainly focussed on physical symptoms, this questionnaire could be supplemented with other QoL domains to receive a full picture of a patient's HRQoL. Future research should therefore focus on which (elements of) HRQoL questionnaires to use.

Currently, ZGT is working on a 'smart' digital platform for oncology, where patients can find relevant information about the twelve habitats affected by cancer. This innovation is called: "Self-learning platform '12 Habitats" [138] and is based on the 12 habitats of Bravis [139]. Instead of using only five QoL domains, the habitats of Bravis are more specific. The current study gained more insight into what subjects patients think are important to address and what the actual health status is of patients per subject. The degree of generalisability of the results of the current study has to be considered. The results of the current study are all based on data and opinions of NSCLC patients, treated with immunotherapy, but whether this also applies to patients with other cancer types needs further research. In order to gain objective health-related information of patients, instead of just self-reported data collected with questionnaires, wearable eHealth devices could also be used. This could lead to more insight in, e.g. the patient's activity and sleep behaviour. More research should be done on privacy and confidentiality of the patients' data. What PROM data should be shared with which HCP? Should the physiotherapist see the same data of the patient as the lung physician? Furthermore, further research should focus on the feasibility, desirability and application of this data in clinical practice. A collaboration with *ZGT Smartup Innovation* could be helpful to keep an eye on the technological requirements that the PROM tool should meet.

Another requirement that must be worked out in future studies, is to identify appropriate thresholds for PRO-based clinical alerts. Many PROMs were designed to analyse population estimates, but in practical use it is desired to be able to react on particular individual changes [36]. Therefore, the meanings of clinical outcomes require guidelines on how to act on certain scores. Before the PROM is implemented, these scores should be fixed in order to respond well to alarming signs. Clinicians should work together on determining those thresholds.

In the current study one element of both the PRISM and de CFIR were not included in the analysis of the results, being the External Environment (PRISM) and Outer Setting (CFIR). For a broader

understanding of the compatibility and acceptance of a PROM tool in current care processes, more research should be done on these elements, to ensure both the short-term and long-term adoption of the PROM tool. These elements provide more information of economic, political, and social context in which the organisation consists. In further research the emphasis should be on continuous involvement and the division of responsibilities of the relevant stakeholders, such as patients, physicians, nurses, and the secretary in the implementation process.

In conclusion, although the patients included in the current study did not directly see the added value of using an ePROM to improve the current care, existing literature states that using an ePROM in practical care has multiple advantages. First, it provides more insight into HRQoL of NSCLC patients, both for patients themselves and for HCPs. Next, it provides starting points for patients to help indicating health issues and provides HCPs guidelines for early recognition and action on those health issues. This would lead to improved communication between NSCLC patients and their HCPs and eventually to better health outcomes. These advantages were also acknowledged by the participating HCPs. The implementation climate of the lung department of ZGT can act as fertile soil for implementing interventions. Encouraged by the outcomes of this study and the existing literature, it is recommended to implement an ePROM tool in the care path of NSCLC patients.

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Appendix 1: Explanation of the frameworks

1A: COGNITIVE-AFFECTIVE UNITS OF THE C-SHIP [63]

Cognitive-affective unit	Description
Health-relevant encodes	Strategies and constructions for self-coding and health and wellbeing, health situations, risks and vulnerabilities, and illness. Contains attention strategies for selecting and processing potential health threats and hazards (i.e. memories of inferences, judgements, and abstractions about illness and its emotional consequences).
Health beliefs and expectancies	Specific beliefs and expectations triggered when processing health information. Contains expectations about it both outcomes and self-efficacy expectations.
Affects (emotions)	Affective states that are activated in the processing of health information (for example, anxiety, depression, hope, negative feelings about self, irritability and anger).
Health goals and values	Desired and appreciated health outcomes and states and their subjective importance and goals for health-relevant life projects
Self-regulatory competencies and skills	Knowledge and strategies for dealing with specific barriers to health protective behaviour and for construction and maintenance of health protective behaviours. Contains self-regulation strategies and behavioural scripts for implementing, maintaining and complying with long-term plans for health-protective behaviour and life projects.

1B: FACTORS WITHIN THE PRISM [42]

PRISM element		Factor
Intervention	*Organisational perspective*	• Readiness • Strength of evidence base • Addresses barriers of frontline staff (HPCs) • Coordination across departments and specialities • Complexity and cost • Usability and adaptability • Trialability and reversibility • Ability to observe results
	Patient perspective	• Patient centeredness • Provides patient choices • Addresses patient barriers • Seamlessness of transition between intervention elements • Service and access • Complexity and cost • Feedback of results
Recipients	*Organisational characteristics*	• Organisational health and culture • Management support and communication • Shared goals and cooperation • Clinical leadership • Systems and training • Data and decision support • Staffing and incentives • Expectation and sustainability
	Patient characteristics	• Demographics • Disease burden • Competing demands • Knowledge and beliefs

Implementation and Sustainability Infrastructure		• Performance data • Dedicated team • Adopter training and support • Relationship and communication with adopters (bridge researchers) • Adaptable protocols and procedures • Facilitation of sharing of best practices • Plan for sustainability

Appendix 2: Information letter and informed consent

Proefpersoneninformatie voor deelname aan medisch-wetenschappelijk onderzoek

Betreft: onderzoek naar de verbetering van patiëntgerichte zorg bij longkankerpatiënten

Officiële titel: Promoting QoL monitoring and communication between NSCLC patients and healthcare professionals in ZGT.

Inleiding

Geachte heer/mevrouw,

Wij vragen u om mee te doen aan een medisch-wetenschappelijk onderzoek. Meedoen is vrijwillig. U bent gevraagd deel te nemen aan het onderzoek naar de verbetering van patiëntgerichte zorg bij longkankerpatiënten.

Voordat u beslist of u wilt meedoen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt. Lees deze informatie rustig door en vraag de onderzoeker uitleg als u vragen heeft. U kunt er ook over praten met uw partner, vrienden of familie.

1. Algemene informatie

Dit onderzoek is opgezet door Universiteit Twente in samenwerking met het ZGT en wordt gedaan in het ZGT.

De haalbaarheidscommissie van het ZGT heeft dit onderzoek beoordeeld.

2. Doel van het onderzoek

Met dit onderzoek willen we meer inzicht verkrijgen in de kwaliteit van leven van longkankerpatiënten door te onderzoeken welke onderwerpen belangrijk zijn voor de patiënt om te bespreken tijdens gesprekken tussen u en uw arts of verpleegkundige. Met deze verkregen informatie willen we de communicatie tussen patiënten en zorgprofessionals verbeteren.

3. Achtergrond van het onderzoek

Uit onderzoek is gebleken dat de kwaliteit van zorg verbetert als de patient volledig wordt betrokken bij belangrijke keuzes voor zijn behandeling. Op dit moment is er nog onvoldoende bekend over de invloed van symptomen en bijwerkingen van de behandeling met immunotherapie op de kwaliteit

van leven van patiënten. Daarom is er van september 2019 tot en met februari 2020 een onderzoek gestart door ZGT in samenwerking met de Universiteit Twente om meer inzicht te krijgen in welke onderwerpen patiënten graag zouden willen bespreken tijdens gesprekken met de longarts of longverpleegkundige. In deze brief wordt het onderzoek toegelicht. Met deze verbetering van de communicatie tussen patiënten en artsen of verpleegkundigen wordt er geprobeerd een beeld te krijgen van wat een patiënt bezighoudt in het dagelijks leven en kan hier uiteindelijk beter op ingespeeld worden.

4. Wat meedoen inhoudt

Als u meedoet betekent dit dat u eenmalig een vragenlijst invult en dat de onderzoeker een interview bij u zal afnemen.

Anders dan bij gebruikelijke zorg

Normaal komt u één keer in de 2 of 3 weken bij uw longarts voor controle van uw longkanker of heeft u een gesprek met uw longverpleegkundige. Bij dit onderzoek wordt op de dag dat u een gesprek heeft met uw longarts of verpleegkundige een extra gesprek ingepland waarin de vragenlijst en interview worden afgenomen. Dit zal betekenen dat u in totaal ongeveer een uur langer in het ziekenhuis zal zijn. Er zal verder niets veranderen in uw gebruikelijke behandeling U hoeft geen rekening te houden met het onderzoek in uw dagelijkse activiteiten.

5. Wat wordt er van u verwacht

Voor deelname aan dit onderzoek ondervindt u geen beperkingen of extra leefregels. Er zal tijdens uw deelname niets veranderen in de zorg hoe u dit gewend bent.

Mogelijke voor- en nadelen

Het is belangrijk dat u de mogelijke voor- en nadelen goed afweegt voordat u besluit mee te doen. U heeft zelf geen direct voordeel bij deelname aan dit onderzoek. Uw deelname kan wel bijdragen aan meer kennis over de communicatie tussen u als patiënt en uw behandeld arts en/of verpleegkundige.

Nadelen van meedoen aan het onderzoek kunnen zijn dat u eenmalig extra tijd kwijt bent aan uw ziekenhuisbezoek.

6. Als u niet wilt meedoen of wilt stoppen met het onderzoek

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig.

Als u niet wilt meedoen, wordt u op de gebruikelijke manier behandeld voor uw longkanker

Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. U wordt ook dan op de gebruikelijke manier behandeld voor uw longkanker. U hoeft niet te zeggen waarom u

stopt. Wel moet u dit direct melden aan de onderzoeker. Stoppen heeft geen nadelige gevolgen voor uzelf.

De gegevens die tot dat moment zijn verzameld, worden gebruikt voor het onderzoek.

Als er nieuwe informatie over het onderzoek is die belangrijk voor u is, laat de onderzoeker dit aan u weten. U wordt dan gevraagd of u blijft meedoen.

7. Einde van het onderzoek

Uw deelname aan het onderzoek stopt voor u als

- De vragenlijst en het interview bij u zijn afgenomen
- U zelf kiest om te stoppen
- De onderzoeker het beter voor u vindt om te stoppen
- De Universiteit Twente/ZGT of de beoordelende medisch-ethische toetsingscommissie, besluit om het onderzoek te stoppen.

Het hele onderzoek is afgelopen als alle deelnemers klaar zijn.

8. Gebruik en bewaren van uw gegevens

Voor dit onderzoek worden uw persoonsgegevens verzameld, gebruikt en bewaard. Het gaat om uw leeftijd en om gegevens over uw gezondheid en behandeling. Het verzamelen, gebruiken en bewaren van uw gegevens is nodig om de vragen die in dit onderzoek worden gesteld te kunnen beantwoorden en de resultaten te kunnen publiceren. Wij vragen voor het gebruik van uw gegevens uw toestemming.

Vertrouwelijkheid van uw gegevens

Om uw privacy te beschermen krijgen uw een code. Uw naam en andere gegevens die u direct kunnen identificeren worden daarbij weggelaten. Alleen met de sleutel van de code zijn gegevens tot u te herleiden. De sleutel van de code blijft veilig opgeborgen in de lokale onderzoeksinstelling. De gegevens bevatten alleen de code, maar niet uw naam of andere gegevens waarmee u kunt worden geïdentificeerd. Ook in rapporten en publicaties over het onderzoek zijn de gegevens niet tot u te herleiden.

Toegang tot uw gegevens voor controle

Sommige personen kunnen op de onderzoekslocatie toegang krijgen tot al uw gegevens. Ook tot de gegevens zonder code. Dit is nodig om te kunnen controleren of het onderzoek goed en betrouwbaar is uitgevoerd. Personen die ter controle inzage krijgen in uw gegevens zijn: de commissie die de

veiligheid van het onderzoek in de gaten houdt, de onderzoekers die betrokken zijn bij dit onderzoek (zie **bijlage A**) en uw behandelaars. Zij houden uw gegevens geheim. Wij vragen u voor deze inzage toestemming te geven.

Bewaartermijn gegevens

Uw gegevens zullen 5 jaar worden bewaard op de onderzoekslocatie.

Bewaren en gebruik van gegevens voor ander onderzoek

Uw gegevens kunnen na afloop van dit onderzoek ook nog van belang zijn voor ander wetenschappelijk onderzoek op het gebied van longkanker en communicatie. Daarvoor zullen uw gegevens 5 jaar worden bewaard. U kunt op het toestemmingsformulier aangeven of u hier wel of niet mee instemt. Indien u hier niet mee instemt, kunt u gewoon deelnemen aan het huidige onderzoek.

Intrekken toestemming

U kunt uw toestemming voor gebruik van uw persoonsgegevens altijd weer intrekken. Dit geldt voor dit onderzoek en voor het bewaren en het gebruik voor het toekomstige onderzoek. De onderzoeksgegevens die zijn verzameld tot het moment dat u uw toestemming intrekt worden nog wel gebruikt in het onderzoek.

Meer informatie over uw rechten bij verwerking van gegevens

Voor algemene informatie over uw rechten bij verwerking van uw persoonsgegevens kunt u de website van de Autoriteit Persoonsgegevens raadplegen.

Bij vragen over uw rechten kunt u contact opnemen met de verantwoordelijke voor de verwerking van uw persoonsgegevens. Voor dit onderzoek is dat: ZGT

Bij vragen of klachten over de verwerking van uw persoonsgegevens raden we u aan eerst contact op te nemen met de onderzoeker: Ester de Groot, e.dgroot@zgt.nl. U kunt ook contact opnemen met de Functionaris voor de Gegevensbescherming van de instelling. Zie hiervoor de contactgegevens genoemd in **bijlage A**.

9. Heeft u vragen?

Bij vragen kunt u contact opnemen met de onderzoeker. Indien u klachten heeft over het onderzoek, kunt u dit bespreken met de onderzoeker of uw behandelend arts. Wilt u dit liever niet, dan kunt u zich wenden tot de klachtenfunctionaris. Alle gegevens vindt u in **bijlage A**: Contactgegevens.

10.Ondertekening toestemmingsformulier

Wanneer u voldoende bedenktijd heeft gehad, wordt u gevraagd te beslissen over deelname aan dit onderzoek. Indien u toestemming geeft, zullen wij u vragen deze op de bijbehorende toestemmingsverklaring schriftelijk te bevestigen. Door uw schriftelijke toestemming geeft u aan dat u de informatie heeft begrepen en instemt met deelname aan het onderzoek.

Zowel uzelf als de onderzoeker ontvangen een getekende versie van deze toestemmingsverklaring.

Dank voor uw aandacht.

11. Bijlagen bij deze informatie

A. Contactgegevens

B. Toestemmingsformulier

Bijlage A: contactgegevens voor het ZGT

Hoofdonderzoeker:

Mw. Dr. A, J. Staal-van den Brekel (longarts)

Telefoonnummer: 088-703 33 00

Uitvoerend onderzoeker:

Ester de Groot

Student Health Sciences, Universiteit Twente / ZGT

Emailadres: e.dgroot@zgt.nl

Klachtenfunctionaris ZGT:

Mw. M. Stegeman

Telefoonnummer: 088-708 52 11

Emailadres: mar.stegeman@zgt.nl

Functionaris voor de Gegevensbescherming:

T.a.v. mw. mr. D.M. Oldenkotte

Postbus 546

7550 AM Hengelo

E-mailadres: gegevensbescherming@zgt.nl

Voor meer informatie over uw rechten:

Functionaris voor de Gegevensbescherming van de Universiteit Twente

dr. Lyan Kamphuis-Blikman

Telefoonnummer: 053- 489 3399

E-mail: l.j.m.blikman@utwente.nl

Bijlage B: toestemmingsformulier proefpersoon

Promoten monitoring kwaliteit van leven en patiënt-dokter-communicatie

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik geef toestemming voor het informeren van mijn behandelend arts dat ik meedoe aan dit onderzoek.
- Ik weet dat voor de controle van het onderzoek sommige mensen toegang tot al mijn gegevens kunnen krijgen. Die mensen staan vermeld in deze informatiebrief. Ik geef toestemming voor die inzage door deze personen.
- Ik geef □ **wel**

  □ **geen**

  toestemming om mijn persoonsgegevens langer te bewaren en te gebruiken voor toekomstig onderzoek op het gebied van longkanker
- Ik geef □ **wel**

  □ **geen**

  toestemming om mij na dit onderzoek opnieuw te benaderen voor een vervolgonderzoek.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn gegevens voor de beantwoording van de onderzoeksvraag in dit onderzoek
- Ik wil meedoen aan dit onderzoek.

Naam proefpersoon:

Handtekening: Datum : __ / __ / __

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de proefpersoon zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening: Datum: __ / __ / __

Aanvullende informatie is gegeven door:

Naam:

Functie:

Handtekening: Datum: __ / __ / __

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* Doorhalen wat niet van toepassing is.

Appendix 3: Questionnaire Patients

VRAGENLIJST

Geachte meneer, mevrouw,

Hartelijk dank voor het invullen van deze vragenlijst voor een onderzoek naar de communicatie tussen patiënten en hun arts of verpleegkundige. U bent geselecteerd om de vragenlijst in te vullen omdat u reeds bent gestart met immunotherapie of binnenkort met immunotherapie gaat starten. De vragenlijst bestaat uit twee delen: het eerste gedeelte bevat vragen over kenmerken van u als patiënt. Het tweede gedeelte van de vragenlijst bestaat uit vragen die betrekking hebben op de communicatie tussen u en uw behandelaar. Het derde onderdeel is gericht op uw voorkeuren op gebied van onderwerpen die u graag ter sprake zou willen laten komen tijdens een gesprek met uw longarts of uw longverpleegkundige. De vragenlijst bestaat zowel uit open als gesloten vragen. De gesloten vragen kunt u beantwoorden door een vinkje in het vakje te zetten dat voor u het meest van toepassing is. Het onderzoek is anoniem en zal niet van invloed zijn op uw behandeling.

Deel 1

Wat is uw geslacht?

- ☐ Man
- ☐ Vrouw
- ☐ Geef ik liever niet aan

Wat is uw leeftijd?

- ☐ Jonger dan 25 jaar
- ☐ 26-35 jaar
- ☐ 36-45 jaar
- ☐ 46-55 jaar
- ☐ 56-65 jaar
- ☐ Ouder dan 65 jaar

Wat is de hoogste opleiding die u heeft afgerond?

- ☐ Geen onderwijs gevolgd
- ☐ Lagere school
- ☐ Lager beroepsonderwijs (lbo)
- ☐ Middelbaar algemeen voortgezet onderwijs (bijv. (m)ulo, mavo)
- ☐ Een middelbaar beroepsonderwijs (mbo, bijv. mts, meao, mhno, inas)
- ☐ Hoger algemeen onderwijs (bijv. hbs, atheneum, gymnasium, mms, havo, vwo)
- ☐ Hoger beroepsonderwijs (hbo)
- ☐ Wetenschappelijk onderwijs (wo)
- ☐ Anders, namelijk ……

Hoe lang geleden bent u gediagnosticeerd met longkanker (ongeveer)?

- ☐ Meer dan een jaar geleden
- ☐ 9-12 maanden geleden
- ☐ 6-9 maanden geleden
- ☐ 3-6 maanden geleden
- ☐ 0-3 maanden geleden

Welke soort behandeling ontvangt u/gaat u (waarschijnlijk) ontvangen?

- ☐ Alleen immunotherapie
- ☐ Een combinatie van immunotherapie en chemotherapie
- ☐ Een andere combinatie therapieën

In welk stadium van de behandeling zit u op dit moment?

- ☐ Ik ga binnenkort starten met de behandeling
- ☐ Ik heb 1-6 kuren gehad
- ☐ Ik heb 7 of meer kuren gehad

Deel 2

De volgende vragen gaan over de communicatie tussen u en uw arts. Met deze vraag willen we onderzoeken hoe de communicatie tussen artsen en patiënten over het algemeen verloopt. Wilt u bij iedere vraag aangeven hoeveel vertrouwen u erin heeft dat u in staat bent om dit uit te voeren? Hoe meer vertrouwen u erin heeft, hoe meer u uw kruisje in de richting van 'Heel veel vertrouwen' plaatst.

Bijvoorbeeld:

Hoeveel vertrouwen heeft u erin dat u in staat bent om de aandacht van een arts te krijgen voor wat u te vertellen heeft?

Wanneer u hier helemaal geen vertrouwen in heeft, kruist u het meest linkse hokje aan:

Helemaal geen vertrouwen ☒ ☐ ☐ ☐ ☐ Heel veel vertrouwen

Hoeveel vertrouwen heeft u erin dat u …

1. Weet welke vragen u een arts moet stellen?

Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen

2. In staat bent om een arts al uw vragen te laten beantwoorden?

Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen

3. Het bezoek aan een arts optimaal weet te benutten?

Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen

4. In staat bent om een arts uw belangrijkste gezondheidsklacht serieus te laten nemen?

Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen

5. In staat bent om een arts iets aan uw belangrijkste gezondheidsprobleem te laten doen?

Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen

Deel 3

In dit gedeelte van de vragenlijst wordt u gevraagd uw voorkeuren voor gespreksonderwerpen aan te geven. Deze voorkeuren zijn gericht op lichamelijk, functioneel, emotioneel, sociaal en psychologisch welzijn. Onder deze domeinen vallen bepaalde kenmerken. In het dagelijks leven kunnen deze kenmerken invloed hebben op uw kwaliteit van leven. Om meer inzicht te krijgen in welke onderwerpen voor patiënten belangrijk zijn om te bespreken met uw longarts/longverpleegkundige, wordt u gevraagd aan te geven welke onderwerpen volgens u de voorkeur krijgen om behandeld te worden tijdens een consult.

Kruis maximaal 10 kenmerken aan die u graag zou willen bespreken met uw arts/ longverpleegkundige tijdens een consult:

1. **Lichamelijk welzijn**

- ☐ ……. (Het kunnen uitvoeren van) dagelijkse activiteiten
- ☐ ……. Energie en vermoeidheid
- ☐ ……. Pijn en ongemak
- ☐ ……. Slaap en rust
- ☐ ……. Bijwerkingen van de behandeling
- ☐ ……. Anders, namelijk…….

2. **Functioneel welzijn**

- ☐ ……. (Het kunnen uitvoeren van) huishoudelijke klussen
- ☐ ……. Uzelf wassen /verzorgen
- ☐ ……. Transport (over grotere afstand)
- ☐ ……. Mobiliteit (binnenshuis)
- ☐ ……. Werkcapaciteit
- ☐ ……. Anders, namelijk……..

3. **Emotioneel welzijn**

- ☐ ……. Depressie / treurigheid / somberheid

☐ ……. Angst

☐ ……. Stress / bezorgdheid

☐ ……. Verlies van controle

☐ ……. Positieve gevoelens

☐ ……. Anders, namelijk……..

4. **Sociaal welzijn**

☐ ……. Humeur

☐ ……. Energie / zin in sociale interactie

☐ ……. Seksualiteit / intimiteit

☐ ……. Sociale steun (support vanuit naasten en familieleden)

☐ ……. Sociale aanvaarding / acceptatie (begrepen voelen door omgeving)

☐ ……. Anders, namelijk……..

5. **Psychologisch welzijn**

☐ ……. Lichaamsbeeld en uiterlijk

☐ ……. Eigenwaarde / religie / persoonlijke overtuigingen

☐ ……. Denken, leren, geheugen en concentratie

☐ ……. Autonomie

☐ ……. Tevredenheid over de levensomstandigheden (financiële situatie, levensrol, enz.)

☐ ……. Anders, namelijk……..

Noteer nu achter de vakjes van uw gekozen onderwerpen een cijfer op basis van belangrijkheid (1 = meest belangrijk om te bespreken, 10 = minst belangrijk om te bespreken.

Appendix 4: Domains and items of QoL

Domain	Item
1. Physical wellbeing	a. Activities of daily living b. Energy and fatigue c. Pain and discomfort d. Sleep and rest e. Side effects of treatment
2. Functional wellbeing	a. Household chores b. Washing / self-care c. Transport d. Mobility e. Work capacity
3. Emotional wellbeing	a. Depression / sadness / unhappiness b. Anxiety / fear c. Stress / worries d. Loss of control e. Positive feelings
4. Social wellbeing	a. Mood b. Social energy / desire for interacting c. Sexuality / intimacy d. Social support e. Social acceptance
5. Psychological wellbeing	a. Bodily image and appearance b. Self-esteem spirituality / religion / personal beliefs c. Thinking, learning, memory and concentration d. Autonomy e. Satisfaction with living conditions (financial situation, life role, etc.)

Appendix 5: Questionnaire Healthcare Professionals

VRAGENLIJST

Geachte meneer, mevrouw,

Hartelijk dank voor het invullen van deze vragenlijst voor een onderzoek naar de communicatie tussen patiënten en hun arts of verpleegkundige. De vragenlijst bestaat uit twee delen: het eerste gedeelte bevat vragen over kenmerken van u als arts of verpleegkundige. Het tweede gedeelte van de vragenlijst bestaat uit vragen die betrekking hebben op de communicatie tussen u en de patiënt en uw voorkeuren op gebied van onderwerpen die u graag ter sprake zou willen laten komen tijdens een gesprek met een patiënt. De vragenlijst bestaat zowel uit open als gesloten vragen. De gesloten vragen kunt u beantwoorden door een vinkje in het juiste vakje te zetten.

Deel 1

Wat is uw geslacht?

- ☐ Man
- ☐ Vrouw
- ☐ Geef ik liever niet aan

Wat is uw leeftijd?

- ☐ Jonger dan 25 jaar
- ☐ 26-35 jaar
- ☐ 36-45 jaar
- ☐ 46-55 jaar
- ☐ Ouder dan 55 jaar

Wat is uw functie?

- ☐ Longarts met aandachtsgebied oncologie
- ☐ Longoncologieverpleegkundige

Hoe lang bent u werkzaam in deze functie?

- ☐ 0-4 jaar
- ☐ 5-9 jaar
- ☐ 10-14 jaar
- ☐ 15-19 jaar
- ☐ Meer dan 20 jaar

Deel 2

In dit gedeelte van de vragenlijst wordt u gevraagd uw voorkeuren aan te geven. Deze voorkeuren zijn gericht op de verschillende domeinen binnen het Kwaliteit-van-Leven model, namelijk lichamelijk, functioneel, emotioneel, sociaal en psychologisch welzijn. In het dagelijks leven kunnen kenmerken van deze domeinen invloed hebben op de kwaliteit van leven van een longkankerpatiënt. Om meer inzicht te krijgen in welke onderwerpen voor u over het algemeen belangrijk zijn om te bespreken met een patiënt, wordt u gevraagd aan te geven welke onderwerpen volgens u de voorkeur krijgen om ter sprake te laten komen tijdens een consult.

Kruis maximaal 10 kenmerken aan die u graag zou willen bespreken met een patiënt tijdens een consult:

1. **Lichamelijk welzijn**

- ☐ ……. (Het kunnen uitvoeren van) dagelijkse activiteiten
- ☐ ……. Energie en vermoeidheid
- ☐ ……. Pijn en ongemak
- ☐ ……. Slaap en rust
- ☐ ……. Bijwerkingen van de behandeling
- ☐ ……. Anders, namelijk…….

2. **Functioneel welzijn**

- ☐ ……. (Het kunnen uitvoeren van) huishoudelijke klussen
- ☐ ……. Uzelf wassen / verzorgen
- ☐ ……. Transport (over grotere afstand)
- ☐ ……. Mobiliteit (binnenshuis)
- ☐ ……. Werkcapaciteit
- ☐ ……. Anders, namelijk……

3. **Emotioneel welzijn**

- ☐ ……. Depressie / treurigheid / somberheid
- ☐ ……. Angst
- ☐ ……. Stress / bezorgdheid
- ☐ ……. Verlies van controle
- ☐ ……. Positieve gevoelens
- ☐ ……. Anders, namelijk……

4. **Sociaal welzijn**

- ☐ ……. Humeur
- ☐ ……. Energie / zin in sociale interactie
- ☐ ……. Seksualiteit / intimiteit
- ☐ ……. Sociale steun (support vanuit naasten en familieleden)
- ☐ ……. Sociale aanvaarding / acceptatie (begrepen voelen door omgeving)
- ☐ ……. Anders, namelijk……

5. **Psychologisch welzijn**

- ☐ ……. Lichaamsbeeld en uiterlijk
- ☐ ……. Eigenwaarde / religie / persoonlijke overtuigingen
- ☐ ……. Denken, leren, geheugen en concentratie
- ☐ ……. Autonomie
- ☐ ……. Tevredenheid over de levensomstandigheden (financiële situatie, levensrol, enz.)
- ☐ ……. Anders, namelijk……..

Noteer nu achter de vakjes van uw gekozen onderwerpen een cijfer op basis van belangrijkheid (1 = meest belangrijk om te bespreken, 10 = minst belangrijk om te bespreken.

Appendix 6: Interview Scheme Patients

Introductie van de interviewer
Interviewer stelt zichzelf voor en bedankt patiënt voor deelname aan het onderzoek.

Context en doel van het interview
Dit interview is onderdeel van het onderzoek naar de gespreksbehoeftes van longkankerpatiënten en zorgprofessionals. Met deze verkregen informatie willen wij kijken welke onderwerpen belangrijk voor u zijn om te bespreken met uw arts of verpleegkundige en waarom u dit belangrijk vindt. Deze informatie willen we uiteindelijk gebruiken om een toepassing te maken voor het monitoren, dus het bijhouden, van uw dagelijkse kwaliteit van leven. Tegenwoordig weten wij vaak alleen hoe u zich voelt op de momenten dat u een afspraak heeft met uw arts of verpleegkundige. Het is daarom vaak lastig in te schatten hoe het verloop is van uw gezondheid. Om hier beter inzicht in te krijgen, willen wij dus een toepassing gaan ontwerpen om uw gezondheid bij te kunnen houden in het dagelijks leven.

Duur
Dit interview duurt maximaal 45 minuten.
Eerst vult u een korte vragenlijst in om aan te geven hoe de communicatie tussen u en uw arts verloopt. Daarna krijgt u een lijst met kenmerken te zien waaruit u maximaal 10 kenmerken kiest die u belangrijk vindt om te bespreken met uw arts. Nadat u dit heeft gedaan gaan we in het interview dieper in op wat u heeft ingevuld in de vragenlijst.

- Alles wat u invult en vertelt zal vertrouwelijk worden verwerkt.
- Het is standaard voor ons dat wij de verkregen informatie van u niet delen met uw arts, tenzij u aangeeft dat u dit graag wil. Dit betekent dus ook dat de gespreksvoering met uw arts niet beïnvloed zal worden door dit interview.

Behandeling van de verzamelde data in dit interview
De resultaten van de vragenlijst en het interview zullen anoniem zijn en het interview wordt alleen uitgevoerd na ondertekening van de Informed Consent door u. De naam en persoonlijke informatie van u zullen niet in het transcript worden opgenomen. Tijdens het interview zullen aantekeningen worden gemaakt. Dit is nodig om mij te helpen bij het leiden van het interview. Vindt u het goed als ik het interview ook opneem?

--- Patiënt vult hier de vragenlijst in ---

“Het kan zijn dat ik af en toe even op mijn blaadje kijk. Dit is voor mijzelf om even te checken of ik alle informatie binnen heb die ik nodig heb voor dit onderzoek. “

U kunt te allen tijde stoppen met het interview, mocht dit nodig zijn. Vindt u het goed als ik het gesprek opneem?

---- De audio-opname wordt gestart -----

What items of QoL should be measured according to NSCLC patients in order to gain better insight into the topics to be addressed during patient-physician consultations?

1) U heeft aangevinkt dat u …. belangrijk vindt om te bespreken tijdens een gesprek met uw arts of verpleegkundige. Waarom zijn deze items belangrijk voor u?

2) Worden deze items nu al tijdens gesprekken met de arts of verpleegkundige besproken?
    a. Zo nee, waarom niet?
        i. Zou u hier verandering in willen zien?
    b. Zo ja,
        i. Vindt u de mate waarin het aan bod komt voldoende?
        ii. Worden de items voornamelijk door uzelf aangedragen of door uw behandelaar?
        iii. Komen deze items alleen sóms ter sprake of tijdens élk gesprek met uw behandelaar?
        iv. Wanneer komen ze ter sprake? (bijvoorbeeld als het slecht ging op dat gebied of omdat het al een tijdje niet ter sprake is gekomen, of zelf met klachten kwam?)
3) Als de lijst van wat u heeft aangegeven als belangrijk wordt besproken met uw arts, heeft u dan het idee dat de arts een compleet beeld heeft van hoe het met u gaat?
4) Met wie (type behandelaar) bespreekt u deze items het liefst?
5) Zijn er ook items die nooit ter sprake komen tijdens een gesprek met uw arts of verpleegkundige?
    a. Weet u hoe dat komt?
    b. Wat vindt u hiervan?
6) Zijn er ook dingen die u niet zou willen bespreken?
    a. Zo ja, waarom niet?
    b. Zo nee, zou u ieder onderwerp zelf ter sprake kunnen brengen of zou u het alleen niet érg vinden als de arts of verpleegkundige het ter sprake brengt?
        i. Uzelf: Waar hangt het vanaf wat u ter sprake laat komen?
        ii. Arts/verpleegkundige: Waarom?
7) Bereidt u zich voor een gesprek altijd voor waarbij u bedenkt wat u graag ter sprake zou willen laten komen tijdens een gesprek met uw arts of verpleegkundige?
    a. Zo ja, waarom?
        i. Hoe?
        ii. Altijd?
        iii. Alleen als iets is voorgevallen?
        iv. Andere redenen?
    b. Zo nee, waarom niet?
8) Bent u na een gesprek met uw behandelaar tevreden over de onderwerpen die tijdens gesprekken met uw arts of verpleegkundige zijn besproken?
    a. Zo nee, waar ligt dat aan?
    b. Zo ja, waar ligt dat aan?
9) Zijn er nog andere dingen waar u behoefte aan heeft op gebied van het gespreken van uw gezondheid met uw behandelaar?

a. Wat heeft u hiervoor nodig?

10) In hoeverre vindt de naaste het fijn dat hij/zij betrokken wordt?
    a. Tijdens gesprekken met de arts?

Wij willen onderzoeken wat patiënten ervan zouden vinden als een toepassing voor het volgen van hun gezondheid zou worden ingevoerd over functioneren in het dagelijks leven. Met deze toepassing kan uw arts of verpleegkundige beter op de hoogte gehouden worden hoe u zich voelt in het dagelijks leven. We willen onderzoeken hoe een dergelijke toepassing eruit moet komen te zien volgens u. De volgende vragen gaan over de kenmerken waar die toepassing aan moet voldoen om deze uitvinding te gebruiken in het dagelijks leven.

What are the expectations of NSCLC patients and healthcare professionals according to mutual information transfer when PROs are measured?

11) Zou u bereid zijn om regelmatig bij te houden hoe het met uw gezondheid gaat?
    a. Waarom?
    b. Welke informatie wel/niet afstaan?
    c. Wanneer wel/niet (randvoorwaarden?) (bv alleen als de arts ook daadwerkelijk iets doet met deze info)
12) Hoe vaak zou u uw gezondheid willen monitoren/vastleggen?
    a. Dagelijks?
    b. Wekelijks?
    c. Alleen voorafgaand aan een gesprek met de arts of verpleegkundige?
13) Wat is er voor u nodig om de arts of verpleegkundige beter op de hoogte houden van uw dagelijkse gezondheid?
14) Ben u naast het beschrijven van uw gezondheid ook bereid informatie over voeding, beweging, etc. te delen met uw behandelaar?
15) Zou u het prettig vinden om meer inzicht te krijgen in uw gezondheid door een monitoringssysteem in te vullen?
16) Denkt u dat het invullen van een monitoringssysteem u zou helpen om meer inzicht te krijgen in uw gezondheid?
17) Op welk gebied zou dit u helpen?
18) Zou het u motiveren om uw leefstijl aan te passen?
19) In hoeverre bent u bereid om het invullen van een vragenlijst over uw gezondheid bij te houden voor langere tijd?
20) In hoeverre heeft u er vertrouwen in dat uw arts of verpleegkundige naar de ingevulde informatie gaat kijken?
21) Wanneer zou u de ingevulde informatie bespreekbaar willen maken tijdens gesprekken?

    a) Wanneer zou u willen dat uw arts of verpleegkundige een melding krijgt over een verandering in uw gezondheidsstatus?

22) Zou u het prettig vinden als de informatie die u heeft ingevuld over uw gezondheid wordt meegenomen in beslissingen die worden gemaakt over uw behandeling?
23) Wat ziet u als mogelijke voordelen van het hebben van inzicht in uw kwaliteit van leven / hoe het in het dagelijks leven met u gaat??
25) En wat ziet u als mogelijke nadelen van het hebben van inzicht in uw kwaliteit van leven?
26) Wilt u verder nog iets kwijt over dit onderwerp of ben ik nog iets vergeten te vragen?

Voor naasten:

1) Welke items van kwaliteit van leven zou u vaker willen aandragen wanneer u mee gaat?
2) Zou u meer inzicht willen in de gezondheidsstatus van ….
3) Denkt u dat een dergelijke monitoringstoepassing daar een geschikte manier voor zou kunnen zijn?
4) Hoe zou u de monitoringstoepassing gaan gebruiken?
    a. Wanneer?
5) Wilt u nog wat toevoegen aan wat (naam patiënt) net heeft verteld?

Afsluiting van het interview
Dan zijn we hierbij aangekomen bij het einde van dit interview.

Respondent bedanken
Ik wil u hartelijk bedanken voor uw bijdrage aan dit onderzoek. Mocht u nog vragen hebben of nog graag iets kwijt willen wat u later nog bedenkt, kunt u mij altijd bereiken. Mijn contactgegevens staan in de informatiebrief.

------- De audio-opname wordt gestopt -------

Feedback
Wat vond u van dit interview? Het u nog feedback voor mij op basis van dit interview?

Appendix 7: Interview Scheme Healthcare professionals

Introductie van de interviewer
Interviewer stelt zichzelf voor en bedankt patiënt voor deelname aan het onderzoek.

Context en doel van het interview
Dit interview is onderdeel van het onderzoek naar de gespreksbehoeftes van longkankerpatiënten en zorgprofessionals. Met deze verkregen informatie willen wij kijken welke onderwerpen die u net heeft bekeken bij het invullen van de vragenlijst belangrijk voor u zijn om te bespreken met de patiënt en waarom u dit belangrijk vindt. Deze informatie willen we uiteindelijk gebruiken om een toepassing te maken voor het monitoren, dus het bijhouden, van de dagelijkse kwaliteit van leven van patiënten. Tegenwoordig is vaak alleen bekend hoe patiënten zich voelen op de momenten dat u een afspraak heeft met de patiënt. Het is daarom vaak lastig in te schatten hoe het verloop is van hun gezondheid. Om hier beter inzicht in te krijgen, willen wij dus een toepassing gaan ontwerpen om de gezondheid bij te kunnen houden in het dagelijks leven. Ik ga u straks een paar vragen stellen over wat u net heeft ingevuld bij de vragenlijst en daarna ga ik wat dieper in op de toepassing zelf voor het monitoren van de gezondheid van patiënten.

Duur
Dit interview duurt maximaal 45 minuten.
Eerst vult u een korte vragenlijst in. U krijgt een lijst met kenmerken te zien waaruit u maximaal 10 kenmerken kiest die u over het algemeen belangrijk vindt om te bespreken met de patiënt. Nadat u dit heeft gedaan gaan we in het interview dieper in op wat u heeft ingevuld in de vragenlijst.

--- Zorgprofessional vult hier de vragenlijst in ---

Behandeling van de verzamelde data in dit interview
De resultaten van dit interview zullen anoniem zijn en het interview wordt alleen uitgevoerd na ondertekening van de Informed Consent door u. De naam en persoonlijke informatie van u zullen niet in het transcript worden opgenomen. Tijdens het interview zullen aantekeningen worden gemaakt. Dit is nodig om mij te helpen bij het leiden van het interview. Vindt u het goed als ik het interview ook opneem?

“Het kan zijn dat ik af en toe even op mijn blaadje kijk. Dit is voor mijzelf om even te checken of ik alle informatie binnen heb die ik nodig heb voor dit onderzoek. “

U kunt te allen tijde stoppen met het interview, mocht dit nodig zijn.

---- De audio-opname wordt gestart -----

What items of QoL are most important to be measured according to healthcare professionals to gain better insight in the quality of life of NSCLC patients?

1) Waarom vindt u deze aangevinkte items van kwaliteit van leven zo belangrijk?

2) Komen deze items tijdens gesprekken met patiënten naar voren?
    a. Zo ja,
        i. Hoe vaak?
        ii. Waarom?

iii. Bent u vaak degene die de items naar voren brengt in gesprekken of doet de patiënt dit vaker?

b. Zo nee, waarom niet?

3) Op welke manier zou het bespreken van deze onderwerpen de zorg voor de patiënt verbeteren?
4) Zijn er ook items die nooit ter sprake komen tijdens een gesprek met de patiënt?
    a. Wat vindt u hiervan?
5) Zijn er ook items die u niet zou willen bespreken?
    a. Zo ja, waarom niet?
    b. Zo nee, zou u ieder onderwerp zelf ter sprake kunnen brengen of zou u het alleen niet érg vinden als de patiënt het ter sprake brengt?
        i. Uzelf: Waar hangt het vanaf wat u ter sprake laat komen?
        ii. Arts/verpleegkundige: Waarom?
6) Bereidt u zich voor een gesprek altijd voor waarbij u bedenkt wat u graag ter sprake zou willen laten komen tijdens een gesprek met de patiënt?
    a. Zo ja, waarom?
        i. Hoe?
        ii. Altijd?
        iii. Alleen als iets is voorgevallen/ervaring in eerdere gesprekken?
    b. Zo nee, waarom niet?
7) Bent u na een gesprek met een patiënt tevreden over de onderwerpen die tijdens gesprekken zijn besproken?
8) Zijn er nog andere dingen waar u behoefte aan heeft op gebied van het bespreken van de gezondheid van de patiënt met u?
    a. Wat heeft u hiervoor nodig?
9) Wat ziet u als mogelijke (andere) voordelen van het hebben van inzicht in de kwaliteit van leven van de patiënt?
10) En wat ziet u als mogelijke nadelen van het hebben van inzicht in de kwaliteit van leven van de patiënt?
11) In hoeverre betrekt u de partner / familielid bij het gesprek?
    a. Bent u hier tevreden mee?

Wij willen onderzoeken wat patiënten ervan zouden vinden als een toepassing voor het volgen van hun gezondheid zou worden ingevoerd over functioneren in het dagelijks leven. Met deze toepassing kan uw arts of verpleegkundige beter op de hoogte gehouden worden hoe u zich voelt in het dagelijks leven. We willen onderzoeken hoe een dergelijke toepassing eruit moet komen te zien volgens u. De volgende vragen gaan over de kenmerken waar die toepassing aan moet voldoen om de tool te gebruiken in het dagelijks leven.

What are the expectations of NSCLC patients and healthcare professionals according to mutual information transfer when PROs are measured?

12) Wat verwacht u van patiënten met betrekking tot de verbetering van inzicht in symptomen en bijwerkingen wanneer zij hun kwaliteit van leven gaan bijhouden?
13) Wat voor randvoorwaarden zou u hebben bij de implementatie van een elektronische Patient Reported Outcome Measure?
14) Hoe goed denkt u dat de ePROM zal voldoen aan de behoeften van patiënten?
15) Hoe denkt u dat patiënten op de ePROM zullen reageren?
16) Met welke belemmeringen zullen patiënten tegenkomen bij de implementatie van een ePROM?
17) In hoeverre zou u de ingevulde informatie bespreken met uw patiënt?
18) In hoeverre zou u de informatie gaan meenemen in beslissingen over de behandeling?
19) In hoeverre verwacht u dat het gedrag van patiënten gaat veranderen als zij voorafgaand aan een consult een Patient Reported Outcome Measures invullen?
20) In hoeverre moet u zich als arts aan deze verandering aanpassen?
    a. Op gebied van mindset?
    b. Op gebied van handelingen?
21) In hoeverre bent u daartoe bereid?

What changes in patient-physician interaction during consultations are necessary to make the implementation of the ePROM tool appropriate and valuable?

22) Hoe staat de longafdeling over het algemeen tegenover de implementatie van een nieuwe interventie?
23) In hoeverre denkt u dat het mogelijk is om nieuwe dingen te proberen om de huidige zorgprocessen te verbeteren?
24) Hoe goed zou een elektronisch Patient Reported Outcome Measure passen in de huidige zorgprocessen voor longkankerpatiënten?
25) Wat is in het algemeen nodig om een Patient Reported Outcome Measure te implementeren in een zorgtraject van een patiënt?
26) Mist daar nog iets aan in het huidige zorgtraject van longkankerpatiënten hier binnen het ZGT?
27) Ziet u barrières voor de implementatie van een ePROM binnen de huidige zorgprocessen?
    a. Zo ja, waar?
28) Wanneer er meer aandacht gevestigd wordt op andere items van kwaliteit van leven, naast het bespreken van de bijwerkingen of symptomen van de patiënt, zou er dan iets veranderd moeten worden in de invulling en planning van het consult?
    a. Zo ja, wat?
29) Welke informatie zou u graag willen zien van de patiënt wanneer hij of zij de ePROM heeft ingevuld?
    a. Wanneer/door welke informatie wilt u gealarmeerd worden?
    b. Wat voor soort signalen ziet u als alarmerende signalen?
30) Welke informatie hoeft u niet te zien van de patiënt?
31) Verwacht u dat er bepaalde middelen nodig zijn om de ePROM te implementeren?
    a. Zo ja, welke?
32) Zullen er andere vaardigheden nodig zijn om een PROM te gebruiken en te bespreken?

a. Hoe denkt u dat uw vaardigheden zijn op dit gebied?

33) Wilt u verder nog iets kwijt over dit onderwerp?

Afsluiting van het interview

Dan zijn we hierbij aangekomen bij het einde van dit interview.

Respondent bedanken

Ik wil u hartelijk bedanken voor uw bijdrage aan dit onderzoek. Mocht u nog vragen hebben of nog graag iets kwijt willen wat u later nog bedenkt, kunt u mij altijd bereiken. Mijn contactgegevens staan in de informatiebrief.

------- De audio-opname wordt gestopt -------

Feedback

Wat vond u van dit interview? Het u nog feedback voor mij op basis van dit interview?

Dingen om te vragen aan de arts:

Het kan zijn dat de patiënt de lijst met kenmerken mee wil nemen naar het gesprek toe om aan te kaarten wat zij wil bespreken. Vindt u dit goed?

Checkbox onderwerpen:

- ☐ Belangrijke /onbelangrijke onderwerpen aan bod
- ☐ Tevredenheid over besproken onderwerpen
- ☐ Goed beeld van gezondheid van patiënt
- ☐ Voor en nadelen inzicht in gezondheid patiënt
- ☐ Implementatie innovaties
- ☐ Added value tool
- ☐ Eisen tool

Appendix 8: Code book

CFIR Codes	
I. Innovation Characteristics	
A. Cost	Definition: Costs of the innovation and costs associated with implementing the innovation including investment, supply, and opportunity costs. Inclusion Criteria: Include statements related to the cost of the innovation and its implementation. Exclusion Criteria: Exclude statements related to physical space and time, and code to Available Resources. In a research study, exclude statements related to costs of conducting the research components (i.e., funding for research staff, participant incentives).
II. Outer Setting	
A. Needs & Resources of Those Served by the Organization	Definition: The extent to which the needs of those served by the organization (i.e., patients), as well as barriers and facilitators to meet those needs, are accurately known and prioritized by the organization. Inclusion Criteria: Include statements demonstrating (lack of) awareness of the needs and resources of those served by the organization. Analysts may be able to infer the level of awareness based on statements about: 1. Perceived need for the innovation based on the needs of those served by the organization and if the innovation will meet those needs; 2. Barriers and facilitators of those served by the organization to participating in the innovation; 3. Participant feedback on the innovation, i.e., satisfaction and success in a program. In addition, include statements that capture whether or not awareness of the needs and resources of those served by the organization influenced the implementation or adaptation of the innovation. Exclusion Criteria: Exclude statements that demonstrate a strong need for the innovation and/or that the current situation is untenable and code to Tension for Change. . Exclude statements related to engagement strategies and outcomes, i.e., how innovation participants became engaged with the innovation, and code to Engaging: Innovation Participants.
B. Peer Pressure	Definition: Mimetic or competitive pressure to implement an innovation, typically because most or other key peer or competing organizations have already implemented or are in a bid for a competitive edge. Inclusion Criteria: Include statements about perceived pressure or motivation from other entities or organizations in the local geographic area or system to implement the innovation. Exclusion Criteria:
III. Inner Setting	
A. Culture	Definition: Norms, values, and basic assumptions of a given organization.

	Inclusion Criteria: Inclusion criteria, and potential sub-codes, will depend on the framework or definition used for "culture." Exclusion Criteria:
B. Implementation Climate	Definition: The absorptive capacity for change, shared receptivity of involved individuals to an innovation, and the extent to which use of that innovation will be rewarded, supported, and expected within their organization. Inclusion Criteria: Include statements regarding the general level of receptivity to implementing the innovation. Exclusion Criteria: Exclude statements regarding the general level of receptivity that are captured in the sub-codes.
C. Tension for Change	Definition: The degree to which stakeholders perceive the current situation as intolerable or needing change. Inclusion Criteria: Include statements that (do not) demonstrate a strong need for the innovation and/or that the current situation is untenable, i.e., statements that the innovation is absolutely necessary or that the innovation is redundant with other programs. Note: If a participant states that the innovation is redundant with a preferred existing program, (double) code lack of Relative Advantage, see exclusion criteria below. Exclusion Criteria: Exclude statements regarding specific needs of individuals that demonstrate a need for the innovation, but do not necessarily represent a strong need or an untenable status quo, and code to Patient Needs and Resources. Exclude statements that demonstrate the innovation is better (or worse) than existing programs and code to Relative Advantage.
D. Compatibility	Definition: The degree of tangible fit between meaning and values attached to the innovation by involved individuals, how those align with individuals' own norms, values, and perceived risks and needs, and how the innovation fits with existing workflows and systems. Inclusion Criteria: Include statements that demonstrate the level of compatibility the innovation has with organizational values and work processes. Include statements that the innovation did or did not need to be adapted as evidence of compatibility or lack of compatibility. Exclusion Criteria: Exclude or double code statements regarding the priority of the innovation based on compatibility with organizational values to Relative Priority, i.e., if an innovation is not prioritized because it is not compatible with organizational values.
E. Relative Priority	Definition: Individuals' shared perception of the importance of the implementation within the organization. Inclusion Criteria: Include statements that reflect the relative priority of the innovation, i.e., statements related to change fatigue in the organization due to implementation of many other programs.

	Exclusion Criteria: Exclude or double code statements regarding the priority of the innovation based on compatibility with organizational values to Compatibility, i.e., if an innovation is not prioritized because it is not compatible with organizational values.
F. Goals & Feedback	Definition: The degree to which goals are clearly communicated, acted upon, and fed back to staff, and alignment of that feedback with goals. Inclusion Criteria: Include statements related to the (lack of) alignment of implementation and innovation goals with larger organizational goals, as well as feedback to staff regarding those goals, i.e., regular audit and feedback showing any gaps between the current organizational status and the goal. Goals and Feedback include organizational processes and supporting structures independent of the implementation process. Evidence of the integration of evaluation components used as part of "Reflecting and Evaluating" into **on-going or sustained** organizational structures and processes may be (double) coded to Goals and Feedback. Exclusion Criteria: Exclude statements that refer to the implementation team's (lack of) assessment of the progress toward and impact of implementation, as well as the interpretation of outcomes related to implementation, and code to Reflecting and Evaluating. Reflecting and Evaluating is part of the implementation process; it likely ends when implementation activities end. It does not require goals be explicitly articulated; it can focus on descriptions of the current state with real-time judgment, though there may be an implied goal (i.e., we need to implement the innovation) when the implementation team discusses feedback in terms of adjustments needed to complete implementation.
G. Learning Climate	Definition: A climate in which: 1. Leaders express their own fallibility and need for team members' assistance and input; 2. Team members feel that they are essential, valued, and knowledgeable partners in the change process; 3. Individuals feel psychologically safe to try new methods; and 4. There is sufficient time and space for reflective thinking and evaluation. Inclusion Criteria: Include statements that support (or refute) the degree to which key components of an organization exhibit a "learning climate." Exclusion Criteria:
H. Readiness for Implementation	Definition: Tangible and immediate indicators of organizational commitment to its decision to implement an innovation. Inclusion Criteria: Include statements regarding the general level of readiness for implementation. Exclusion Criteria: Exclude statements regarding the general level of readiness for implementation that are captured in the sub-codes.
I. Leadership Engagement	Definition: Commitment, involvement, and accountability of leaders and managers with the implementation of the innovation. Inclusion Criteria: Include statements regarding the level of engagement of organizational leadership. Exclusion Criteria: Exclude or double code statements regarding leadership engagement to Engaging: Formally Appointed Internal Implementation Leaders or Champions, if an organizational leader is also an implementation leader, i.e., if

	a director of primary care takes the lead in implementing a new treatment guideline. Note that a key characteristic of this Implementation Leader/Champion is that s/he is also an Organizational Leader.
J. Available Resources	Definition: The level of resources organizational dedicated for implementation and on-going operations including physical space and time. Inclusion Criteria: Include statements related to the presence or absence of resources specific to the innovation that is being implemented. Exclusion Criteria: Exclude statements related to training and education and code to Access to Knowledge & Information. Exclude statements related to the quality of materials and code to Design Quality and Packaging. In a research study, exclude statements related to resources needed for conducting the research components (i.e., time to complete research tasks, such as IRB applications, consenting patients).
IV. Characteristics of Individuals	
A. Knowledge & Beliefs about the Innovation	Definition: Individuals' attitudes toward and value placed on the innovation, as well as familiarity with facts, truths, and principles related to the innovation. Inclusion Criteria: Exclusion Criteria: Exclude statements related to familiarity with evidence about the innovation and code to Evidence Strength and Quality.
B. Self-efficacy	Definition: Individual belief in their own capabilities to execute courses of action to achieve implementation goals. Inclusion Criteria: Exclusion Criteria:
C. Individual Identification with Organization	Definition: A broad construct related to how individuals perceive the organization, and their relationship and degree of commitment with that organization. Inclusion Criteria: Exclusion Criteria:
D. Other Personal Attributes	Definition: A broad construct to include other personal traits such as tolerance of ambiguity, intellectual ability, motivation, values, competence, capacity, and learning style. Inclusion Criteria: Exclusion Criteria:
V. Process	
E. Engaging	Definition: Attracting and involving appropriate individuals in the implementation and use of the innovation through a combined strategy of social marketing, education, role modeling, training, and other similar activities.

	Inclusion Criteria: Include statements related to engagement strategies and outcomes, i.e., if and how staff and innovation participants became engaged with the innovation and what their role is in implementation. Note: Although both strategies and outcomes are coded here, the outcome of engagement efforts determines the rating, i.e., if there are repeated attempts to engage staff that are unsuccessful, or if a role is vacant, the construct receives a negative rating. In addition, you may also want to code the "quality" of staff - their capabilities, motivation, and skills, i.e., how good they are at their job, and this data affects the rating as well. Exclusion Criteria: Exclude statements related to specific sub constructs, i.e., Champions or Opinion Leaders. Exclude or double code statements related to who participated in the decision process to implement the innovation to Innovation Source, as an indicator of internal or external innovation source.
F. Opinion Leaders	Definition: Individuals in an organization that have formal or informal influence on the attitudes and beliefs of their colleagues with respect to implementing the innovation. Inclusion Criteria: Include statements related to engagement strategies and outcomes, i.e., how the opinion leader became engaged with the innovation and what their role is in implementation. Note: Although both strategies and outcomes are coded here, the outcome of efforts to engage staff determines the rating, i.e., if there are repeated attempts to engage an opinion leader that are unsuccessful, or if the opinion leader leaves the organization and this role is vacant, the construct receives a negative rating. In addition, you may also want to code the "quality" of the opinion leader here - their capabilities, motivation, and skills, i.e., how good they are at their job, and this data affects the rating as well. Exclusion Criteria:
G. Formally Appointed Internal Implementation Leaders	Definition: Individuals from within the organization who have been formally appointed with responsibility for implementing an innovation as coordinator, project manager, team leader, or other similar role. Inclusion Criteria: Include statements related to engagement strategies and outcomes, i.e., how the formally appointed internal implementation leader became engaged with the innovation and what their role is in implementation. Note: Although both strategies and outcomes are coded here, the outcome of efforts to engage staff determines the rating, i.e., if there are repeated attempts to engage an implementation leader that are unsuccessful, or if the implementation leader leaves the organization and this role is vacant, the construct receives a negative rating. In addition, you may also want to code the "quality" of the implementation leader here - their capabilities, motivation, and skills, i.e., how good they are at their job, and this data affects the rating as well. Exclusion Criteria: Exclude or double code statements regarding leadership engagement to Leadership Engagement if an implementation leader is also an organizational leader, i.e., if a director of primary care takes the lead in implementing a new treatment guideline.

H. Champions	Definition: “Individuals who dedicate themselves to supporting, marketing, and ‘driving through’ an overcoming indifference or resistance that the innovation may provoke in an organization. Inclusion Criteria: Include statements related to engagement strategies and outcomes, i.e., how the champion became engaged with the innovation and what their role is in implementation. Note: Although both strategies and outcomes are coded here, the outcome of efforts to engage staff determines the rating, i.e., if there are repeated attempts to engage a champion that are unsuccessful, or if the champion leaves the organization and this role is vacant, the construct receives a negative rating. In addition, you may also want to code the "quality" of the champion here - their capabilities, motivation, and skills, i.e., how good they are at their job, and this data affects the rating as well. Exclusion Criteria: Exclude or double code statements regarding leadership engagement to Leadership Engagement. if a champion is also an organizational leader, i.e., if a director of primary care takes the lead in implementing a new treatment guideline.
I. Key Stakeholders	Definition: Individuals from within the organization that are directly impacted by the innovation, i.e., staff responsible for making referrals to a new program or using a new work process. Inclusion Criteria: Include statements related to engagement strategies and outcomes, i.e., how key stakeholders became engaged with the innovation and what their role is in implementation. Note: Although both strategies and outcomes are coded here, the outcome of efforts to engage staff determines the rating, i.e., if there are repeated attempts to engage key stakeholders that are unsuccessful, the construct receives a negative rating. Exclusion Criteria: Exclude statements related to implementation leaders' and users' access to knowledge and information regarding using the program, i.e., training on the mechanics of the program, and code to Access to Knowledge & Information. Exclude statements about general networking, communication, and relationships in the organization, such as descriptions of meetings, email groups, or other methods of keeping people connected and informed, and statements related to team formation, quality, and functioning, and code to Networks and Communication.
J. Innovation Participants	Definition: Individuals served by the organization that participate in the innovation, i.e., patients in a prevention program in a hospital. Inclusion Criteria: Include statements related to engagement strategies and outcomes, i.e., how innovation participants became engaged with the innovation. Note: Although both strategies and outcomes are coded here, the outcome of efforts to engage participants determines the rating, i.e., if there are repeated attempts to engage participants that are unsuccessful, the construct receives a negative rating. Exclusion Criteria: Exclude statements demonstrating (lack of) awareness of the needs and resources of those served by the organization and whether or not that awareness influenced the implementation or adaptation of the innovation and code to Needs and Resources of those Served by the Organization.

Additional Codes (C-SHIP)		
A.	Health-relevant encodes	Definition: Strategies and constructions for self-encoding and health and wellbeing, health situations, risks and vulnerabilities and illness. Inclusion Criteria: Contains attention strategies for selection and processing potential health threats and hazards (i.e. memories of inference, judgements and abstractions about illness and its emotional consequences). Exclusion Criteria:
B.	Health beliefs and expectancies	Definition: Specific beliefs and expectations triggered when processing health information. Inclusion Criteria: Contains expectations about it both outcomes and self-efficacy expectations. Exclusion Criteria:
C.	Affects (emotions)	Definition: Affective states that are activated in processing of health information. Inclusion Criteria: Contains emotions (i.e. anxiety, depression, hope). Exclusion Criteria:
D.	Health goals and values	Definition: Desired and appreciated health outcomes and states and their subjective importance and goals for health-relevant life projects. Inclusion Criteria: Exclusion Criteria:
E.	Self-regulatory competences and skills	Definition: Knowledge and strategies for dealing with specific barriers to health protective behaviour and for construction and maintenance of health protective behaviours. Inclusion Criteria: Exclusion Criteria:
Additional Codes		
A.	(Not) to discuss	Definition: Current state of what is or what is not discussed during patient-doctor conversation. Inclusion Criteria: Exclusion Criteria:
B.	(Not) to note in electronic patients file	Definition: What information should or what should not be noted in electronic patients file. Inclusion Criteria: Before implementation of the monitoring tool and after implementation of it. Exclusion Criteria:
C.	(Not) to show (pop-up) in electronic patients file	Definition: What information should or what should not be highlighted in the electronic patients file.

		Inclusion Criteria: Exclusion Criteria:
D.	Additional professional help	Definition: Other professionals involved in care path patient. Inclusion Criteria: Additional professions mentioned, such as: physiotherapist, social worker or general practitioner. Exclusion Criteria:
E.	Advantage more insight in QoL/using the tool.	Definition: Perks of gaining more information about the QoL of patients after implementation of the monitoring tool. Also, the perks of using the tool. Inclusion Criteria: Exclusion Criteria:
F.	Barriers - HCP	Definition: Barriers for implementing the monitoring tool. Inclusion Criteria: Mentioned by the HCP. Exclusion Criteria:
G.	Conversation input	Definition: All information related to what is addressed during consultation and the course of a consultation. Inclusion Criteria: Exclusion Criteria: Exclude or double code specific addressed QoL items during consultation. For this the code (Not) to discuss should be used.
H.	Current state insight QoL	Definition: Quotations of knowledge about QoL of patients and its opinion about it. Inclusion Criteria: Exclusion Criteria:
I.	Desired outcomes HCP / satisfaction	Definition: Current satisfaction of discussed topics during patient-doctor conversations. Inclusion Criteria: Exclusion Criteria:
J.	Disadvantage more insight in QoL	Definition: Drawbacks of gaining more information about the QoL of patients after implementation of the monitoring tool. Inclusion Criteria: Exclusion Criteria:
K.	Example	Definition: Practical examples. Inclusion Criteria: Examples and experiences from practice. Exclusion Criteria:

L.	Health goals and values – opinion HCP	Definition: Desired and appreciated health outcomes and states and their subjective importance and goals for health-relevant life projects, but filled in by the HCP for the patient. Inclusion Criteria: Opinion of HCP what the patient's goals and values are, spoken from experience of the HCP. Exclusion Criteria: The health goals and values mentioned by the patient itself.
M.	Important QoL items	Definition: Items to be addressed during patient-doctor conversation. Inclusion Criteria: QoL items that really are mentioned in current conversations and QoL items that should be mentioned in conversations. Exclusion Criteria:
N.	Involvement in decision-making	Definition: Opinion related to desire to be involved in decision-making Inclusion Criteria: Exclusion Criteria:
O.	Involving relatives – opinion HCP	Definition: Engaging relatives of patients during patient-doctor conversation. Inclusion Criteria: Opinion of the HCP whether involving others than the patient itself during conversation is good or bad. Exclusion Criteria: Opinion of the patient.
P.	Involving relatives – opinion patient	Definition: Engaging relatives of patients during patient-doctor conversation. Inclusion Criteria: Opinion of the patient whether involving others than the patient itself during conversation is good or bad. Exclusion Criteria: Opinion of the HCP.
Q.	Openness / honesty patients	Definition: Influence of openness or honesty of the patient on the conversation with the HCP. Inclusion Criteria: Both good and bad influences. Opinion of HCP. Exclusion Criteria: Opinion of patient.
R.	Patient Needs and Resources – opinion HCP	Definition: Inclusion Criteria: Exclusion Criteria:
S.	Patient's Affects (emotions) – opinion HCP	Definition: Affective states that are activated in processing of health information, mentioned by the HCP. Inclusion Criteria: Opinion of HCP about emotions of patient. Exclusion Criteria: Patient's opinion.

T.	Patient's Self-regulatory competences & skills – opinion HCP	Definition: Knowledge and strategies for dealing with specific barriers to health protective behaviour and for construction and maintenance of health protective behaviours. Inclusion Criteria: Opinion of HCP about patient's self- regulatory competences & skills. Exclusion Criteria: Patient's opinion.
U.	Preparation consultation HCP	Definition: All information related to preparation of the consultation by the HCP and its influence of it on the consultation. Inclusion Criteria: Opinion of HCP Exclusion Criteria:
V.	Preparation consultation Patient	Definition: All information related to preparation of the consultation by the patient and its influence of it on the consultation. Inclusion Criteria: Opinion of HCP Exclusion Criteria: Opinion of patient itself.
W.	Process changes due to implementation	Definition: Items of care process that need to change or will change due to implementation of the monitoring tool. Inclusion Criteria: Exclusion Criteria:
X.	Readiness for Implementation	Definition: Preparedness/willingness to implement a PROM tool in current care processes Inclusion Criteria: Exclusion Criteria:
Y.	Requirement monitoring tool	Definition: All requirements and conditions mentioned for successful implementation of the monitoring tool. Inclusion Criteria: For both implementation of the tool and the content of the tool. Mentioned by HCPs and patients. Exclusion Criteria:
Z.	Responsibility/role physician	Definition: Relation between patient and physician. Inclusion Criteria: Trust in the physician regarding information transfer and decision making. Exclusion Criteria:
AA.	Result implementation tool	Definition: The influence of the monitoring tool on the quality of care for the patient. Inclusion Criteria:

	Exclusion Criteria: Exclude the influence of the tool on care processes. For this the code Process changes due to implementation should be used.
BB. Satisfaction patient	Definition: Fulfilment of patient's conversation needs. Inclusion Criteria: Regarding communication and possibilities in addressing needs. Exclusion Criteria:
CC. Shared decision-making	Definition: Opinion related to desire to be involved in decision-making Inclusion Criteria: Exclusion Criteria:
DD. Use PROM	Definition: Attitude towards using a PROM. Inclusion Criteria: Exclusion Criteria: Exclude requirements. For this the code Requirements should be used.

Appendix 9: Results

9A: PATIENT CHARACTERISTICS

Table 1: Patient characteristics

Respondent	Sex	Age	Education	Diagnosis	Treatment Stage (# of cycles)
1	Male	56-65	Secondary vocational education	>1 year	>7
2	Male	>65	Secondary vocational education	>1 year	<6
3	Male	>65	Secondary vocational education	9-12 months	<6
4	Male	46-55	Secondary vocational education	>1 year	>7
5	Male	>65	General secondary education	>1 year	<6
6	Male	>65	Primary school	9-12 months	<6
7	Female	56-65	Lower vocational education	>1 year	>7
8	Female	>65	General secondary education	>1 year	>7
9	Female	56-65	General secondary education	>1 year	>7
10	Male	>65	Scientific education	3-6 months	<6

9B: HEALTHCARE PROFESSIONAL CHARACTERISTICS

Table 1: Healthcare professional characteristics

Respondent	Sex	Age (# *years)*	Profession	Working time in profession (# *years)*
1	Female	>55	Lung nurse	10-14
2	Female	46-55	Lung physician	15-19
3	Male	46-55	Lung physician	10-14
4	Female	46-55	Lung nurse	10-14
5	Male	>55	Lung physician	> 20
6	Female	46-55	Lung nurse	10-14

9C: FREQUENCIES AND MEAN RANKINGS PER QOL ITEM

Table 1: Selected Quality of Life item frequencies and mean rankings per respondent group.

		Patient		Lung physician		Lung nurse	
Domain	Items	Frequency selected item	Mean ranking	Frequency selected item	Mean ranking	Frequency selected	Mean ranking
Physical wellbeing	Activities of daily living	3	9.4	1	7.7	2	5.3
	Energy and fatigue	7	6.6	2	6.0	3	2.0
	Pain and discomfort	5	7.4	3	2.7	1	7.7
	Sleep and rest	3	8.6	-	-	-	-
	Side effects of treatment	5	6.9	3	2.0	2	4.7
Functional wellbeing	Household chores	3	9.5	-	-	2	8.3
	Washing / self-care	4	8.9	3	6.7	2	7.7
	Transport	5	9.6	-	-	-	-
	Mobility	2	10.2	2	8.0	1	9.7
	Work capacity	1	10.0	-	-	1	10.3
Emotional wellbeing	Depression / sadness / unhappiness	5	8.0	2	7.0	1	9.7
	Anxiety / fear	6	6.6	-	-	3	4.3
	Stress / worries	6	8.1	1	9.3	1	9.7
	Loss of control	6	8.0	2	7.7	1	9.0
	Positive feelings	3	9,8	-	-	-	-
Social wellbeing	Mood	2	10.0	-	-	-	-
	Social energy / desire for interaction	7	6.8	1	8.7	3	7.7
	Sexuality / intimacy	-	-	-	-	-	-
	Social support	4	8.6	2	8.7	2	9.7

	Social acceptance	6	9.2	2	9.7	1	8.7
Psychological wellbeing	Bodily image and appearance	-	-	-	-	1	10.3
	Self-esteem spirituality / religion / personal beliefs	5	8.7	2	7.7	2	9.0
	Thinking, learning, memory and concentration	4	8.7	1	10.7	-	-
	Autonomy	2	10.1	2	8.0	1	9.3
	Satisfaction with living conditions	5	9	1	10.7	-	-

Colored yellow: top-3 most selected item per respondent group; Thick red border: top-3 highest mean ranking per respondent group.

9D: PEPPI-5 RESULTS

Table 1: Scores per patient on the PEPPI-5

Patient	(1)[a]	(2)[a]	(3)[a]	(4)[a]	(5)[a]	Mean patient
1	4	4	3	4	4	**3.8**
2	4	4	4	4	3	**3.8**
3	5	5	5	5	5	**5.0**
4	5	5	5	5	5	**5.0**
5	5	5	5	5	5	**5.0**
6	5	5	5	5	5	**5.0**
7	5	5	5	5	5	**5.0**
8	5	5	5	5	5	**5.0**
9	4	3	4	4	4	**3.8**
10	4	4	3	4	3	**3.6**
Mean question	**4.6**	**4.5**	**4.4**	**4.6**	**4.4**	

[a]PEPPI-5 questions:

1. Knowing which questions to ask;
2. Being able to get an HCP to answer all their questions;
3. Making the most of a visit to an HCP;
4. Being able to have an HCP take your most important health complaint seriously;
5. Being able to get an HCP to do something about your most important health problem.

Appendix 10: Implementation plan PROM tool pilot