

# **Process evaluation of the implementation of the Transmural Palliative Care Pathway in the Westelijke Mijnstreek**

*A mixed methods design*

**PALLIATIEVE ZORG**

**LEVEN DOE JE  
OP JE EIGEN MANIER**

**STERVEN OOK**

*Loesje*

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## **Preface and acknowledgements**

This report is the final result of my master study ‘‘Healthcare Policy, Innovation and Management’’ at Maastricht University. The aim of this report is to give insight into the implementation of the Transmural Palliative Care Pathway (TZPZ) in the Westelijke Mijnstreek, six months after the start of the pilot. This report was written at the request of the project group of the TZPZ. During the research, I have become acquainted with the implementation of a huge intervention, and with all that it entails, i.a.: dealing with the involved organizations and people and coping with the encountered obstacles. I’ve learnt that, during the implementation of an intervention, a well thought out preparation is crucial. In addition, the writing process itself was a learning experience: occasionally disassociating from the report was vital for me to deliver this report.

This report could not be finished without the support from my supervisors. Special thanks to Dr. J.M.M. Meijers for her time, trust and understanding. Furthermore, I would like to thank the members of the project group of the TZPZ, in particular dr. V. Braeken, drs. L. Dijkstra, Mr. E. van den Berken and Mrs. C. Timmers for their help. Moreover, I would like to express my appreciation to Ms. L. Cornelissen, a fellow student, who has motivated me during this period. Finally, I would like to thank my family and friends for their good advice.

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## Abstract

*Background:* Palliative care has the potential to improve the quality of life of patients during the last phase of their lives. However, the current quality of palliative care is considered suboptimal. In the southern part of the Netherlands, the Westelijke Mijnstreek, a pro-active, multidisciplinary approach is developed to improve the quality of palliative care: the Transmural Palliative Care Pathway, in Dutch known as Transmuraal Zorgpad Palliatieve Zorg (TZPZ). A pilot of the TZPZ started in December 2015 at eight general practices and the geriatric and oncology outpatient clinic of the Zuyderland Hospital in Sittard. To attain the intended results of the TZPZ on improving the quality of palliative care, successful implementation of the TZPZ is needed. An important manner to increase the chance of successful implementation is by performing a process evaluation.

*Aims:* The purposes of this study were to investigate whether the TZPZ has been implemented as intended within the general practices (six months after the start of the pilot) and consequently, to identify the facilitators and/or barriers during the implementation of the TZPZ.

*Methods:* To gain insight into the process of implementation of the TZPZ, a review of documents and forms of patients participating in the TZPZ (N = 11) was performed. A semi-structured focus group (N = 3) and a one-to-one interview (N = 1) with general practitioners (GPs) participating in the pilot were conducted to identify the facilitators and/or barriers during the implementation of the TZPZ.

*Results:* The results show that a small number of palliative patients are marked, several palliative patients are marked at the end of their lives (instead of one year before the expected death), the questionnaires of the assessment (excl. the 'Ervaren Druk Informele Zorg' (EDIZ)) are not completely filled in as intended, the multidisciplinary team meeting (MTM) and the medication review are not executed in all patients participating in the pilot, and care plans are not created as intended. The main facilitator during the implementation of the TZPZ is that GPs regard the TZPZ as a good point of departure to deliver pro-active, patient-centered palliative care. The main barriers during the implementation are starting the conversation about end of life (especially when the patient is still treated), the time-consuming administration associated with the TZPZ, the fixed nature of the TZPZ and the complexity of the TZPZ.

*Discussion:* The results of this study are in line with earlier research: implementation of care pathways is difficult as it requires collaboration of several health care professionals, incorporates many elements and often pursues multiple aims. The main limitations during this research were small study populations, both for the document review and the focus group, and the many unavailable or not accessible information. The prime recommendations to improve the implementation of the TZPZ are adapting the training and/or education program and using a digital system.

*Conclusion:* However the GPs are positive about the TZPZ, it is not yet fully implemented as intended.

## Samenvatting

*Achtergrond:* Palliatieve zorg heeft de potentie om de kwaliteit van leven van patiënten tijdens hun laatste levensfase te verbeteren. Echter, de huidige kwaliteit van palliatieve zorg schiet tekort. In de zuidelijke regio van Nederland, de Westelijke Mijnstreek, is een proactieve, multidisciplinaire aanpak ontwikkeld om de kwaliteit van palliatieve zorg te verbeteren: het Transmuraal Zorgpad Palliatieve Zorg (TZPZ). In december 2015 is een pilot van het TZPZ gestart in acht huisartsenpraktijken en de geriatrische en oncologische polikliniek van het Zuyderland Ziekenhuis te Sittard. Om de beoogde resultaten van het TZPZ te bereiken, is succesvolle implementatie nodig. De kans op een succesvolle implementatie kan worden verhoogd middels het uitvoeren van een procesevaluatie.

*Doelstellingen:* Deze studie heeft onderzocht of het TZPZ geïmplementeerd is zoals beoogd (zes maanden na de start of de pilot) binnen de huisartsenpraktijken en wat de faciliterende en hinderende factoren waren tijdens de implementatie van het TZPZ.

*Methoden:* Om inzicht te verkrijgen in het implementatieproces van het TZPZ zijn verschillende documenten en formulieren onderzocht van patiënten die meedoen aan de pilot (N = 11). Daarnaast zijn de faciliterende en hinderende factoren tijdens de implementatie van het TZPZ geïdentificeerd middels een focus groep (N = 3) en een interview (N = 1) met huisartsen die meedoen aan de pilot.

*Resultaten:* Uit de resultaten blijkt dat er een gering aantal palliatieve patiënten is gemarkeerd, een aantal patiënten aan het einde van hun leven zijn gemarkeerd (in plaats van één jaar voor het verwachte overlijden), de vragenlijsten van het assessment (excl. de vragenlijst Ervaren Druk Informele Zorg (EDIZ)) niet volledig zijn ingevuld, het multidisciplinaire overleg en de medicatie review niet bij alle patiënten zijn uitgevoerd en de zorgplannen niet zijn gemaakt in het format zoals bedacht door de projectgroep. De voornaamste faciliterende factor is dat de huisartsen het TZPZ beschouwen als een goed uitgangspunt voor het leveren van proactieve, patiëntgerichte palliatieve zorg. De hinderende factoren zijn het aangaan van het gesprek over de laatste levensfase (vooral indien de patiënt nog wordt behandeld), de tijdrovende administratie verbonden aan het TZPZ, het dwingende karakter van het TZPZ en de complexiteit van het TZPZ.

*Discussie:* De resultaten van deze studie komen overeen met eerder onderzoek: de implementatie van een zorgpad is moeilijk aangezien het samenwerking van meerdere zorgverleners vereist, uit vele elementen bestaat en vaak meerdere doelen nastreeft. De voornaamste beperkingen tijdens dit onderzoek zijn de kleine aantallen patiënten en huisartsen in de studiepopulaties, en grote hoeveelheid missende informatie. Om de implementatie van het TZPZ te verbeteren, wordt aanbevolen om de trainingsprogramma's aan te passen (voor huisartsen die meedoen aan de pilot) en een digitaal systeem te gebruiken.

*Conclusie:* Hoewel de huisartsen positief zijn over het TZPZ, is het TZPZ nog niet (volledig) geïmplementeerd zoals beoogd.

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# 1. Introduction

In 2014 approximately 140.000 people died in the Netherlands (CBS, 2015). It is estimated that this number will increase to 200.000 in 2050 (NFU, 2012). Most of these people die due to a non-acute disease such as cancer, chronic lung diseases or cardio-vascular diseases (NIVEL, 2009). This will lead to a growing number of people in need of palliative care. According to the European Association for Palliative Care (EAPC), palliative care is ‘‘the active, total care of patients whose disease is not responsive to curative treatment’’ (EAPC, 2010). Palliative care has the potential to improve the quality of life of patients during the last phase of their lives (WHO, 2015). Therefore, palliative care of high quality is becoming more and more important. However, the current quality of palliative care is considered suboptimal (Berendsen et al., 2014). Soesters & Verhoek (2013) identified three shortcomings of the current quality of palliative care. First of all, there is lack of early identification and registration of palliative patients (Soesters et al., 2013). As a consequence, palliative patients do not have the possibility to disclose their needs and wishes early on (Knapen, 2014). Moreover, palliative patients often have multiple problems within the physical, psychological, functional and social domain. This requires multidisciplinary collaboration between intra- and extramural health care professionals. However, the current palliative care shows lack of coordination and structural exchange of information between intra- and extramural health care professionals (Soesters et al., 2013). Finally, health care professionals often lack expertise in the area of palliative care (Soesters et al., 2013). These shortcomings result in inadequate pain and symptom relief, unwanted life-sustaining treatment, and unplanned hospital or nursing home admissions leading to unnecessary costs (Gade et al, 2008; Knapen, 2014). Moreover, patients do not die at their preferred location: merely 30% of the patients die at home, while 73% of the patients want to (Knapen, 2014; Soesters et al., 2013). In order to fulfil the potential of palliative care to improve the quality of life of palliative patients, improvement of palliative care is needed.

## 1.1 Improving palliative care

Previous research has shown that palliative care can be improved by using a pro-active, multidisciplinary approach, tailored to the needs, values and wishes of the patient and his or her family (Knapen, 2014). To actualize a pro-active approach, early identification and registration of palliative patients is necessary. Timely palliative care enables the patient, the informal caregiver and the health care professional to anticipate on the wishes, needs and future problems related to the patient’s situation (Soesters et al., 2013). This will result in a higher quality of life and more patients dying at their preferred location (Knapen, 2014; Temel et al., 2010). Additionally, a pro-active approach will lead to less unplanned hospital or nursing home admissions and less unnecessary general practitioner (GP) consultations resulting in a decrease in health care costs (Gade et al., 2008; NFU, 2012). Multidisciplinary collaboration enhances the continuity of palliative care and provides a good support

structure for palliative patients (Bowen, 2014; Soesters et al., 2013). Moreover, to improve palliative care, it is important that palliative care is provided by health care professionals specialized in palliative care (Soesters et al., 2013).

## **1.2 Transmural Palliative Care Pathway in the Westelijke Mijnstreek**

In the southern part of the Netherlands, the Westelijke Mijnstreek, a pro-active, multidisciplinary approach is realized by the development of a Transmural Palliative Care Pathway, in Dutch known as Transmuraal Zorgpad Palliatieve Zorg (TZPZ). The TZPZ is part of the project ‘‘Gewenste zorg in de laatste levensfase’’ (‘‘Desired care in the last phase of life’’) and is governed and managed by a project group and a steering group (Projectgroep TZPZ, 2014; Schoffeleers, 2015). The involved organizations, composition and tasks of the project group and steering group are described in Appendix 1. A pilot of the TZPZ started in December 2015 at the geriatric (with seven specialists in geriatric medicine participating) and oncology (with six oncologists participating) outpatient clinic of the Zuyderland Hospital in Sittard, eight GP practices (with a total of 16 GPs) and eight pharmacies (with nine pharmacists) located in Geleen, Munstergeleen and Sittard. After that, the TZPZ will be further disseminated to other outpatient clinics of the Zuyderland Hospital and other GP practices and nursing homes in the Westelijke Mijnstreek (De Weerd-Spaetgens et al., 2015). The TZPZ consists of the following elements: early identification and registration of palliative patients, a consultation in which the identification of the patient as a palliative patient is discussed, a palliative care assessment with the patient and his or her relatives, multidisciplinary collaboration and consultation between intra- and extramural health care professionals, a medication review by the pharmacist, the creation of a pro-active care plan, coordination of the care of the palliative patient and, after the death of the patient, a closing evaluation with the relatives of the patient. The TZPZ is the first palliative care pathway in the Netherlands incorporating all these elements. In addition, during the entire TZPZ of a palliative patient, pro-active treatment of symptoms, transmural collaboration between primary and secondary care, shared-decision making and focus on the needs and wishes of the patient and his or her family are of primary importance ((Projectgroep TZPZ, 2014; Schoffeleers, 2015).

The TZPZ starts by marking a patient with a life expectancy up to one year by using the surprise question, supported by the use of RADPAC+. RADPAC+ is a measurement tool which integrates both the RADboud indicators for Palliative Care Needs (RADPAC) and the Supportive and Palliative Care Indicators Tool (SPICT). During a consultation, the GP or medical specialist asks him- or herself the question: ‘‘Would I be surprised if this patient is still alive in a year from now?’’. If the question can be answered with a yes, the GP and the medical specialist of the patient deliberate and decide together about the final marking of the patient and who will be the main practitioner during the TZPZ. If the GP and medical specialist agree about this, the patient is invited for a consultation. During this consultation, the marking of the patient as a palliative patient will be discussed. Subsequently, the palliative patient is assigned to a care coordinator. Who the care coordinator is, depends on whether the main practitioner

is the GP or the medical specialist. If the main practitioner is the GP, the care coordinator is the GP him- or herself, or the ‘‘Praktijkondersteuner’’ (POH). The POH is a nurse practitioner working at the general practice. If the main practitioner is the medical specialist, the care coordinator is a nurse practitioner employed by the Zuyderland Hospital in Sittard. The care coordinator conducts a palliative assessment. The palliative assessment identifies, by using a questionnaire, a) the potential physical, practical and socio-emotional problems and, b) the needs and wishes of the patient during the palliative phase. The questionnaire integrates the following tools: the Lastmeter (assesses psychosocial problems), the Confusion Assessment Method (CAM) (helps to identify a delirium), the Numeric Rating Scale (NRS) (measures the level of pain) and the Hospital Anxiety Depression Scale (HADS) (measures the level of fear and depression). Also, the pressure experienced by the informal caregiver is assessed by using the questionnaire ‘‘Ervaren Druk door Informele Zorg’’ (EDIZ). Based on the results of the EDIZ, appropriate action can be taken to relieve the pressure experienced by the informal caregiver. After the palliative assessment, the palliative patient is discussed in a multidisciplinary team meeting (MTM) and the pharmacist reviews the medication of the palliative patient. The palliative assessment and the MTM are the starting point for composing a pro-active care plan. The pro-active care plan, which is composed by the care coordinator, can be seen as a summary of the agreements and wishes that have emerged during the assessment and the multidisciplinary team meeting. The care coordinator contacts the patient to discuss the advice resulting from the multidisciplinary team meeting and the pro-active care plan. Throughout the palliative phase, the care coordinator is responsible for the coordination of the multidisciplinary care and is thereby supported by the pro-active care plan and several health care professionals specialized in palliative care. These specialized health care professionals are available for consultation during the entire TZPZ. Besides the care coordinator, other health care professionals responsible for the care of the patient can also consult these specialized health care professionals. If the question of the care coordinator or another health care professional responsible for the care of the patient is too complex or needs (transmural) collaboration of different health care professionals, the patient can be discussed in a MTM again. Approximately six weeks after the death of the patient, the care coordinator plans a consultation with the relatives of the patient to evaluate the TZPZ (Projectgroep TZPZ, 2014; Schoffeleers, 2015; De Weerd-Spaetgens et al., 2015). An extensive description of the TZPZ is drawn up in Appendix 2.

The intended results of the TZPZ are, amongst others, a higher quality of life and higher quality of dying for palliative patients, more patients dying at their preferred location, greater satisfaction of patients with the care in the last phase of their lives, relieving the burden on informal caregivers and better collaboration and communication between the involved health care professionals (intra- and extramural). Moreover, the TZPZ aims to reduce the number of unplanned hospital or nursing home admissions and unnecessary GP consultations, resulting in less stress for the patient and his or her family and a decline in health care costs (Projectgroep TZPZ, 2014).

### **1.3 Implementation of the Transmural Palliative Care Pathway in the Westelijke Mijnstreek**

To achieve these intended results, successful implementation of the TZPZ is needed. Implementation can be regarded as successful when an “all elements of the TZPZ, as mentioned in paragraph 1.2, have a structural place in professional practice” (Grol et al., 2013). Successful implementation is important for the following reasons. At first, successful implementation leads to an unambiguous use and execution of the care pathway, which ensures that the effects measured can be attributed to the elements of the TZPZ (Dane et al., 1998). An unambiguous use and execution implies that all elements of the TZPZ, as mentioned in paragraph 1.2, are performed with any palliative patient participating in the TZPZ. Secondly, the effects of an innovation can even be counterproductive if implementation is unsuccessful (Berwick, 2003). Finally, unsuccessful implementation of the TZPZ could be distressing and demotivating given the investment and effort of resources and people (NJI, 2015). Because of the aforementioned reasons, it can be assumed that successful implementation strengthens the intended results of the TZPZ. However, in practice it turns out that successful implementation is complex and difficult: 70% of the implemented innovations in Dutch organizations end prematurely or do not achieve their intended effect (NJI, 2015). The chance of unsuccessful implementation is even higher when the innovation is complex, requires changes in the organization of care and requires transmural collaboration between different health care professionals, which is the case in the TZPZ (Grol et al., 2013). An important manner to decrease the chance of unsuccessful implementation, and thereby, strengthen the intended results of the TZPZ, is by performing a process evaluation. A process evaluation determines whether all intervention elements are implemented as planned, the experience of the target group concerning the intervention and the contextual factors associated with variation in outcomes (CDC, 2014; Moore, 2015; SAMHSA, 2015). An important aim of a process evaluation is to provide an early warning for problems occurring during implementation. This information can be used to improve further implementation (CDC, 2014).

### **1.4 Research question**

Much emphasis within evaluations of health care innovations is placed on outcome evaluations (Saunders et al., 2005). Outcome evaluations determine whether a certain innovation is effective (Saunders et al., 2005). But, an outcome evaluation alone, without a process evaluation, will not provide enough information to conclude why an innovation did or did not work and which factors facilitated or hindered the implementation (Linnan et al., 2002; SAMHSA, 2015). Therefore, during the entire pilot of the TZPZ, outcome and process evaluations are performed (three months, six months, one year and two years after the start of the pilot). This study performs a process evaluation six months after the start of the pilot. Hence, the main research question of the current study is the following: *Is the Transmural Palliative Care Pathway (TZPZ) implemented as intended?* To answer the main research question, several sub-questions are conducted: 1) *Are the different elements of the TZPZ implemented?* 2) *If an element of the TZPZ is implemented, is the element implemented as intended?* 3) *Are the different*

*elements of the TZPZ implemented by the persons as intended? 4) Are the different elements of the TZPZ implemented in the order as intended? 5) What characteristics of patients can influence the implementation of the different elements of the TZPZ? 6) What are the facilitators and barriers during the implementation of the different elements of the TZPZ? After gaining a better understanding of the facilitators and barriers during implementation, an advice will be proposed how to reinforce the effect of facilitators and weaken the effect of barriers, and thereby improve the implementation of the TZPZ (Stals et al. 2008).*

### **1.5 Relevance**

This study holds relevancy from a societal, political and scientific point of view. The results of this study can be used to make adjustments to the TZPZ, and thereby improve further implementation of the TZPZ. The identified facilitators and/or barriers can be considered, planned for and incorporated directly into the pathway. A successful implementation strengthens the intended results of the TZPZ, for example: by improving the further implementation of the TZPZ, this study can reinforce the reduction of unplanned hospital or nursing home admissions and unnecessary GP consultations, resulting in less stress for the patient and his or her family and a decrease in health care costs. This is important both from a societal and political point of view. Moreover, the results can be used by other organizations implementing a similar palliative care pathway. In addition, from a scientific perspective, this research contributes to the need for in-depth knowledge of the barriers and facilitators during the implementation of a palliative care pathway.

### **1.6 Overall research approach**

A mixed method approach is used to answer the research question. The researcher explores in depth the process of implementation of the TZPZ by using three types of data collection procedures: an internal document review, a focus group with GPs and a one-to-one interview with a GP. The qualitative and quantitative data resulting from the document review will be used to answer sub-questions 1-5. Qualitative and quantitative data arising from the semi-structured focus group and the one-to-one interview will be used to answer sub-questions 6.

## **2. Theory and concept model**

As mentioned in Chapter 1, this study executes a process evaluation regarding the implementation of the TZPZ six months after the start of the pilot. A process evaluation examines what happens during implementation of an innovation (Saunders, 2015). This chapter will discuss the following subjects: the functions of executing a process evaluation (paragraph 2.1), the relationship between implementation and process evaluation (paragraph 2.2), the development of a process evaluation plan (paragraph 2.3), the characteristics of patients that can influence the implementation of an innovation (paragraph 2.4, and the in the literature known categories of facilitators and barriers influencing the implementation of an innovation (paragraph 2.5). The paragraphs also discuss the application of the theory to the current study. Paragraph 2.6 presents the concept model of this study.

### **2.1 Functions of executing a process evaluation**

Several functions of a process evaluation are described in the literature:

- A. If the results of the process evaluation are combined with the results of the outcome evaluation, the process evaluation can aid in understanding the relationship between the effectiveness of the innovation and the specific elements of the innovation (WHO, 2000).
- B. If the results of the process evaluation are combined with the results of the outcome evaluation, the process evaluation helps to distinguish between theory failure (the innovation itself was not effective) and implementation failure (the innovation was not executed as planned) (Saunders, 2015).
- C. The results of a process evaluation can be used to make adjustments to the innovation itself. This can improve further implementation, and thereby strengthen the intended results of an innovation (SAMHSA, 2015).
- D. The results of a process evaluation can help other organizations implementing a similar health care innovation (WHO, 2000).
- E. As a process evaluation assesses the contextual factors influencing implementation, the results of a process evaluation can contribute to the development of a plan to reinforce the facilitators and weaken the barriers during the implementation of an innovation (Schneider et al., 2009).

Initially, the results of the process evaluation executed in the current study are not combined with the results of the outcome evaluation of the TZPZ. Hence, the current study especially aims to fulfil the functions C-E of executing a process evaluation.

### **2.2 The relationship between implementation and process evaluation**

Implementation can be defined as a ‘‘planned process and systematic introduction of innovations and/or changes of proven value; the aim being that these are given a structural place in professional practice, in the functioning of organizations or in the health care structure’’ (ZON, 1997).

The ‘‘Implementation of Change Model’’ of Grol et al. (2013) distinguishes several phases within the process of implementation. The model starts with a problem noticed in health care. Inspiration for improvement of care can come from research, but also from practice (Grol et al., 2013). Before developing a proposal for change, the implementation process should be planned and organized: a team should be created, the target group has to be identified, a timetable should be drafted and the budget has to be determined. Thereafter, the implementation process starts. In the first phase, a proposal for change has to be developed. This proposal can include new routines, guidelines or new techniques. In the second and the third phase, the actual performance, the target group and the setting have to be analyzed. In this way, the facilitators and/or barriers during the implementation of the innovation are identified. In the fourth phase, the identified facilitators and/or barriers have to be used to develop an implementation strategy. Thereafter, an implementation plan should be developed and executed. Subsequently, the changes should be integrated into routine care. Finally, during phase 7, the integration of the change has to be evaluated (Grol et al., 2013).

This study performs a process evaluation during phase 7 of the implementation of the TZPZ. The results of the process evaluation will give feedback to the several other phases in the ‘‘Implementation of Change Model’’ of Grol et al. (2013), namely to:

- Phase 1: by adapting or improving the proposal for change
- Phase 2: by measuring the extent to which the TZPZ has been implemented in practice
- Phase 3: by offering a supplementary problem analysis of the facilitators and/or barriers during implementation of the TZPZ
- Phase 4: by proposing an advice how to reinforce the effect of the facilitators and weaken the effect of the barriers during the implementation of the TZPZ
- Phase 5: by adaptation of the implementation plan
- Phase 6: by changing and/or creating the conditions for change

### **2.3 Development of a process evaluation plan**

To execute the process evaluation of the current study accurately, a process evaluation plan should be developed. Several frameworks exist to guide the development of a process evaluation plan (Saunders et al., 2005). One of the most prominent frameworks is the ‘‘How-To Guide’’ described by Saunders et al. (2005). This guide describes six steps for developing a process evaluation plan and can be used to plan the current study. In step 1 and 2, the innovation, including its purpose and expected outcomes, should be described in detail (Saunders et al., 2005). The TZPZ is shortly described in paragraph 1.2 and in more detail in Appendix 2. In step 3, a list of process evaluation questions should be stated (Saunders et al., 2005). This list should be guided by the recommended components of a process evaluation, which are (Linnan et al., 2002; Moore et al., 2015; Saunders et al., 2005):

- Dose delivered: how often the elements of an innovation are delivered

- Fidelity: extent to which the elements of an innovation are implemented as intended
- Reach: proportion of the target group that participates in the innovation
- Dose received, which is subdivided into:
  - Exposure: extent to which the target group actively engages with and/or uses materials or recommended resources of the innovation;
  - Satisfaction: reaction of the target group to the innovation
- Recruitment: the procedures and resources used to approach and attract the target group; including the barriers to recruitment
- Context: any factor external to the innovation that may act as a facilitator or barrier to its implementation

In the current study, the target group can be the GPs, but also the palliative patients participating in the TZPZ. Therefore, the operationalization of the components reach, dose received and recruitment can be interpreted in two ways. By using the recommended components of a process evaluation plan, the following list of process evaluation questions is drafted:

- Are the different elements of the TZPZ implemented? (sub-question 1) (dose delivered and, dose received by the GPs (exposure))
- Are the different elements of the TZPZ implemented as intended? (sub-question 2) (dose received by the GPs (exposure) and fidelity)
- Are the different elements of the TZPZ implemented by the persons as intended? (sub-question 3) (fidelity)
- Are the different elements of the TZPZ implemented in the order as intended? (sub-question 4) (fidelity)
- What proportion of the GPs have marked patients for the TZPZ? (dose received by the GPs (exposure) and reach of the GPs)
- What is the opinion of the GPs concerning the use of the TZPZ? (dose received by the GPs (satisfaction))
- To what extent are patients marked as intended? (recruitment of patients)
- What are the facilitators and/or barriers in marking patients for the TZPZ? (recruitment of patients)
- What are the facilitators and barriers during the implementation of the different elements of the TZPZ? (sub-question 6) (context)

The components dose received (exposure and satisfaction) by the patients, the reach of the patients and recruitment of the GPs are not assessed in the current study. The list of process evaluation questions will be used to develop the checklist and the topic list, respectively for the document review and, the focus group and the interview. In step 4 of the ‘How-to Guide’ described by Saunders et al. (2005) the methods used in the process evaluation should be explained. The methods used in the current study are

explained Chapter 3. In step 5, the resources available should be considered (Saunders et al., 2005). In the current study, especially the available time and information were taken into account.

## **2.4 Characteristics of patients that can influence the implementation of an innovation**

Grol et al. (2013) acknowledges that patients' beliefs, knowledge, opinion, and behavior can influence the uptake of an innovation. In the current study, these characteristics are difficult to measure as merely GPs are interviewed. However not described in the literature, it can be assumed that certain characteristics of patients such as age, gender, diagnose, and the type of relationship with the informal caregiver can have an impact on the implementation of a palliative care pathway. To answer sub-question 5, these topics will be included in the checklist for the document review.

## **2.5 Categories of facilitators and barriers influencing the implementation of an innovation**

To create a topic list for the focus group and the interview, and thereby answer sub-question 6, the main categories of factors which could possibly influence the implementation of an innovation should be identified. The impact theory of Grol et al. (2013) will be used as a main theory to identify these categories, complemented with factors mentioned in other theories, books or articles. Subsequently, the following categories of potential facilitators and/or barriers are identified:

- Characteristics of the individual health care professional intended to deliver the innovation (Grol et al., 2013). Sense of competence, knowledge, opinion, motivation and attitude (e.g. regarding the effectiveness of an innovation or the applicability of the innovation to a specific patient), routine, awareness and familiarity with the innovation and the willingness to innovate of health care professionals can facilitate or impede implementation (Chiche et al., 2009; Francke et al., 2008; Grol et al., 2013). Moreover, the opinion, motivation and attitude of a professional is influenced by a sense of urgency, which is required for the implementation of an innovation. The individual health care professional in this study is the GP.
- Factors of the organizational context (Grol et al., 2013). These factors include availability and quality of resources (e.g. knowledgeable staff and/or equipment such as an ICT system), clear task divisions, time constraints and dissemination of clear information about the use and effectiveness of the innovation (Chiche et al., 2009; Grol et al., 2013; Richards et al., 2015).
- Factors of the economic and legal context (Grol et al., 2013). The degree of reimbursement, financial incentives and legislation are factors of the economic and legal context which can facilitate and/or hinder implementation (Chiche et al., 2009; Grol et al., 2013).
- Factors of the social context, also called the social environment (Grol et al., 2013). The social environment can be defined as "the total sum of social and cultural conditions, circumstances and human interactions that encompass human beings and groups" (Kirst-Ashman, 2007, p. 6). One of the factors of the social context which can facilitate and/or hinder implementation of an

innovation is culture (Rycroft-Malone et al., 2002; Grol et al., 2013). Culture is “the set of shared values that control organizational members’ interaction with each other and with people outside the organization” (Jones, 2010, p. 179). To achieve successful implementation in health care, organizations have to develop a quality culture, in which continuous learning, teamwork and patient focus are central (Grol et al., 2013). Interlinked to culture is leadership. Evidence supports the importance of leadership for quality improvement of health care (Grol et al., 2007). Leadership is about the ability to mobilize followers towards a particular goal (Hamel, 2001). In the current study, leadership can come from the project group, but also from enthusiastic GPs. For a quality culture to develop, leaders are required to involve all members in the social context, focus on continuous learning and clearly present the mission and vision of the innovation (Boan et al., 2003). Other factors within the social context which can facilitate and/or hinder implementation of an innovation are attitude and behavior of colleagues, the degree of support and pressure from peers and the quality of the relationship with the patient (Francke et al., 2008; Grol et al. 2013).

- Factors related to the innovation itself (Grol et al., 2013). According to the “How-to guide” described by Saunders et al. (2005), executing an accurate process evaluation implies identifying the facilitators and/or barriers during the implementation of an innovation by assessing the context. The context is defined as “any factor external to the innovation that may act as a facilitator or barrier to its implementation” (Moore et al., 2015, p. 2). However factors related the innovation itself are not “external tot the innovation”, several impact theories confirm that factors related the innovation itself can have a great influence on the implementation process. Rogers (2003) put forward five main characteristics of an innovation determining the success of implementation: benefit (the degree to which the innovation is seen as an improvement), compatibility (the degree to which the innovation complies with existing norms, needs, opinions and values), complexity (the degree to which the innovation is considered as difficult to understand and use), triability (the degree to which the innovation can be tested on a small scale) and visibility (the degree to which the results of innovation are visible).

These potential facilitators and/or barriers during the implementation of an innovation will be used to create a topic list for the focus group and the interview, with the aim to answer sub-question 6.

## 2.6 Concept model

All the relevant discussed aspects are incorporated in the concept model (Figure 1). The “Implementation of Change Model” of Grol et al. (2013) is used as a starting point for the concept model. As shown in Figure 1, the process evaluation of the current study is executed in phase 7 of the “Implementation of Change Model”. Furthermore, the process evaluation performed in the current

study is guided by the final process evaluation plan. The results of the current study give feedback to the several other phases in the “Implementation of Change Model”, as explained in paragraph 2.2.

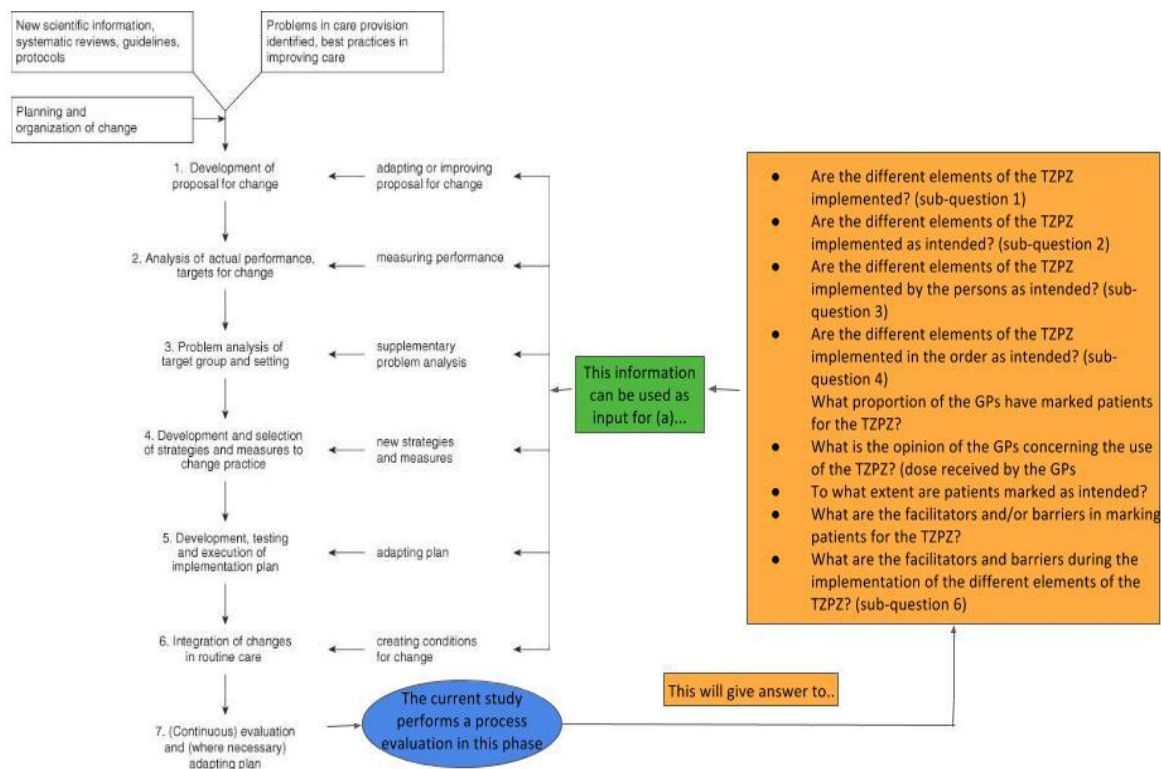


Figure 1: Concept model of the current study

### **3. Methods**

This chapter presents the methods that were used in this research. First, the research design is described. Thereafter, the setting and the study population are explained. Consequently, the measurement instruments, the procedures for data collection, and the methods for data analysis are described for the document review, and the focus group and the interview. Finally, the strategies to obtain validity and reliability are elaborated.

#### **3.1 Design of the research**

The nature of this study was explorative. A mixed method approach, by using quantitative and qualitative data emerging from the document review, focus group and interview, was applied to answer the research question. This study had a cross-sectional design.

#### **3.2 Setting and study population**

##### *3.2.1 Document review*

The process evaluation of this study focused on the implementation of the TZPZ within the eight GP practices (with a total of 16 GPs) participating in the pilot. These 16 GPs marked palliative patients for participation in the pilot. The inclusion criteria for the (forms of the) patients included in the document review were:

- The care pathway coordinator (a nurse practitioner specialized in palliative care, whom has a coordinating role in the TZPZ) has noted the patient as “participating in the pilot” before 17<sup>th</sup> of May.
- The patient has signed informed consent to participate in the study (effect and process evaluation) accompanying the pilot
- The assessment is performed within primary care (by the GP or the POH)
- Forms of the patient are accessible and available for the researcher

##### *3.2.2 Focus group and interview*

The sixteen GPs participating in the pilot were located in the region “de Westelijke Mijnstreek”, in Geleen, Munstergeleen and Sittard. The GPs were associated with “Medita”, which is an organization supporting GPs with practical issues. The inclusion criteria for the GPs participating in the focus group and the interview were:

- Participation in the pilot
- The GP has signed informed consent to participate in the study

#### **3.3 Measurement instruments**

##### *3.3.1 Checklist for the document review*

The topics on the checklist (Appendix 3) were identified after studying:

- The list of process evaluation questions based on the recommended components of a process evaluation by Saunders et al. (2005) (Chapter 2, paragraph 2.3)
- The extensive description of the TZPZ (Appendix 2)
- The forms that have to be filled in during the execution of the different elements of the TZPZ of a patient

The checklist was composed in collaboration with the care pathway coordinator and checked by an expert in the field of implementation. The finalized checklist (Appendix 3) consisted of the following topics:

- General information (who is the GP, whether the care coordinator is the GP or the POH, whether the GP or the medical specialist marked the patient)
- Patient information (date of birth, gender, diagnose, medical history, medication, type of relationship with the informal caregiver)
- Dates of the execution of the elements in the TZPZ (used to answer sub-question 4)
- For the alignment between the GP and the medical specialist, consultation about the marking as a palliative patient, the assessment (incl. EDIZ), registration for the MTM, advice emerging from the MTM, the medication review, the coordination of the multidisciplinary care and the care plan sub-question 1, 2 and 3 are asked

### *3.3.2 Topic list for the focus group and interview*

The topic list used for the focus group and the interview is similar, and was created by:

- Making use of the categories of potential facilitators and/or barriers during the implementation of an innovation, as identified by Grol et al. (2013) (Chapter 2, paragraph 2.5)
- Studying the extensive description of the TZPZ (Appendix 2)
- Making use of the results of the document review

After an extensive discussion with several members of the project group (with the project leader and two researchers involved in the process evaluation of the TZPZ, i.a. an expert in the field of implementation), the topic list was finalized. The finalized topic list (Appendix 4) consisted of:

- An introduction of the GPs (incl. how many patients they have seen in the past few weeks who were eligible for marking)
- Open-ended questions regarding the perceived added value, barriers and potential solutions to these barriers for the following elements: marking, assessment, MTM, medication review and creation of the care plan. The elements “coordination of the multidisciplinary care” and “evaluation after the death of the patient” have received no or less attention considering time constraints and, as the pilot has just started six months ago, most GPs probably had no experience in using these elements.

- Remaining (open-ended) questions, which were not specific to any element (e.g. the ICT system, complexity of the TZPZ, perceived added value of the entire TZPZ, recommendations for further implementation of the TZPZ)

### **3.4 Procedures for data collection**

#### *3.4.1 Document review*

Informed consent (to participate in the effect and process evaluation accompanying with the pilot) was asked during the consultation about the marking as a palliative patient. The checklist was filled in for each patient included in the document review by extracting data from:

- Forms: these forms were completed during the execution of the different elements of the TZPZ of a patient. The forms were filled in by the GP, medical specialist, care coordinator or care pathway coordinator. The forms were anonymously retrieved from Flycatcher (an online database) or, if not available in Flycatcher, obtained via the secretary of the project “Gewenste zorg in de laatste levensfase” or the care pathway coordinator, and anonymized by them.
- Internal documents:
  - “Pseudonimisatie bestand”
  - “Overzicht geïnccludeerde patiënten week 19”

These internal documents were anonymized and obtained via the secretary of the project “Gewenste zorg in de laatste levensfase” or the care pathway coordinator.

- E-mails with the care pathway coordinator, the pharmacist and the GP practice: if information was missing or not requested on the forms or internal documents, an e-mail was sent by the secretary of the project “Gewenste zorg in de laatste levensfase”. When a response was received, the secretary anonymized the e-mails and sent the e-mails to the researcher.

#### *3.4.2 Focus group and interview*

A semi-structured, face-to-face focus group and interview were used to explore GPs’ perceptions of the facilitators and/or barriers during the implementation of the TZPZ, and potential solutions to these identified barriers. The GPs were invited via e-mail, by the “hagro-ondersteuner” (whom has the function of supporting the GPs in this project). One GP, who was the main practitioner of seven of the 11 patients included in the document review, could not be present at the focus group. Therefore, an interview was held with this GP. The planned duration of, respectively, the focus group and the interview was 1,5 and 1 hour(s). The focus group and the interview, respectively, took place at Meditta (one of the organizations which was involved in the development and implementation of the TZPZ) in Sittard and the GP practice of the GP interviewed. Before the start of the focus group and the interview, the following matters were addressed:

- Informed consent was asked

- Permission to record the interview was asked
- The participants were told that they will remain anonymous during the study

The interviewer was a researcher working for the Zuyderland Hospital in Sittard. Several other persons involved in the implementation of the TZPZ were present at the focus group: a researcher whom executes the process evaluation for the project “Gewenste zorg in de laatste levensfase”, the project leader and a student performing her master thesis regarding the project “Gewenste zorg in de laatste levensfase”. No other persons, besides the interviewer, were present at the one-to-one interview. The focus group and the interview were transcribed (non-verbatim) immediately after the focus group and the interview.

### **3.5 Data analysis**

#### *3.5.1 Document review*

The completed checklist of all patients were bundled in several tables. These tables were analyzed both quantitatively (by doing a frequency count of e.g. how often the assessment was performed) and qualitatively (e.g. by comparing what questions were filled in on the questionnaires of the assessment of different patients).

#### *3.5.2 Focus group*

The transcripts of the recorded focus group and interview functioned as a starting point for the analysis. The coding process was done by hand. The questions regarding the barriers/ facilitators during the implementation of the TZPZ were coded deductively, and per element (except for the remaining questions which are not specific for any element), by using the list of categories of potential facilitators and/or barriers during the implementation of an innovation, as identified by Grol et al. (2013) (Chapter 2, paragraph 2.5). Additionally, “potential solutions” was used as a main code. The form used for coding the transcripts is listed in Appendix 5.

Both quantitative (by doing a frequency count of how often the perceived barriers and/or facilitators and the potential solutions are mentioned) and qualitative (by extracting remarkable statements from the transcription) analysis were performed.

### **3.6 Validity and reliability**

Validity can be distinguished in internal and external validity. To assure the internal validity, several strategies were used. Firstly, the checklist for the document review was composed in collaboration with the care pathway coordinator and checked by an expert in the field of implementation. Moreover, the checklist was created according to the recommended components of a process evaluation by Saunders et al. (2005) (Chapter 2, paragraph 2.3). The topic list was developed in accordance with

the members of the project group. Secondly, to create an open-minded view, the researcher was someone not involved in the development and implementation of the TZPZ. Thirdly, throughout the entire duration of the study, feedback was provided by fellow students and an expert in implementation. Concerning the external validity, this research is a case study about the TZPZ. Therefore, the results are not representative to other palliative care pathways. However, the results can be used as an aid to weaken the facilitators and/or barriers during the implementation of other palliative care pathways.

The main strategy to reach reliable findings is to give thick and accurate description of the methodology and results of this study (Esterberg, 2002).

## 4. Results

This chapter describes the results of the current study. In paragraph 4.1, the results of the document review are presented. Paragraph 4.2 describes the results of the focus group and the interview.

### 4.1 Results of the document review

In paragraph 4.1.1, the characteristics of the study population are explained. Paragraph 4.2.2 describes the results with regard to sub-question 1, 2 and 3. In paragraph 4.2.3, the results concerning sub-question 4 will be presented.

#### 4.1.1 Characteristics of the study population

By 17<sup>th</sup> of May 2016, 17 patients (have) participate(d) in the pilot. Eleven of the 17 participating patients (64,7%) were marked within primary care. These 11 patients were marked by four different GPs, meaning that 25% of all the participating GPs had marked palliative patients thus far. Six of the 17 participating patients (35,3%) were marked within secondary care.

The study population comprised 11 patients, as 11 of the 17 participating patients fulfilled the inclusion criteria (Figure 2) (response rate is 100%).

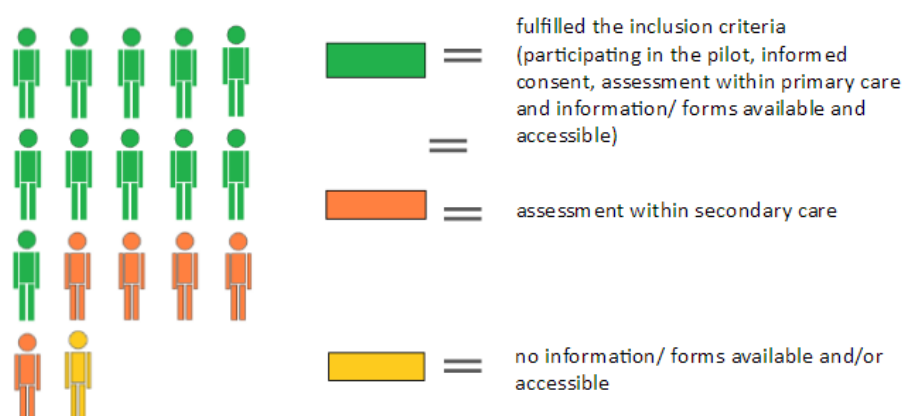


Figure 2: Patients who fulfilled the inclusion criteria (of the 17 patients participating in the pilot)

The characteristics of the patients included in the study are presented in, respectively, Table 1 and Figure 3. The information concerning the care coordinator (GP or POH) of the patient and the type of relationship with the informal caregiver was missing.

Table 1: Characteristics of the study population

|                          |                  |
|--------------------------|------------------|
| <b>Age</b>               |                  |
| Mean age                 | 79,6 years       |
| N(%) older than 65 years | N = 9 (81,8%)    |
| <b>Gender</b>            |                  |
| N (%) ♂;                 | N = 6 (54,5%) ♂; |
| N (%) ♀                  | N = 5 (45,5%) ♀  |

|                                                                                                                                                              |                                                                                                                                                                                                                                                                                                          |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Deceased</b><br>N (%): <ul style="list-style-type: none"> <li>Time between marking and date of death;</li> <li>Moment of death within the TZPZ</li> </ul> | N = 4 (36,4%): <ul style="list-style-type: none"> <li>N = 3 the date of marking and/or date of death was unknown, N = 1 passed away 1½ months after marking;</li> <li>N = 2 (50%) passed away after the assessment but before the MTM could take place, N = 2 (50%) passed away after the MTM</li> </ul> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

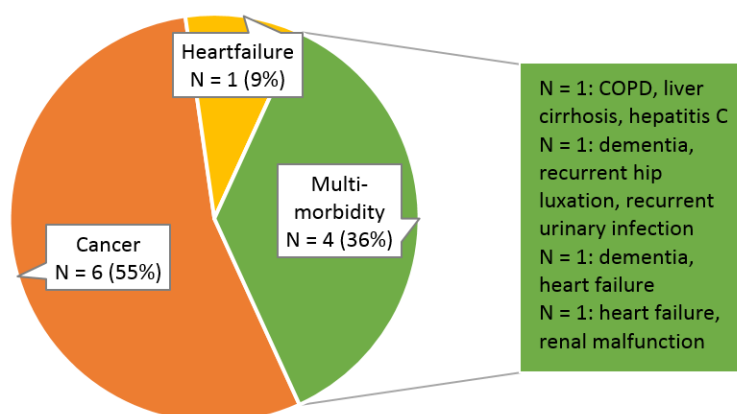


Figure 3: Types of diagnoses of the study population

Ten of the 11 included patients (90,1%) were marked within primary care. These ten patients were marked by three different GPs, of whom one GP had marked seven patients (which is 63,6% of all patients included in this study). The other two GPs had marked one or two patient(s). In addition, all the 11 included patients in the document review had a GP as a main practitioner. In total, four GPs of three different GP practices were involved. Two GP practices were located in Geleen, and one GP practice was located in Sittard.

#### 4.1.2 Are the different elements of the TZPZ implemented (as intended)? (sub-questions 1,2 and 3)

Table 2 shows the results regarding sub-question 1, 2 and 3 of the following elements: marking, assessment (excl. EDIZ), EDIZ, MTM and the medication review. As shown in the Table 2, it was not always possible to answer all three sub-questions for all these elements as information of one, some or all patients was missing (the parts colored grey and light grey).

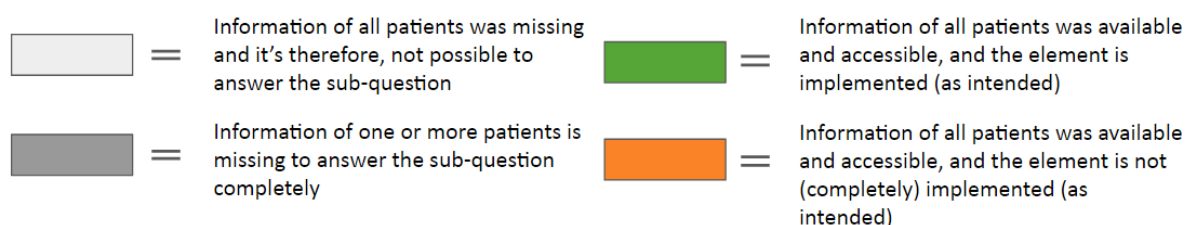


Figure 4: Legend of table 2

Table 2: The results concerning sub-question 1,2 and 3 for the elements of the TZPZ<sup>1</sup>

| Elements of the TZPZ               | Sub-question 1: Is the element implemented?                                                                                                                                                                                                          | Sub-question 2: Is the element implemented as intended?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Sub-question 3: Is the element implemented by the person as intended?                                                                                                                                                                                                             |
|------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Marking</b>                     | - N = 11 are marked                                                                                                                                                                                                                                  | - Regarding the basis of marking: <ul style="list-style-type: none"> <li>N = 4 (36,4%); marking is based on the surprise question</li> <li>N = 6 (54,5%); marking is based on the RADPAC+ indicators</li> <li>N = 1 (9,1%); marking is based on the surprise question and the RADPAC+ indicators</li> </ul> - Regarding the moment of marking: <ul style="list-style-type: none"> <li>N = 1 (9,1%); deceased and marking was 1½ months before date of death</li> <li>N = 3 (27,3%); deceased, but date of marking and/or date of death is unknown</li> </ul> | - Regarding the person who marked the patient as a palliative patient: <ul style="list-style-type: none"> <li>N = 10 (90,9%); marked by the GP</li> <li>N = 1 (9,1%); marked by the medical specialist</li> </ul>                                                                 |
| <b>Assessment (excl. the EDIZ)</b> | - Regarding the cover page: <ul style="list-style-type: none"> <li>N = 2 (18,2%); cover page is completed</li> <li>N = 9 (81,8%); unknown whether the cover page was completed, as the information was missing at the moment of the study</li> </ul> | - Regarding the cover page: <ul style="list-style-type: none"> <li>N = 1 (50%); cover page was filled in completely</li> <li>N = 1 (50%); cover page was not filled in completely</li> </ul> - Regarding the questionnaire: <ul style="list-style-type: none"> <li>N = 3 (33,3%); questionnaires were filled in completely</li> </ul>                                                                                                                                                                                                                        | - Regarding the person who performed the assessment: <ul style="list-style-type: none"> <li>N = 2 (18,2%); assessment was performed by the POH</li> <li>N = 9 (81,8%); unknown who performed the assessment, as the information was missing at the moment of the study</li> </ul> |

<sup>1</sup> The following elements were not included in Table 2 as all information concerning sub-question 1, 2 and 3 was missing:

- Consultation about the marking as a palliative patient
- Alignment between the GP and the medical specialist. The GPs consider the alignment as an important part of the TZPZ.
- Care plan
- Coordination multidisciplinary care
- Evaluation after the death of the patient

| Elements of the TZPZ | Sub-question 1: Is the element implemented?                                                                                                                                                                                                                                                 | Sub-question 2: Is the element implemented as intended?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Sub-question 3: Is the element implemented by the person as intended? |
|----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------|
|                      | <p>- Regarding the questionnaire:</p> <ul style="list-style-type: none"> <li>• N = 9 (81,8%); questionnaire of the assessment is completed</li> <li>• N = 2 (18,2%); unknown whether the questionnaire was completed, as the information was missing at the moment of the study</li> </ul>  | <ul style="list-style-type: none"> <li>• N = 6 (66,7%); questionnaires were not filled in completely (answers on one or more questions were missing)</li> </ul> <p>The following questions were skipped more than once:</p> <ul style="list-style-type: none"> <li>- Question 7h (regarding problems with appearance) was skipped in N = 3 (33,3%) (in N = 1, it was stated that the question was unclear)</li> <li>- Question 11 (regarding the wishes and needs of the patient) was skipped in N = 2 (22,2%)</li> <li>- Question 23 (whether there are signs for an acute change in the cognitive status, in comparison with the initial situation) was skipped in N = 2 (22,2%) (in N = 1, it was stated that the question was unclear)</li> </ul> |                                                                       |
| <b>EDIZ</b>          | <p>N = 7 (63,6%); EDIZ was completed</p> <p>N = 1 (9,1%); EDIZ was not completed (for the reason that the informal caregiver was not present at the assessment)</p> <p>N = 3 (27,3%); unknown whether the EDIZ was completed, as the information was missing at the moment of the study</p> | <p>N = 7 (100%); EDIZ questionnaires were filled in completely</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                       |

| Elements of the TZPZ | Sub-question 1: Is the element implemented?                                                                                                                                                                                                                                                       | Sub-question 2: Is the element implemented as intended?                                                                                                                                                                                                                                                                                                                                                | Sub-question 3: Is the element implemented by the person as intended?                                                                                                                                                                                                                                                          |
|----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| MTM                  | N = 9 (81,8%); MTM has taken place, and both the registration and advice form were completed<br>N = 2 (18,2%); the MTM advice form was delivered at the care pathway coordinator and the date on which these patients were to be discussed was planned, however the patients deceased before this | <p>- Regarding the registration form:</p> <ul style="list-style-type: none"> <li>N = 9 (81,8%); registration forms were not filled in completely</li> <li>N = 2 (18,2%); registration forms were filled in completely</li> </ul> <p>The following information was not filled in more than once:</p> <ul style="list-style-type: none"> <li>N = 7 (63,6%); the date of marking was not noted</li> </ul> | <p>- Regarding the person who registered the patient for the MTM:</p> <ul style="list-style-type: none"> <li>N = 2 (18,2%); the registration for the MTM was performed by the POH</li> <li>N = 9 (81,8%); unknown who registered the patient for the MTM, as the information was missing at the moment of the study</li> </ul> |

| Elements of the TZPZ | Sub-question 1: Is the element implemented? | Sub-question 2: Is the element implemented as intended?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | Sub-question 3: Is the element implemented by the person as intended?                                                                                                                                                |
|----------------------|---------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                      | date. The advice forms were not filled in.  | <ul style="list-style-type: none"> <li>- N = 6 (54,5%); the date of diagnose was not noted</li> <li>- N = 7 (63,6%); a question for the MTM was not completed</li> <li>- N = 6 (54,5%); the summary (of the patient) was not noted</li> <li>- N = 3; the scores of the assessment were not noted on or attached to (by using the score form) the registration forms, although the score form did not yet exist when the registration form of N = 2 (18,2%) was sent.</li> <li>- N = 2 (18,2%); the scores were noted on or attached to the registration form, but one or two scores were missing.</li> </ul> <p>- Regarding the advice form:</p> <ul style="list-style-type: none"> <li>• N = 9 (100%); advice forms were not filled in completely</li> </ul> <p>The following information was not filled in more than once:</p> <ul style="list-style-type: none"> <li>- N = 5 (55,5%); the general information was missing</li> <li>- N = 8 (88,9%); the potential problems were missing</li> </ul> <p>N = 3 (100% of all patients with high scores); scores of the assessment were high (Lastmeter: <math>\geq 5</math>, CAM: yes, NRS (pain): <math>&gt; 4</math>, HADS: <math>&gt; 8</math> for fear and/or depression, EDIZ: score between 7 and 9), and the scores were discussed (at least one of the high scores) in the MTM)</p> | <p>- Regarding the person who filled in the advice form:</p> <ul style="list-style-type: none"> <li>• N = 9 (100%); the advice form was completed (also the color coding) by the care pathway coordinator</li> </ul> |

| Elements of the TZPZ     | Sub-question 1: Is the element implemented?                                                          | Sub-question 2: Is the element implemented as intended?                                                                                                                                                                                                                                                 | Sub-question 3: Is the element implemented by the person as intended? |
|--------------------------|------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------|
|                          |                                                                                                      | N = 1 ((33,3% of all patients with a MTM question on the registration form and a completed advice form); the MTM question was not answered in the MTM.<br>N = 4 (44,4%); the summary on the advice form was classified in the four domains (the physical, psychological, functional and social domain). |                                                                       |
| <b>Medication review</b> | N = 1 (9,1%); medication review was performed<br>N = 10 (90,9%); medication review was not performed |                                                                                                                                                                                                                                                                                                         |                                                                       |

#### 4.1.3 Are the different elements of the TZPZ implemented in the order as intended? (sub-question 4)

Table 3 presents an overview of the available and correctly documented information (column 1), the available but incorrectly documented information (column 2), and the unavailable information (column 3) regarding sub-question 4.

Table 3: Frequencies of available and correctly or incorrectly documented information regarding sub-question 4

| Information necessary to answer sub-question 4                 | Frequency of available information and correctly documented information | Frequency of available, but incorrectly documented information                                                                                                                                              | Frequency of unavailable information |
|----------------------------------------------------------------|-------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------|
| Date of marking                                                | N = 3 (27,3%)                                                           | N = 3 (27,3%) of which: <ul style="list-style-type: none"> <li>N = 2 (66,7%); dates are before the start of the pilot</li> <li>N = 1 (33,3%); the marking date is similar as the date of the MTM</li> </ul> | N = 5 (45,5%)                        |
| Date of consultation about the marking as a palliative patient | N = 0 (0%)                                                              | N = 0 (0%)                                                                                                                                                                                                  | N = 11 (100%)                        |
| Date of assessment                                             | N = 2 (18,2%)                                                           | N = 0 (0%)                                                                                                                                                                                                  | N = 9 (81,8%)                        |

|                                               |               |                                                                                                                                                                 |                |
|-----------------------------------------------|---------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------|
| Date of registration for the MTM              | N = 2 (18,2%) | N = 9 (81,8%); these are the dates that the secretary has entered the registration form in Flycatcher, and not the “real” dates of the registration for the MTM | N = 0 (0%)     |
| Date of MTM                                   | N = 11 (100%) | N = 0 (0%)                                                                                                                                                      | N = 0 (0%)     |
| Date of composing a care plan                 | N = 0 (0%)    | N = 0 (0%)                                                                                                                                                      | N = 11 (100%)  |
| Date of death                                 | N = 1 (25%)   | N = 0 (0%)                                                                                                                                                      | N = 10 (90,9%) |
| Date of evaluation after death of the patient | N = 0 (100%)  | N = 0 (0%)                                                                                                                                                      | N = 11 (100%)  |

#### 4.1.4 What characteristics of patients can influence the implementation of the different elements of the TZPZ? (sub-question 5)

Patients younger than 65 years were marked exclusively based on the RADPAC+ indicators. No relationship could be found between the implementation of the TZPZ and the characteristics gender and diagnosis.

## 4.2 Results of the focus group and interview

Three GPs (response rate is 18,8%), comprised of two men and one woman, participated in the focus group. The GP interviewed by means of a one-to-one interview was female and was the main practitioner of seven of the 11 patients included in the document review.

This chapter will first describe the general facilitators and/or barriers during the implementation of the TZPZ. Thereafter, the facilitators and/or barriers will be discussed for the following elements of the TZPZ: marking, assessment, MTM, medication review and creation of the care plan. Also, in every paragraph, the recommendations adduced by the GPs to improve the implementation of the TZPZ will be presented.

#### 4.2.1 The TZPZ in general

The GPs (N = 4) regarded the TZPZ as valuable: it was seen as a point of departure to deliver high quality palliative care. One GP mentioned that the TZPZ will especially be of advantage for the group of GPs that currently withdraws of providing palliative care. Furthermore, it was believed that the TZPZ raises awareness (N = 1):

*“It makes you realize that palliative care is more than just care for the group of patients in the final, terminal phase”*

A barrier to use the TZPZ was its fixed nature (N = 1):

*“It seems like the project has an on/ off button: you join or you do not. Everything should be filled in and done immediately (...), but sometimes you need several conversations with the patient.”*

*“In addition, the wishes of a patient can change. (...) We need to be flexible.”*

The questionnaire of the assessment should not have to be completed immediately, as patients need some time for consideration (N = 1). Additionally, it should not be obligated to use the format designed by the project group (e.g. for the care plan) (N = 1). Furthermore, the administration associated with using the TZPZ was perceived as a barrier: it was considered as time-consuming, complex and cumbersome (N = 2). Especially in the beginning, it was very unclear where and how the forms should be sent (N = 1).

*“It is a huge amount of paperwork!”*

*“It was very ambiguous for the assistant of the GP in the beginning.”*

Furthermore, the GPs (N = 2) considered the pro-active character of the TZPZ, i.a. starting the conversation about end of life early, as time-consuming and were in doubt whether it saves time at the end of the palliative phase.

*“There are always ad hoc things which should be arranged last minute.”*

Another barrier to use the TZPZ was the lack of support from colleagues (N = 1). It was believed that, to improve the implementation of the TZPZ, the GPs should share experiences with each other regarding their use of the TZPZ. Another recommendation suggested by the GPs is that, after the pilot, all elements of the TZPZ should be critically examined for their added value (N = 2)/

*“The TZPZ has many elements, it is questionable whether all elements are useful.”*

*“For the implementation of the TZPZ on a larger scale, (...) you have to downsize.”*

#### 4.2.2 Marking

Marking was considered as useful: it gives an alibi to start the conversation about the end of life (N = 2) and it creates awareness (N = 1).

*“As a consequence of the marking, I’m aware of the palliative patients in my practice.”*

The alignment between primary and secondary care was regarded as a formality, but though important (N = 1). Starting the conversation about the end of life was considered as the main barrier in marking palliative patients pro-actively (N = 3). According to one GP, some GPs lack experience concerning starting conversations about the end of life. Another obstacle in starting conversations about end of life was patient-related: when a patient is still being treated, starting a conversation about end of life was perceived as even more difficult (N = 3).

*“I do not want to take away the hope.”*

*“If a patient has high expectations of the treatment, (...) he or she is not ready for conversations about the end of life.”*

In addition, the attitude of the patient was considered as an obstacle in starting the conversation about the end of life (N = 3).

*“It is hard to start conversations about the end of life when a patient do not want to face the poor prognosis and still has hope.”*

Moreover, the reaction of the patient was regarded as a barrier in marking palliative patients (N = 1).

*“If participating in the pilot takes away the patients’ energy, the patient is not included in the pilot.”*

A facilitator regarding starting the conversation about end of life was regular and intensive contact with the patient (N = 1). Also, if the patient is intelligent and/or falls in the same age category as the GP, it was considered easier to start a conversation about the end of life (N = 1). The opinions were divided with regard to the need for extra training and/or education regarding starting conversations about the end of life. Two GPs believed that more training and/or education will not help, the other two GPs believed it will. Though, there was agreement that extra tips and tricks regarding starting the conversation about end of life would be beneficial, for example by round-table discussions with GPs (N = 4). In this way, GPs can share ideas of how to start a conversation about end of life. One GP thought that it needs time to integrate early discussions regarding the end of life into the routine. Next to the difficulties in starting the conversation about the end of life, another barrier in the marking of palliative patients was the information letter that had to be given in the consultation about the marking as a palliative patient (N = 1). To remove this barrier, certain confronting terms should be left out of the information letter (e.g. “dead”) (N = 1).

#### 4.2.3 Assessment

According to the GPs (N = 3), the assessment was helpful:

*“The conversations are special and meaningful.”*

*“It gives you a complete overview of what to discuss.”*

Also, the assessment was regarded as confronting, but in a justifiable way: it makes people think about certain subjects such as euthanasia and sedation (N = 1).

*“You cannot bury your head in the sand”*

As reported by a GP, the situation and the relationship with the patient affects whether you fill in all questions on the questionnaire. A perceived barrier in executing the assessment was the questionnaire: the questions regarding fear and depression were regarded as too similar (N = 1) and the questions regarding sexuality and the appearance were considered as inappropriate for older, terminal patients (N = 1). In addition, it was perceived that questions or information were asked several times (N = 1). Also, it was not clear that the questions on the questionnaire were categorized in the four domains (the physical, psychological, functional and social domain) (N = 1). Furthermore, a GP thought that executing the assessment takes too long: the time necessary to conduct the assessment should be reduced from one hour and a half to one hour. Two GPs believed that a checklist instead of a questionnaire would be more convenient.

*“Filing in the questionnaire is a fuss. A checklist would be more practical, I just want a good conversation”*

However, the GPs agreed that, before changing the questionnaire into a checklist, research should reveal whether calculating the scores (of the Lastmeter, CAM, etc.) is useful and thus, whether the questions are indispensable (N = 3). Furthermore, the GPs (N = 2) recommended that, if questions are not filled in on the questionnaire by the GP, an e-mail should be sent to the GP practice to retrieve the missing information.

#### 4.2.4 MTM

The GPs considered the MTM as useful (N = 2):

*“Multiple heads are better than one”*

In addition, the GPs (N = 3) believed that it is beneficial to discuss all patients in the MTM. However, a distinction should be made between the care-intensive patients and the non-complex patients. The non-complex patients should be discussed shortly (N = 1). This will especially be important when the total number of patients participating in the TZPZ increase (N = 1). One GP put forward two major barriers to the use of the MTM: lack of structure and lack of good reporting during the MTM. A protocol of “how the MTM should be executed” could remove these barriers (N = 1). In addition, the advice of the MTM should be organized in the four domains (the physical, psychological, functional and social

domain) (N = 1). In this way, the advice emerging from the MTM functions as a point of departure for creating the care plan (N = 1).

*‘The better the reporting of the MTM, the more valuable the MTM is’*

During the focus group and the interview, it became apparent that two GPs had patients who were not discussed at the MTM. One GP believed that a patient should not be discussed at the MTM when the patient does not have a medical specialist participating in the pilot. Furthermore, it was remarked that the administration concerning the registration for the MTM did not work as it should (N = 2). The GPs (N = 2) recommended that, to prevent patients participating in the pilot not being discussed at the MTM, the secretary should inform the care pathway coordinator regarding the patients included in the TZPZ. Additionally, the list of included patients in the TZPZ of the secretary and the care pathway coordinator should be compared (N = 1).

#### 4.2.5 Medication review

The GPs (N = 2) thought that it is important that the pharmacist knows that the patient is marked as palliative. However, the GPs (N = 2) believed that the pharmacist should not start a conversation about end of life as it could be confusing for the patient. Moreover, a GP considered that pharmacists do not have the competence to conduct medication reviews of palliative patients. The GPs (N = 2) agreed that the medication review should remain in the TZPZ during the duration of the pilot, however, research should reveal whether the medication review is of any added value.

#### 4.2.6 Care plan

The GPs regarded the care plan as unhelpful.

*‘It is made, ends with the papers and little is done with it’*

According to three GPs, it takes a lot of extra time to document it separately in the format made by the project group.

*‘I do it in my own system’*

*‘Paper is time’*

*‘By scanning the assessment and the advice emerging from the MTM, you have your care plan, (...) you do not write it down separately.’*

One GP suggested that the usefulness of the care plan could be increased by adding the PaTz (Palliatieve Thuiszorg; a palliative care intervention in which GPs and district nurses meet on a regular basis to identify patients with palliative care needs and to discuss the appropriate care for these patients) component to the TZPZ.

## 5. Discussion

The main findings and interpretation of these findings are described in paragraph 5.1. In paragraph 5.2, the strengths and weaknesses of this study are described. Paragraph 5.3 presents the recommendations emerging from the results of this study. An overall conclusion of this research report is given in paragraph 5.4.

### 5.1 Main findings and interpretation of these findings

Overall, the GPs regard the TZPZ as a good point of departure to deliver pro-active, patient-centered palliative care. The main research question of this study was: ‘‘Are the different elements of the TZPZ implemented as intended?’’ From the information that was available and accessible, it could be inferred that the TZPZ is not yet implemented as intended since a small number of palliative patients are marked, several palliative patients are marked at the end of their lives instead of one year before the expected death, the questionnaires (excl. EDIZ) of the assessment are not completely filled in as intended, the MTM and the medication review are not executed in all patients participating in the pilot, and care plans are not created as intended by GPs or POHs. These results have to be put into context, since:

- a) The implementation of the TZPZ started merely six months ago. It requires time to integrate a care pathway into daily routine (Van Kraaij, 2014; Lo et al., 2009). Earlier research has also shown that implementation of care pathways is difficult as it requires collaboration of several health care professionals, incorporates many elements and often pursues multiple aims (van Hoeve et al., 2014).
- b) Insufficient information was available and/or accessible to assess the implementation of the other elements of the TZPZ: consultation about the marking as a palliative patient, alignment between the GP and the medical specialist, the EDIZ, coordination of the multidisciplinary care and evaluation after the death of the patient. Also, too little (correctly documented) information was available to assess whether the different elements of the TZPZ are implemented in the order as intended.

The main barriers during the implementation are starting the conversation about end of life and the time-consuming administration associated with the TZPZ. During the entire TZPZ of a patient, eight different forms have to be filled in by the GP (or his or her assistant). The forms have to be sent to different persons, and via different means (e-mail, fax or an Edifact message). In addition, as merely four GPs have marked 11 patients, the GPs might be yet insufficiently familiar with filling in and sending the forms. Earlier research has also shown that bureaucratic procedures can be a main barrier in the delivery of palliative care (Groot et al., 2007). Furthermore, the GPs have indicated that the fixed nature of the TZPZ, interpreted as too little space for a GP to deliver the palliative care that he or she considers as fitting in a certain situation or for a certain patient, is a barrier in the implementation of the TZPZ. Moreover, the GPs reported that the TZPZ has many elements. According to the definition of complex

interventions given by Pawson et al. (2005)<sup>2</sup>, this makes the TZPZ rather complex. Complexity, as proposed by Rogers (2003), can act as a barrier to the implementation of an innovation. Therefore, it is important to downsize the TZPZ on a long-term: critically examining all elements for their added value in delivering high quality palliative care.

The following section will discuss the findings of the elements of the TZPZ which are not implemented as intended in more detail. In addition, the remaining findings (regarding the study population of the document review) will also be discussed.

#### *5.1.1 Marking*

The objective, as written in the implementation plan, is to mark 400 patients by September 2017. As merely 17 patients are marked by half of May, it will be a challenge to achieve this objective. In addition, these 17 patients are marked by a small group of GPs. Furthermore, four of the 11 patients in the study population of the document review have deceased within six months after the start of the pilot, demonstrating that the patients are not marked pro-actively (one year before the expected death). These results indicate difficulties in early identification of palliative patients, which is in line with earlier research as Beertnaert et al. (2014) confirms that identification of palliative patients is more problematic in earlier stages than in the terminal phase and; Thoonsen et al. (2015) shows that, even after training in early identification of palliative patients, GPs only identify a small proportion (24%) of the entire group of patients who die from non-acute diseases. Despite the difficulties in early identification of palliative patient, the results of the focus group show that the willingness to mark patients early in the palliative phase is present.

As emerged from the focus group and the interview, the main explanation for the difficulties in early identification of palliative patients is that GPs encounter problems in starting the conversation about end of life: they do not want to deprive a patient's hope and lack experience and/or time. A qualitative study on the facilitators and/or barriers in early identification of palliative patients also identified the GPs' fear of depriving hope, lack of skills and lack of time as barriers in early identification of palliative patients (Beernaert et al., 2014). In addition, a research of IKNL and the professional association 'Palliactief' has shown that the discussion regarding end of life is considered as even more difficult when the patient is still being treated, which is in accordance with the results of this study (Boddaert et al., 2015). As emerged from the focus group, one GP believed a patient is not ready for a conversation about end of life if he or she still has high expectations of the treatment. However, it is questionable whether the patient is not ready for such a conversation, or the GP is not ready. Also, one GP considered the information letter that should be given in the consultation about the marking as too confronting. It is, again, debatable whether the information letter is too confronting for the patient or for the GP. As a consequence of these kinds of believes, GPs may adopt a reactive rather than a proactive

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<sup>2</sup> Complex interventions are long journeys, embedded in multiple social systems, which are open and adaptive

attitude in the interaction with patients (Bloomer, 2010; Claessen et al., 2013). Another explanation for the difficulties in early identification of palliative patients might be that GPs do not make (enough) use of the surprise question, as shown by the results of the document review. These results correspond to earlier research, which demonstrated that GPs experience difficulties in using the surprise question in practice (Van der Rijt, 2016). However, the lack of use of the surprise question may also be due to incorrect documentation, as marking patients without using the surprise question is very difficult. An alternative explanation for the difficulties in early identification of palliative patients as described in the literature is uncertainty about the course of disease, which is particularly the case in non-cancer patients (e.g. heartfailure, COPD) (Mahtani-Chugani et al., 2010; Thoonsen et al., 2016). Though, this cannot be confirmed by the results of the current study as almost half of the included patients are non-cancer patients.

The results of the focus group show that good and intensive contact with the patient act as a facilitator in starting the conversation about end of life. These results are consistent with previous research, which has shown that regular contact between the GP and the patient is essential for the GP to identify the need for palliative care in patients (Beernaert et al., 2014).

It was doubtful, as expressed in the focus group and the interview, whether extra training and/or education would help in the early identification of palliative patients. Though, one GP marked seven of the 11 included patients in the document review, and attended a specialized training course in palliative care, suggesting that extra training and/or education can increase the number of patients marked for the TZPZ. Yet, the great interest in palliative care may also be an explanation for the high number of marked patients by this GP. According to the literature, training and/or education can significantly improve communication skills and thereby, support physicians in discussing end-of-life aspects (Fallowfield et al., 2002). However, earlier research also endorses that educational interventions do have influence on the self-efficacy of physicians, but have a limited effect on their daily behavior (Alvarez et al., 2006; Shaw et al., 2010). Therefore, changing behavior takes more than only educational interventions. The GPs of the focus group would like to share experiences regarding starting the conversation about end of life.

#### *5.1.2 Assessment*

The questionnaires (excl. EDIZ) of the assessment are not filled in as intended because the results of the document review show that two thirds (66,7%) of the filled in questionnaires miss answers on one or more questions. As a consequence, the scores of the tools (Lastmeter, CAM etc.) used in the assessment cannot be calculated.

The GPs regard the assessment as helpful: it leads to meaningful conversations and provides an overview of what to discuss during these conversations. A possible explanation for not filling in all questions might be dissatisfaction with the questionnaire: the questions are too similar, the same information is asked several times and some questions are not appropriate for certain types of patients

(e.g. questions regarding sexuality for older, terminal patients). In addition, conducting the questionnaire takes too long. A possible reason for the dissatisfaction with the questionnaire might be that, except for one GP, the GPs were not involved in creation of the questionnaire. This may limit the willingness to use the questionnaire among the GPs.

The GPs would prefer the following concerning the assessment:

- spreading out the completion of the assessment over several moments in time, because sometimes more consultations are needed;
- to have the opportunity to alter the answers on the questionnaire or the checklist, as the wishes of patients can change;
- to be able to ‘not fill in’ questions, as not all questions are appropriate for all patients (e.g. the questions regarding sexuality)

These results demonstrate that GPs want more freedom in the way the assessment could be conducted. This is in line with earlier research, which has shown that it is important that an assessment tool, such as a questionnaire, is seen for what it is: a tool to aid the assessment process, not a panacea for conducting a perfect assessment (McIlfatrick et al., 2014). A checklist (instead of a questionnaire), in combination with a digital system, would be a manner to increase the freedom in the way the assessment can be conducted. However, in the case of a checklist, it would not be possible to calculate the scores (of Lastmeter, CAM etc.) and therefore, research should determine whether the scores are essential in the identification of the needs, values and wishes of the patient.

### *5.1.3 MTM*

Although the results of the document review show that all patients are discussed in the MTM, in the focus group and the interview it was concluded that GPs (N = 2) have patients who are not discussed in the MTM. A possible explanation for this discrepancy is that the group of main practitioners of the included patients in the document review does not correspond to the group of GPs participating in the focus group and interview. Another explanation could be the used inclusion criteria for the patients of the document review: the patients included in the document review should have been noted by the care pathway coordinator as ‘participating in the pilot’. Though, the care pathway coordinator does not have insight into all participating patients in the pilot, merely the patients registered for the MTM.

The GPs believe that it is beneficial to discuss patients in a MTM. This is in line with earlier research, which indicates that MTMs improve decision making for example by providing a better assessment of the treatment options (Haward et al., 2003; Mikan, 2005; Wagner, 2004). A possible reason for the fact that some patients are not discussed in the MTM is the cumbersome administration concerning the registration for the MTM. Additionally, there is no verification by the organization of the TZPZ that all patients participating in the pilot are discussed in the MTM.

### *5.1.4 Medication review*

Earlier research has demonstrated that medication reviews, executed by a pharmacist, improve the quality of prescribing (Stuijt et al., 2009). In addition, it also cuts costs (Hanning et al., 2011). Yet, as the results of the document review show, the medication review is executed in merely one of the eleven patients (9,1%) included in the document review. An explanation for this finding might be that the medication review was added to the TZPZ after the start of the pilot. Furthermore, the focus group have identified two barriers in the execution of the medication review: the believe that it is confusing for patients when pharmacists enter into a dialogue with the patient regarding end of life aspects and the perceived lack the competence of pharmacists to conduct palliative medication reviews. Though, in order to draw a conclusion regarding the reason of not executing the medication review, the perspectives of the pharmacists have to be taken into account.

#### 5.1.4 Care plan

Although the implementation of the care plan could not be assessed in the document review (as the information was missing), the results of the focus group and the interview show that most GPs do not make a care plan in the format designed by the project group of the TZPZ. The GPs make a care plan in their own system and regard documenting it separately, in the format designed by the project group, as time-consuming and meaningless. This indicates that the element of “creation of a care plan” does not comply with the existing way of working and therefore, lacks compatibility. Compatibility is also mentioned by Rogers (2003) as one of the characteristics of an innovation that can influence the implementation of an innovation.

## 5.2 Remaining findings (regarding the study population of the document review)

However a small group of patients is included in the document review, the results suggest that the patients participating in the TZPZ are a proper reflection, in terms of age and types of diagnoses, to the Dutch population in need of palliative care (which is assumed to be similar to the Dutch population dying of non-acute diseases) (NIVEL, 2009). In the Netherlands, 75% of the people dying of non-acute diseases is older than 65 years, which is 82% in the study population (IKNL, 2010). In Table 4, a comparison of the diagnoses in the Dutch population dying of non-acute diseases with the diagnoses in the study population is presented (IKNL, 2010). As shown, the percentages of the different diagnoses of the Dutch population dying of non-acute diseases and the study population correlate considerably to one another (excluding the percentages for CVA and heart failure).

| Diagnoses | % in the Dutch population dying of non-acute diseases | % in the study population       |
|-----------|-------------------------------------------------------|---------------------------------|
| Cancer    | 52%                                                   | 55%                             |
| CVA       | 13%                                                   | 0%                              |
| Dementia  | 10%                                                   | 18% (as part of multimorbidity) |
| COPD      | 8%                                                    | 9% (as part of multimorbidity)  |

|                      |    |                                                               |
|----------------------|----|---------------------------------------------------------------|
| <b>Heart failure</b> | 8% | 9% (as the only diagnose) and 18% (as part of multimorbidity) |
|----------------------|----|---------------------------------------------------------------|

Table 4: Comparison of the diagnoses in the Dutch population dying of non-acute diseases with the diagnoses in the study population (IKNL, 2010)

### 5.3 Strengths and weaknesses of the study

This study provides insight into the implementation of the different elements of the TZPZ six months after the start of the pilot. In addition, this study gives valuable information regarding the factors impeding the use of the TZPZ by GPs. A strength of this research is the mixed method approach. Another strength of this research is that the execution of the study (e.g. the creation of the checklist for the document review) is guided by a process evaluation plan, which was created by using the ‘‘How-To Guide’’ of Saunders et al. (2005) (Paragraph 2.3). In this way, the recommended components of a process evaluation are taken into account. Additionally, the checklist and the topic list, respectively for the document review and the focus group, are composed in collaboration with an expert in the field of implementation.

The findings of this study must be considered in light of the study’s limitations. A small group of patients was used for the document review. Yet, all patients fulfilling the inclusion criteria were included. Also, many included patients had the same GP. As a consequence, the results of the document review might not provide a comprehensive picture of the implementation of the TZPZ by all 16 GPs participating in the pilot. Another limitation is that only three GPs took part in the focus group interview. A possible explanation might be that the date of the meeting was not forwarded in a timely manner and the name ‘‘focus group’’ was confusing and deterring for the GPs. It might be that the participating GPs are more enthusiastic about the TZPZ than the other 13 GPs (selection bias). As a consequence, it could be that the problems regarding the implementation of the TZPZ are marginalized. However, the results show that they have expressed their criticism with respect to the TZPZ. Furthermore, this study has several limitations concerning the data collection of the document review. Multiple data sources (Flycatcher, internal documents, e-mails) are used to answer the sub-questions, which complicates the data collection process. In addition, many forms necessary to answer the sub-questions were missing in Flycatcher, probably because not one, but several persons are responsible for processing the forms. If the form was saved in Flycatcher, it occurred that the necessary information was not filled in by the GP or the care coordinator. Also, some necessary information was not requested on the forms, for example the date of consultation about the marking as a palliative patient. It was sometimes possible to obtain the forms or the information necessary to answer the sub-questions via the care pathway coordinator, the secretary, or the GP practice. However of each patient the missing information was requested at the GP practice, merely one response (regarding one patient) was received. Moreover, the information that was available on the forms was occasionally incorrect (e.g. in two patients, the date of marking was before the start of the pilot). Also, it is questionable whether the forms used for the document review

are an accurate reflection of the reality: it could be that the GP or care coordinator did not document the execution of a certain element of the TZPZ, but it was performed as intended or vice versa. During the focus group, the emphasis was mainly on exploring the barriers and/or facilitators during the implementation of the following elements: marking, assessment, (registration for) the MTM, and creation of the care plan. The reason is that most GPs (probably) have not executed the other elements yet (as the pilot started in December 2015). It is recommended to explore the barriers and/or facilitators during the implementation of the other elements of the TZPZ (coordination of the care, evaluation after the death of the patient) in detail in the future. Additionally, during the current process evaluation, the dose received (satisfaction) (a recommended component of a process evaluation) regarding the opinion of the patient about the TZPZ did not receive any attention. It is important that, in future research, the patient is asked concerning his or her opinion of the TZPZ and which elements are important for the patients' quality of life. This can help to reduce the complexity of the TZPZ. Previous research has shown that palliative patients do not experience being interviewed as stressful (Gysels et al., 2008). Furthermore, to generate valid conclusions within a short time period, it was deliberately chosen to focus on the implementation of TZPZ within primary care. However, the addition of the perspectives of medical specialists regarding the barriers and/or facilitators during the implementation of the TZPZ could have provided additional insights. Also, to retrieve the barriers and/or facilitators during the implementation of the medication review, it is recommended to involve the pharmacists in future research. Moreover, the results of this study might have been strengthened by making field notes of meetings of the project group. A lot of data regarding the facilitators and/or barriers during the implementation were discussed within these meetings, but these data could not be used. However, as the researcher was present during these meetings, it could have (unconsciously) influenced the results. Furthermore, the person whom assesses this research report is part of the project group, and therefore, closely involved in the development and implementation of the TZPZ. During the writing process, this might have acted as a barrier in criticizing the TZPZ itself.

## **5.4 Recommendations**

The recommendations emerging from this study are directed to the project group of the TZPZ. Nevertheless, when other organizations implement a palliative care pathway, they can take these recommendations into consideration.

Several studies describe that there is more effect (on the long-term) of combined strategies (than of a single one) on the implementation of an innovation (Francke et al., 2008). Therefore, the recommendations emerging from this study encompass multiple components, focusing on several barriers:

### *1. Recommendations regarding the dissemination of the TZPZ*

- Start early (at least three months before starting to use the TZPZ) with training and education regarding the TZPZ: the training and education of the first group of GPs participating in the pilot was quite late, namely in November and March. This may be an explanation for the teething problems (e.g. difficulties in early identification of palliative patients).
- Engage GPs and patients already participating in the TZPZ in the training and/or education sessions: a GP can share his or her experience regarding ‘‘how to use the TZPZ’’ or the effects of the TZPZ on themselves and/or their patients. In this way, the feeling of support by other colleagues and sense of urgency might be increased. Another way of increasing the sense of urgency is letting participating (relatives of) patients share their experience with the TZPZ during training and/or education sessions. Previous research has shown that creating a sense of urgency, for example by generating emotions, is necessary for the sustainability of the implementation of an innovation (Greenhalgh et al., 2004; Kotter, 1996).
- Round-table discussions: the GPs could benefit from discussing their experiences concerning the use of the TZPZ with other GPs and/or medical specialists and hence, learn from each other.
- Early feedback to the GPs by visiting the GP practice: Greenhalgh et al. (2004) advocates that feedback regarding task issues during the early use of the program affects successful implementation. Early feedback can be given by visiting the GP practice, preferably by a GP already participating in the pilot, who helps the GP with a patient eligible for participation in the TZPZ. The expectation is that this will increase the chance of changing the GPs daily behavior, in comparison with only educational interventions (Alvarez et al., 2006; Shaw et al., 2010).

To summarize, figure 5 presents a proposal of how the training and/or education program could look like when disseminating the TZPZ.

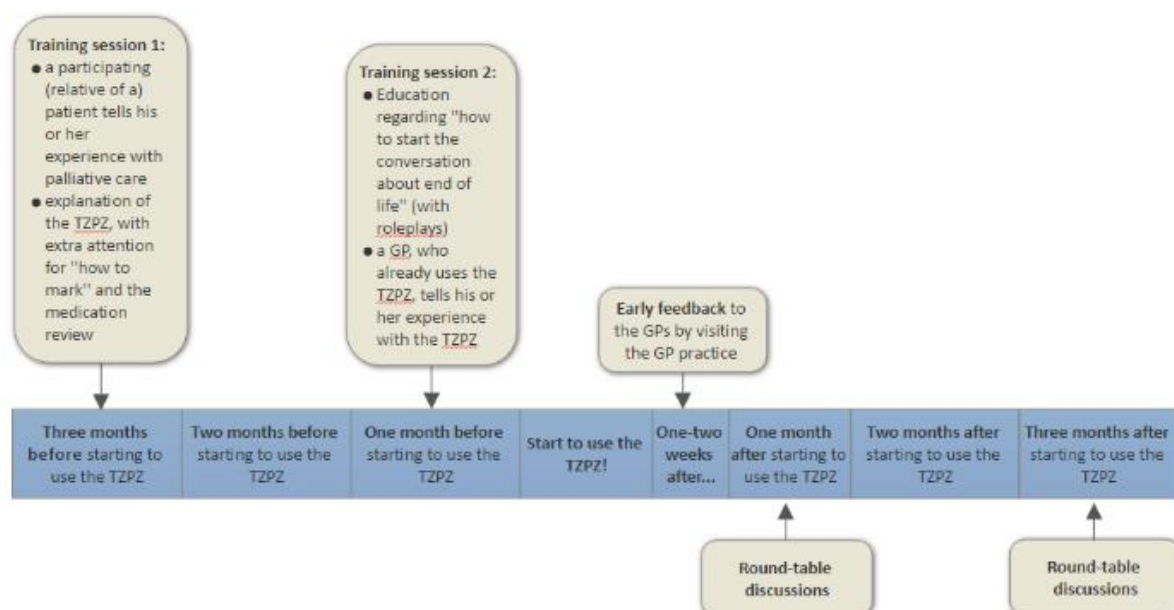


Figure 5: Proposal of the training and/ or education program when disseminating the TZPZ

## *2. Recommendations regarding the current group of GPs participating in the TZPZ*

- Round-table discussions (see recommendation 1)
- Feedback to the GPs who have not marked patients thus far by visiting the GP practice, preferably by a GP who already marked patients (see recommendation 1)
- As the medication review was not implemented, extra attention should be given (during the next training and/or education sessions) to the importance of the medication review
- Gauge how and if the training and education sessions can be improved

## *3. Use a digital system*

The time-consuming administration involved in using the TZPZ is identified as one of the main barriers to the implementation of the TZPZ. To solve this problem, a digital system should be developed in which the GP can upload forms or information by him- or herself. Also, the medical specialist, the care coordinator and the care pathway coordinator should be able to upload forms and information into this system. If possible, the digital system should be linked with the HIS ('Huisartsen Informatie Systeem') and the EPD ('Elektronisch Patiënten Dossier) of the hospital, for example by making an extra tab within the HIS and the EPD. By linking these systems, the GP and the medical specialist have the same information of the TZPZ of a patient (without having to make extra effort by sending it to each other) and some information (which is already in the HIS and/or EPD) does not have to be filled in twice, but the physician can copy and paste this in the digital system. A digital system will have the following benefits:

- The GP/ medical specialist/ care coordinator can keep an eye on the actions which should be undertaken in the TZPZ of his or her patients, and has to spend less time on the documentation.
- The project group can, by using the digital system, improve the monitoring of the progress of the implementation of the TZPZ.
- The researchers involved in the effect- and process evaluations of the TZPZ can, by using the digital system, ease their data collection. In the current study, incorrect or missing documentation/ forms was a main limitation during the data collection. The information of the patient and the informal caregiver should not be showed when a researcher logs in, but the digital system should generate a number for the patient.

The forms and/ or information that should be included in the digital system are drawn up in Appendix 6. Furthermore, Appendix 6 describes the measures to be taken as long as the digital system is not yet constructed.

## *4. Adaptations to the innovation itself*

The GPs feel enforced to execute the elements of the TZPZ in the way designed by the project group and/or steering group. As a consequence, the GPs may feel that their professional autonomy is at stake. The TZPZ must leave more space for the decisions of the GP, for example by:

- Not requiring the execution of all elements. The GP should be able to decide, in collaboration with other health care professionals (intra- and extramural), whether an element (e.g. the MTM or the medication review) is useful. In this way, the multidisciplinary collaboration remains at the heart of TZPZ, and the provided palliative care is (even more) tailored to the needs of the patient. This would also decrease the costs. Moreover, on the long-term, research should determine which elements are of added value in the delivery of high quality palliative care. This helps to reduce the complexity, which is currently seen as a barrier in the implementation of the TZPZ.
- Conveying the TZPZ, its elements and the formats belonging to the elements (questionnaire, the care plan etc.) as an aid or tool in the delivery of high quality palliative care, not as an obligation.

Examples to achieve this are:

- By having the assessment in a digital system, it is possible to spread out the completion of assessment and/or alter answers over time. This is both beneficial for the GP/ care coordinator and the patient, as it allows them to have multiple conversations regarding the patients' wishes and needs.
- Changing the questionnaire into a checklist increases the freedom in the way the assessment can be conducted. The checklist should be organized in the four domains (the physical, psychological, functional and social domain). Having a checklist instead of a questionnaire might also reduce the time necessary for the assessment. However, first, research should show whether the scores (of Lastmeter, CAM etc.) are essential for the identification of the needs and wishes of the patient. If the scores are essential, research should determine which questions are most important and/or relevant with the goal to reduce the length of the assessment.
- By having the care plan in a digital system and linking this system to the systems of the physicians, it is possible for GPs to create the care plan or something similar in their own system, and just copy and paste it to the digital system of the TZPZ.

In addition to the above mentioned recommendations:

- Patients (or relatives) participating in the pilot should be asked for their opinion on the information letter. If they regard it as too confronting, the information letter should be adapted.
- A protocol should be drafted of how patients should be discussed and reported in a MTM.
- As the results of this study show that the color coding is executed by the care pathway coordinator instead of by the attendees of the MTM, the added value of the color coding is questioned. Research should help to determine the usefulness of the color coding.
- The medication review must remain in the TZPZ for the duration of the pilot. However, research has to determine the barriers and/or facilitators in executing the medication review from the perspective of the pharmacist. After the pilot, it has to be investigated whether it is useful that a pharmacist starts a conversation about the end of life with the patient.

### *5. Central monitoring the progress of the implementation of the TZPZ*

Currently, the care pathway coordinator keeps an eye on the patients whom are registered for the MTM, but it is not clear if and when these patients complete the other elements of the TZPZ. To get insight into the number of patients participating in the TZPZ as yet, and which elements of the TZPZ they already have completed, it is necessary to create a document or a system in which this is noted. If possible, this can be extracted from the digital system. One person should be responsible for the monitoring process.

### *6. Renew the sense of urgency*

As merely 17 patients are marked thus far, it might help to increase the visibility of the TZPZ. In this way, it is expected that the sense of urgency is renewed. Several measures can be taken to achieve this:

- The newsletter can be used to inform the GPs about the number of patients participating in the TZPZ and to share ‘success stories’ of patients, relatives of patients and GPs or medical specialists. ‘Success stories’ enhances the confidence in this new approach to palliative care. Kotter (1996) also emphasizes the importance of making ‘(quick) wins’ visible. The newsletters can be distributed at meetings, such as the focus group and/or the training and education sessions. In addition, in these newsletters, a year schedule of the meetings should be noted. Also, the focus group should be named differently, for example a ‘tussenevaluatie’, as the name focus group creates confusion.
- LinkedIn and/or Twitter can be used to share news within the field of palliative care (e.g. articles emphasizing the importance of pro-active palliative care) with the aim of drawing attention to the TZPZ.
- Communicating the results (in the form of a short summary) of a focus group or a meeting (within a week) to the GPs (e.g. by e-mail). It is important that not only the results of the focus group with the GPs should be sent to the GPs, but also the results of the focus group with the medical specialists, as they can learn from each other.

### *7. Future research*

The recommendations regarding future research are mentioned in paragraph 5.3. In short, suggestions for future research are:

- Evaluate the dose received (satisfaction) of the patient
- Evaluate the perspectives of medical specialists, POHs and the pharmacists regarding the barriers and/or facilitators during the implementation of the TZPZ
- Explore the barriers and/or facilitators during the elements coordination of the multidisciplinary care and evaluation after the death of the patient.

## **5.5 Conclusion**

Overall, the GPs regarded the TZPZ as a good point of departure to deliver pro-active, patient-centered palliative care. However, the results seem to indicate that the TZPZ is not yet fully applied (as intended) in general daily practice. These results have to be put into context: the implementation of the TZPZ started merely six months ago, the implementation of several elements of the TZPZ could not be assessed as much information was unavailable or not accessible and the study populations for the document review and focus group were small. The main barriers during the implementation of the TZPZ were starting the conversation about the end of life, the time-consuming administration, the fixed nature of the TZPZ and the complexity of the TZPZ. To attain the intended results of the TZPZ, the implementation of the TZPZ has to be improved. The prime recommendations to achieve this are: adapting the training and/or education program, and using a digital system.

## 6. References

- Alvarez, M. P., & Agra, Y. (2006). Systematic review of educational interventions in palliative care for primary care physicians. *Palliative medicine*, 20(7), 673-683.
- Beernaert, K., Deliens, L., De Vleminck, A., Devroey, D., Pardon, K., Van den Block, L., & Cohen, J. (2014). Early identification of palliative care needs by family physicians: a qualitative study of barriers and facilitators from the perspective of family physicians, community nurses, and patients. *Palliative medicine*, 28(6), 480-490.
- Berendsen, A. J., & Soest, F. M. (2014). *Inzichten in de palliatieve zorg: voor de huisartspraktijk*. Houten: Bohn Stafleu van Loghum, p. 38.
- Berwick, D. M. (2003). Disseminating innovations in health care. *Journal of the American Medical Association*, 289, 1969-1975.
- Bloomer, M., Tan, H., & Lee, S. (2010). End of life care: the importance of advance care planning. *Australian family physician*, 39(10), 734.
- Boan, D., & Funderburk, F. (2003). Healthcare quality improvement and organizational culture. *Delmarva Foundation*, 3.
- Boddaert, M., Douma, J., Van Aalst, B., Bijkerk, M., Brinkman, A., Brom, L., & Degenaar, A. (2015). *Palliatieve zorg in de Nederlandse Ziekenhuizen, resultaten 2015*. Retrieved from [https://www.iknl.nl/docs/default-source/default-document-library/palliatieve-zorg-in-nederlandse-ziekenhuizen-\(2015\).pdf?sfvrsn=2](https://www.iknl.nl/docs/default-source/default-document-library/palliatieve-zorg-in-nederlandse-ziekenhuizen-(2015).pdf?sfvrsn=2)
- Bowen, L. (2014). The multidisciplinary team in palliative care: A case reflection. *Indian journal of palliative care*, 20(2), 142.
- Centers for Disease Control and Prevention (CDC). (2009). *Data Collection Methods for Evaluation: Document Review*. Retrieved from <http://www.cdc.gov/healthyyouth/evaluation/pdf/brief18.pdf>
- Centraal bureau voor de statistiek. (2015). *Bevolking en bevolkingsontwikkeling; per maand, kwartaal en jaar*. Retrieved from [http://statline.cbs.nl/StatWeb/publication/?VW=T&DM=SLNL&PA=37943NED&D1=0-9&D2=203,220,237,254,271,288,\(1-17\)-I&HD=130605-0932&HDR=T&STB=G1](http://statline.cbs.nl/StatWeb/publication/?VW=T&DM=SLNL&PA=37943NED&D1=0-9&D2=203,220,237,254,271,288,(1-17)-I&HD=130605-0932&HDR=T&STB=G1)
- Chiche, J., Moreno, R., Putensen C., & Rhodes, A. (2009). *Patient Safety and Quality of Care in Intensive Care Medicine*. Berlin: Medizinisch Wissenschaftliche Verlagsgesellschaft.
- Claessen, S. J., Francke, A. L., Engels, Y., & Deliens, L. (2013). How do GPs identify a need for palliative care in their patients? An interview study. *BMC family practice*, 14(1), 1.
- Dane, A., & Schneider, B. (1998). Program integrity in primary and early secondary prevention: Are implementation effects out of control? *Clinical Psychology Review*, 18, 23-45.
- De Weerd-Spaetgens, C., van den Berken, E. (2015). *Transmuraal palliatief zorg pad*. Retrieved from

<http://www.palliatievezorglimburg.nl/Portals/66/documenten/workshop%20transmuraal%20zorgpad.pdf>

European Association for Palliative Care. (2010). *Definition of palliative care*. Retrieved from <http://www.eapcnet.eu/Corporate/AbouttheEAPC/Definitionandaims.aspx>

Esterberg, K. G. (2002). *Qualitative methods in social research* (No. 300.18 E8). Boston: McGraw-Hill.

Fallowfield, L., Jenkins, V., Farewell, V., Saul, J., Duffy, A., & Eves, R. (2002). Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *The Lancet*, 359(9307), 650-656.

Francke, A. L., Smit, M. C., Veer, A. J., & Mistiaen, P. (2008). Factors influencing the implementation of clinical guidelines for health care professionals: a systematic meta-review. *BMC medical informatics and decision making*, 8(1), 1.

Gade, G., Venohr, I., Conner, D., McGrady, K., Beane, J., Richardson, R. H., Marilyn P. W., Williams, M. S., Liberson, M., Blum, M. D., & Penna, R. D. (2008). Impact of an inpatient palliative care team: a randomized controlled trial. *Journal of palliative medicine*, 11(2), 180-190.

Greenhalgh, T., Robert, G., Bate, P., Kyriakidou, O., Macfarlane, F. & Peacock, R. (2004). *How to spread good ideas. A systematic review of the literature on diffusion, dissemination and sustainability of innovations in health service delivery and organization*. Retrieved from <http://www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1201-038>

Grol, R., Bosch, M. C., Hulscher, M. E., Eccles, M. P., & Wensing, M. (2007). Planning and studying improvement in patient care: the use of theoretical perspectives. *Milbank Quarterly*, 85(1), 93-138.

Grol, R., Wensing, M., Eccles, M., & Davis, D. (Eds.). (2013). *Improving patient care: the implementation of change in health care*. John Wiley & Sons.

Groot, M. M., Vernooij-Dassen, M. J., Verhagen, S. C., Crul, B. J., & Grol, R. P. (2007). Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliative Medicine*, 21(8), 697-703.

Gysels, M., Shipman, C., & Higginson, I. J. (2008). Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC medical ethics*, 9(1), 7.

Hamel, M. (2001). *The Entrepreneur's Creed: The Principles & Passions of 20 Successful Entrepreneurs*. Armour Publishing Pte Ltd.

Hanning, R., Hardeman, F., Wigboldus, M.E. (2011). *Periodieke medicatiebeoordeling: veilige zorg en minder kosten*. Retrieved from <http://www.tijdschriftkiz.nl/artikel/12296/Periodieke-medicatiebeoordeling-veilig-zorg-en-minder-kosten>

Haward, R., Amir, Z., Borrill, C., Dawson, J., Scully, J., West, M., & Sainsbury, R. (2003). Breast cancer teams: the impact of constitution, new cancer workload, and methods of operation on their effectiveness. *British Journal of Cancer*, 89(1), 15-22.

Integraal Kankercentrum Nederland (IKNL). (2010). *Algemene inleiding richtlijnen palliatieve zorg*. Retrieved from <http://www.iknl.nl/docs/default-source/Palliatieve-zorg-in-de-ziekenhuizen/algemene-inleiding-richtlijnen-palliatieve-zorg.pdf?sfvrsn=0>

Jones G. (2010). *Organizational Theory, Design and Change*. Upper Saddle River NJ: Pearson.

Kirst-Ashman, K. (2007). *Human behavior, communities, organizations, and groups in the macro social environment: An empowerment approach*. Thomson Learning.

Knapen, E. (2014). *Project: Proactieve zorgplanning binnen een Transmuraal Zorgpad Palliatieve Zorg in de Westelijke Mijnstreek*. Retrieved from <http://www.zonmw.nl/nl/projecten/project-detail/proactieve-zorgplanning-binnen-een-transmuraal-zorgpad-palliatieve-zorg-in-de-westelijke-mijnsteek/samenvatting/>

Kotter, J. P. (1996). *Leading change*. Harvard Business Press.

Linnan, L., & Steckler, A. (2002). *Process evaluation for public health interventions and research* (pp. 1-23). San Francisco, California: Jossey-Bass.

Lo, S. H., Chan, C. Y., Chan, C. H., Sze, W. K., Yuen, K. K., Wong, C. S., Ng, T.Y., & Tung, Y. (2009). The implementation of an end-of-life integrated care pathway in a Chinese population. *International journal of palliative nursing*, 15(8), 384.

Mahtani-Chugani, V., González-Castro, I., de Ormijana-Hernández, A. S., Martín-Fernández, R., & de la Vega, E. F. (2010). How to provide care for patients suffering from terminal non-oncological diseases: barriers to a palliative care approach. *Palliative medicine*.

Mason, B., Boyd, K., Murray, S. A., Steyn, J., Cormie, P., Kendall, M., Munday, D., Weller, D., Fife, S., Murchie, P., Campbell, C., & Campbell, C. (2015). Developing a computerised search to help UK General Practices identify more patients for palliative care planning: a feasibility study. *BMC family practice*, 16(1), 1.

McIlfatrick, S., & Hasson, F. (2014). Evaluating a holistic assessment tool for palliative care practice. *Journal of clinical nursing*, 23(7-8), 1064-1075.

Mickan, S. M. (2005). Evaluating the effectiveness of health care teams. *Australian Health Review*, 29(2), 211-217.

Moore, G. F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., Moore, L., Cathain, A., Tinati, T., Wight, D., & Baird, J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *Bmj*, 350, h1258.

Nederlandse Federatie van Universitair Medische Centra (NFU). (2012). *Beter zorgen voor mensen in hun laatste levensfasen*. Retrieved from <http://www.nfu.nl/actueel/beter-zorgen-voor-mensen-in-laatste-levensfase>

Nederlands instituut voor onderzoek van de gezondheidszorg (NIVEL). (2009). *Hoeveel mensen hebben behoefte aan palliatieve zorg?* Retrieved from <https://www.nivel.nl/dossier/hoeveel-mensen-hebben-behoefte-aan-palliatieve-zorg>

- Nederlands Jeugd Instituut (NJI). (2015). *Het belang van implementatie*. Retrieved from <http://www.nji.nl/nl/Implementatie/Implementeren-met-effect/Wat-is-het-belang>
- Pawson, R., Greenhalgh, T., Harvey, G., & Walshe, K. (2005). Realist review—a new method of systematic review designed for complex policy interventions. *Journal of health services research & policy*, 10(suppl 1), 21-34.
- Projectgroep TZPZ. (2014). *Projectplan: Transmuraal Zorgpad Palliatieve Zorg Westelijke Mijnstreek*.
- Richards, D. A., & Hallberg, I. R. (2015). *Complex interventions in health: an overview of research methods*. New York: Routledge.
- Rogers, E.M. (2003). *Diffusion of innovations*. New York: Simon & Schuster Ltd.
- Rycroft-Malone, J., Kitson, A., Harvey, G., McCormack, B., Seers, K., Titchen, A., & Estabrooks, C. (2002). Ingredients for change: revisiting a conceptual framework. *Quality and safety in Health care*, 11(2), 174-180.
- Saunders, R. P., Evans, M. H., & Joshi, P. (2005). Developing a process-evaluation plan for assessing health promotion program implementation: a how-to guide. *Health Promotion Practice*, 6(2), 134-147.
- Saunders, R. P. (2015). *Implementation Monitoring and Process Evaluation*. Sage Publications.
- Schneider, M., Hall, W. J., Hernandez, A. E., Hindes, K., Montez, G., Pham, T., Rosen, L., Sleight, A., Thompson, D., Volpe, S.L., Steckler, A., & Zeveloff, A. (2009). Rationale, design and methods for process evaluation in the HEALTHY study. *International Journal of Obesity*, 33, S60-S67.
- Schoffeleers, S. (2015). *Toolkit gewenste zorg in de laatste levensfase*. Anders Beter.
- Shaw, E. A., Marshall, D., Howard, M., Taniguchi, A., Winemaker, S., & Burns, S. (2010). A systematic review of postgraduate palliative care curricula. *Journal of palliative medicine*, 13(9), 1091-1108.
- Soesters, M. & Verhoeks, G. (2013). *Mogelijkheden voor verbeteren palliatieve zorg: leren van bestaande multidisciplinaire samenwerking*. KWF Kanker Bestrijding. Retrieved from <http://www.stichtingfibula.nl/Portals/158/Documenten/2013-11-KWF-Rapport%20'Mogelijkheden%20voor%20verbeteren%20palliatieve%20zorg'.pdf>
- Stals, K., Yperen, T. V., Reith, W., & Stams, G. (2008). *Effectieve en duurzame implementatie in de jeugdzorg. Een literatuurrapportage over belemmerende en bevorderende factoren op implementatie van interventies in de jeugdzorg*. Utrecht: Universiteit Utrecht. Retrieved from [http://www.nji.nl/nl/Download-NJi/Publicatie-NJi/Effectieve\\_en\\_duurzame\\_implementatie\\_in\\_de\\_jeugdzorg.pdf](http://www.nji.nl/nl/Download-NJi/Publicatie-NJi/Effectieve_en_duurzame_implementatie_in_de_jeugdzorg.pdf)

Stuijt, C.C.M., Franssen, E.J.F., Egberts, A.C.G., Hudson S.A. (2009). Effect van door een apotheker geleide medicatiereviews op de voorschrijfkwaliteit voor verzorgingshuisbewoners. *Wetenschappelijk platform*, 3 (2), 28-33.

Substance Abuse and Mental Health Services Administration (SAMHSA). (2015). *Using process evaluation to monitor program implementation*. Retrieved from <http://www.samhsa.gov/capt/tools-learning-resources/process-evaluation-monitor-implementation>

Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., Dahlin, C.M., Blinderman, C.D., Jacobsen, J., Piri, W.F., Billings, J. A., & Lynch T.J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733-742.

Thoonsen, B., Vissers, K., Verhagen, S., Prins, J., Bor, H., van Weel, C., Groot, M., & Engels, Y. (2015). Training general practitioners in early identification and anticipatory palliative care planning: a randomized controlled trial. *BMC family practice*, 16(1), 1.

Van der Rijt, C. (2016). *ZonMw: Voldoet de surprise question nog? Naar een wetenschappelijk onderbouwd en door zorgverleners gedragen markeringsinstrument voor de laatste levensfase*. Retrieved from <http://www.zonmw.nl/nl/projecten/project-detail/voldoet-de-surprise-question-nog-naar-een-wetenschappelijk-onderbouwd-en-door-zorgverleners-g/samenvatting/>

Van Hoeve, J., De Vries, J. (2014). Ontwikkeling en implementatie van zorgpaden. Retrieved from <http://www.tijdschriftmeno.nl/artikel/13950/Ontwikkeling-en-implementatie-van-zorgpaden>

Van Kraaij. (2014). Implementatie Zorgpad Stervensbegeleiding. ZonMw. Retrieved from <http://www.zonmw.nl/nl/projecten/project-detail/implementatie-zorgpad-stervensbegeleiding-goede-voorbeeld/voortgang/>

Wagner, E. H. (2004). Effective teamwork and quality of care. *Medical care*, 42(11), 1037-1039.

World Health Organization (WHO). (2000). *Workbook 4: Process evaluations*. Retrieved from [http://apps.who.int/iris/bitstream/10665/66584/5/WHO\\_MSD\\_MSB\\_00.2e.pdf](http://apps.who.int/iris/bitstream/10665/66584/5/WHO_MSD_MSB_00.2e.pdf)

World Health Organization (WHO). (2015). *Palliative care*. Retrieved from <http://www.who.int/mediacentre/factsheets/fs402/en/>

ZorgOnderzoek Nederland (ZON) (1997). *Met het oog op toepassing*. Beleidsnota Implementatie ZON 1997–1999. Den Haag: ZorgOnderzoek Nederland.

## Appendix 1: Initiation and organization of the Transmural Palliative Care Pathway

The TZPZ is initiated in 2013 by the ‘Netwerk Palliatieve Zorg Westelijke Mijnstreek’ (NPWM) (NPWM, 2015; Projectgroep TZPZ, 2014). NPWM was founded in 2002 as a collaboration between several institutions and organizations involved in palliative care and located in the Westelijke Mijnstreek (GPs, hospitals, nursing homes, home care institutions, hospices and several voluntary bodies). NPWM organizes palliative care in the Westelijke Mijnstreek which includes the municipalities Born, Sittard, Geleen, Stein, Beek and Schinnen and covers approximately 153.000 people. The goal of NPWM is to improve the organization of care for palliative patients. NPWM intends to achieve this goal by facilitating the coordination and communication between the different health care professionals and institutions involved in palliative care, using knowledge within the network efficiently, and offering palliative care tailored to the needs and wishes of the patient (NPWM, 2015). Several health organizations became involved in the development and implementation of the TZPZ, including ‘‘Anders Beter’’. ‘‘Anders Beter’’ is a collaboration between several health care organizations in the Westelijke Mijnstreek aiming to provide the right care in the right place at affordable costs (Anders Beter, 2015). One of the projects of ‘‘Anders Beter’’ is ‘‘Gewenste Zorg in de laatste levensfase’’, aiming to improve the quality of palliative care. The TZPZ is part of this project. ‘‘CZ Zorgverzekeraar’’ (a health insurance company) funds both research concerning the outcome and the process evaluation of the implementation of the TZPZ. The other organizations involved in the development and implementation of the TZPZ are (Projectgroep TZPZ, 2014):

- ‘‘Medita’’ (an organization supporting GPs with practical issues) (Medita, 2016)
- ‘‘Samenwerkende Apotheken Maasland’’ (an organization representing several pharmacies in de Westelijke Mijnstreek) (Anders Beter, 2015)
- ‘‘Zuyderland’’ (consisting of two hospitals located in Sittard and Heerlen, several nursing homes, a home care organization, and two hospices) (Zuyderland, 2015)
- ‘‘Huis voor de Zorg’’ (an organization dedicated to support patients) (HvdZ, 2015)
- ‘‘Medisch Coördinatie Centrum Omnes’’ (MCC Omnes) (an organization providing primary care diagnostics for GPs in the Westelijke Mijnstreek) (MCC Omnes, 2015)
- ‘‘Intergraal Kankercentrum Nederland’’ (IKNL), location Maastricht (quality institute for oncological and palliative research and practice) (IKNL, 2015)
- ‘‘Academische werkplaats ouderenzorg’’ (a collaboration between the Maastricht University, Zuyd University of Applied Sciences and several health care organizations, with the aim of improving the quality of life for elderly by increasing knowledge) (AWO, unknown)
- ‘‘Netwerk Palliatieve Zorg Westelijke Mijnstreek’’ (NPZWM)

All these organizations are represented in the project group or the steering group. The project group developed the TZPZ in collaboration with two advisory groups: an advisory group consisting of patients

and informal caregivers, and an advisory group consisting of health care professionals. The project group comprises (Projectgroep TZPZ, 2014):

- Project leader of ‘‘Gewenste zorg in de laatste levensfase’’
- Geriatricist of Zuyderland Hospital, Sittard
- Representative of CZ
- Coordinator of NPWM
- GP
- Pharmacist
- Care pathway coordinators of ‘‘Gewenste zorg in de laatste levensfase’’
- Researcher of the effect evaluation of ‘‘Gewenste zorg in de laatste levensfase’’
- Researcher of the process evaluation of ‘‘Gewenste zorg in de laatste levensfase’’
- Patient representative
- A secretary

The steering group has an important role in monitoring of the development and implementation of the TZPZ, and comprises (Projectgroep TZPZ, 2014):

- Project leader of ‘‘Gewenste zorg in de laatste levensfase’’
- RVE Manager of Zuyderland Hospital, Sittard
- Director of MCC Omnes
- GP
- Representative of CZ
- Representative of ‘‘Huis voor de zorg’’
- Representative of IKNL
- Coordinator of NPZWM
- A secretary

## References

Academische Werkplaats Ouderenzorg (AWO). (Unknown). Academische Werkplaats Ouderenzorg: over ons. Retrieved from <https://www.academischewerkplaatsouderenzorg.nl/over-ons-0>

Anders Beter. (2015). *Homepage*. Retrieved from <http://www.andersbeterwm.nl/>  
Huis voor de Zorg (HvdZ). (2015). *Organisatie*. Retrieved from <http://www.huisvoordezorg.nl/organisatie.html>

Integraal Kankercentrum Nederland (IKNL). (2015). *About IKNL*. Retrieved from <https://www.iknl.nl/over-iknl/about-iknl>

MCC Omnes. (2015). *Homepage*. Retrieved from <http://www.mcc-omnes.nl/over-mcc-omnes>

Medita. (2016). *Homepage*. Retrieved from <http://www.medita.nl/>

- Netwerk Palliatieve Zorg Westelijke Mijnstreek (NPWM). (2015). *Activiteitenplan 2016*.
- Projectgroep TZPZ. (2014). *Projectplan: Transmuraal Zorgpad Palliatieve Zorg Westelijke Mijnstreek*.
- Zuyderland. (2015). *Homepage*. Retrieved from <https://www.zuyderland.nl/>

## **Appendix 2: Description of the TZPZ (intended situation)**

This following description of the TZPZ is composed by making use of internal documents and in collaboration with a nurse practitioner who was involved in the development and implementation of the TZPZ.

### **A. Marking a patient with a life expectancy up to one year**

The aim is to mark, by the end of the pilot (September 2017) 400 patients.

1. When a patient visits the GP or medical specialist, patients with a life expectancy up to one year will be marked by using the surprise question (“Would I be surprised if this patient is still alive in a year from now?”), supported by the use of RADPAC+. RADPAC+ is a measurement tool which integrates both the RADboud indicators for Palliative Care Needs (RADPAC) and the Supportive and Palliative Care Indicators Tool (SPICT) (Schoffeleers, 2015b).
2.
  - a. When the surprise question can be answered with a yes and the patient is treated within primary and secondary care, the GP and the medical specialist will deliberate and decide by telephone about the marking of the patient and who will be the main practitioner: the GP or the medical specialist (Schoffeleers, 2015b).
  - b. When the surprise question can be answered with a yes and the patient is only treated in primary care, the GP will be the main practitioner (Schoffeleers, 2015b).

### **B. After marking a patient with a life expectancy up to one year**

1. The main practitioner invites the patient for a consultation. During this consultation, the marking of the patient as a palliative patient will be discussed (Schoffeleers, 2015b).
2. At the end of the consultation, the main practitioner gives an information package to the patient, including (Schoffeleers, 2015b; Personal communication with the care pathway coordinator, 2016):
  - A patient letter with the discussed information
  - A guidebook about palliative care
  - A telephone note (with the telephone numbers of the involved health care providers)
  - An informed consent form for sharing medical information with other health care professionals
  - An informed consent form for participation in the pilot (and the effect and process evaluation accompanying with the pilot)
  - The declaration of intention (“Wilsverklaring”)

3. The main practitioner within secondary care creates a document ('het markeringsdocument') regarding palliative care, which is saved in the 'Elektronisch Patiënten Dossier' (EPD). The following information is saved within this document (Schoffeleers, 2015b):
  - Patient data
  - Date of marking
  - The basis of marking (surprise question and/or RADPAC+)
  - Palliative diagnose
  - Whether marking is discussed with the patient
  - Whether marking is discussed with the GP (Personal communication with the care pathway coordinator, 2016)
  - Possible additional information (i.a. who the main practitioner is: the GP or the medical specialist) (Personal communication with the care pathway coordinator, 2016)
4. The main practitioner assigns a care coordinator to the patient, which is the GP itself or the 'Praktijkondersteuner' (POH) (a nurse practitioner working at the general practice) within primary care or a nurse practitioner within secondary care. The care coordinator contacts the patient to make an appointment for an assessment (Schoffeleers, 2015b).

## C. Assessment

1.
  - a. The care coordinator conducts the assessment. The assessment should take place within 3-5 working days after the consultation about the marking as a palliative patient (Projectgroep, unknown).
  - b. The assessment identifies, by using a questionnaire, a) the potential physical, practical and socio-emotional problems and, b) the needs and wishes of the patient during the palliative phase. The questionnaire integrates several tools (Schoffeleers, 2015b):
    - Lastmeter (measures psychosocial problems)
    - Confusion Assessment Method (CAM) (helps to identify delirium)
    - Numeric Rating Scale (NRS) (measures the level of pain)
    - The Hospital Anxiety Depression Scale (HADS) (measures fear and depression)

Additionally, the questionnaire includes some other questions, i.a. top 3 of wishes and/or needs, and questions regarding the level of communication and cognitive functioning of the patient. Besides the questionnaire, the care coordinator has to fill in a cover page during the assessment. The cover page contains general information about the care coordinator, patient and the contact person (Schoffeleers, 2015b). The questionnaire and cover page will be completed in Word during the assessment, and can be sent to the secretary of the TZPZ via a secured email. The secretary will calculate the scores of

LAST, CAM, NRS (pain) and HADS via Excel. These scores are filled in at a score sheet. The score sheet is sent to the care coordinator (Personal communication with the care pathway coordinator, 2016).

- c. If the informal caregiver is present during the assessment, a questionnaire, the *Ervaren Druk door Informele Zorg (EDIZ)*, regarding the pressure experienced by the informal caregiver will be given in an envelope to the informal caregiver. The questionnaire and a return envelope are included within the envelope. If the informal caregiver is not present during the assessment, the envelope will be sent to the address of the informal caregiver. The informal caregiver can complete the questionnaire at home and return it by using the return envelope, or the informal caregiver can complete the questionnaire during a phone call with the care coordinator. The EDIZ questionnaire will (also) be sent to IQ Healthcare (Personal communication with the care pathway coordinator, 2016). Based on the results of the EDIZ, appropriate action can be taken to relieve the pressure experienced by the informal caregiver (Schoffeleers, 2015b).
  - d. During the assessment, the informed consent forms are checked for a signature (Schoffeleers, 2015b). If the main practitioner is from secondary care, the informed consent forms are saved within the EPD (Personal communication with the care pathway coordinator, 2016). If the main practitioner is from primary care, the informed consent forms are saved within the 'Huisartsen Informatie Systeem' (HIS) (Schoffeleers, 2015b).
  - e. If the telephone note and the document concerning the declaration of intention were not given at the end of the previous consultation, these documents will be discussed and completed during the assessment (Schoffeleers, 2015b)
2. After the assessment, the case-manager registers the patient for a multidisciplinary team meeting (MTM) by using a registration form ('aanmeldformulier'). The results of the assessment (i.a. scores of LAST and HADS) should be attached to this registration form. If the care coordinator of the patient is from primary care, the registration form is sent via fax to the department of geriatrics in the hospital. If the care coordinator of the patient is from secondary care, the registration form should be emailed to the department of geriatrics. The patient is placed on the agenda of the MTM by the care pathway coordinator ('zorgpadcoordinator') (Schoffeleers, 2015b). If the care coordinator has registered the patient 48 hours before the MTM of that week, the patient should be placed on the agenda of the MTM of that week. If the registration is later than 48 hours before the MTM of that week, the patient will be placed on the agenda of the MTM of the next week (Projectgroep TZPZ, unknown). The care pathway coordinator is a nurse practitioner specialized in palliative care. He or she has a coordinating role in the TZPZ. The registration form (including the results of the assessment) is dispersed by the care pathway

coordinator to the members of the MTM (Schoffeleers, 2015b; Personal communication with the care pathway coordinator, 2016).

3. The care coordinator within secondary care adds the following information within the previously created document regarding palliative care (Schoffeleers, 2015b):
  - The informed consent forms
  - The questionnaire and cover page of the assessment
  - A registration form MTM (including the scores of the assessment)

This will be saved in the EPD (Schoffeleers, 2015b).

4. The care coordinator within primary care creates a document regarding palliative care which is saved in HIS. The following information is included in this document (Schoffeleers, 2015b):
  - The informed consent forms
  - The questionnaire and cover page of the assessment
  - A registration form MTM (including scores of the assessment)
5. After the assessment, the care coordinator starts with creating a care plan for the patient. This care plan can be finalized after the MTM (Schoffeleers, 2015b).

#### **D. Multidisciplinary team meeting (MTM)**

1. The care pathway coordinator invites the care coordinator for the MTM. The care coordinator participates in the MTM by telephone, skype or in real-life (Projectgroep TZPZ, 2014; Personal communication with the care pathway coordinator, 2016).
2. After the MTM, an advice form is completed by the care pathway coordinator (Projectgroep TZPZ, 2014). Within this form, the potential problems, advice and the complexity/ severity (by using color coding) of the patient's disease are described. The advice form is saved within the EPD and the HIS (via an Edifact message) (Schoffeleers, 2015b).

#### **E. Medication review**

1. After the assessment, the GP (if the main practitioner is the GP) or the care coordinator (if the main practitioner is the specialist) informs the pharmacist about the marking of the patient. Subsequently, the pharmacist reviews the medication of the patient (Schoffeleers, 2015b).

#### **F. Care plan**

1. The care plan, which is composed by the care coordinator, is a summary of agreements and wishes that have emerged during the assessment and the multidisciplinary team meeting. The care coordinator saves the care plan in the HIS (if the care coordinator is from primary care) or in the EPD (if the care coordinator is from secondary care) (Schoffeleers, 2015b).

2. The care coordinator contacts the patient to discuss the advice resulting from the multidisciplinary team meeting and the care plan (Schoffeleers, 2015b). This should take place within 5-7 working days after the MTM has taken place (Projectgroep TZPZ, unknown)
3. The GP informs the general practice center ('huisartsenpost') about the marking of the patient by using a form. This form is added to the document regarding palliative care, which is saved within the HIS (Schoffeleers, 2015b).

#### **G. Coordination of the multidisciplinary care**

1. The care coordinator gives advice to the patient (within office hours) and monitors the care plan (Schoffeleers, 2015b).
2. During the entire palliative phase, (reactive) consultation is possible. Consultation takes place between two health care professionals, and aims to answer questions concerning patient related problems. The consultation will be executed by an IKNL doctor consultant or a nursing consultant specialized in palliative care. Besides the care coordinator, every health care professionals responsible for the care of the patient can consult these specialized health care professionals. Within office hours, a primary health care professional can contact the nursing consultant by telephone or via ZorgDomein. A secondary health care professional can order a consultation via SAP. Depending on the complexity of the question, the question will be answered by the nursing consultant, IKNL doctor consultant or the patient will be registered for a MTM. Outside office hours, a regional consulting team palliative care can be contacted. Any new or additional information after consultation should be saved within the HIS and the EPD (Schoffeleers, 2015b). After a couple of days, the nursing or doctor consultant will contact the health care professional about the effect of the advice (Personal communication with the care pathway coordinator, 2016).
3. The care plan can be adjusted during the entire palliative phase. If the care plan is adjusted, the care coordinator ensures that the patient and other health care professionals are aware of these changes. If the main practitioner is from primary care, the HIS will be updated by the care coordinator and health care professionals within secondary care are informed by a fax or secured email. They add this information within the EPD. If the main practitioner is from secondary care, the EPD will be updated by the care coordinator and the GP is informed by an Edifact message. The GP updates the HIS (Schoffeleers, 2015b).

#### **H. Following the death of the patient...**

1. The main practitioner informs other health care professionals both within primary and secondary care about the death of the patient (Schoffeleers, 2015b).

2. The GP informs IQ healthcare about the death of the patient and gives the email address of the informal caregiver to IQ healthcare. IQ healthcare sends digitally an evaluation form to the GP (Schoffeleers, 2015b).
3. Six to eight weeks after the death of the patient, an evaluation form including an informed consent form to participate in this study will be sent digitally to the informal caregiver (Schoffeleers, 2015b).
4. Six to eight weeks after the death of the patient, an evaluation takes place between the main practitioner and/or the care coordinator and the relatives of the patient. Thereafter, the care plan is saved in the HIS and/or EPD and closed (Schoffeleers, 2015b).

## References

- Personal communication with the care pathway coordinator (2016).
- Projectgroep TZPZ. (2014). *Projectplan Transmuraal Zorgpad Palliatieve Zorg Westelijke Mijnstreek*.
- Projectgroep TZPZ (Unknown). *Processtappen "Gewenste zorg in de laatste levensfase"*.
- Schoffeleers. (2015a). *Implementatieplan: Gewenste zorg in de laatste levensfase*. Anders Beter.
- Schoffeleers. (2015b). *Toolkit gewenste zorg in de laatste levensfase*. Anders Beter.

## Appendix 3: Checklist for the document review

All the information that is between brackets and in italics tells where the information can be found (e.g. on what form/ internal document). If there is no information between brackets, the data must be retrieved (if possible) via e-mails with the care pathway coordinator, the pharmacist or the GP practice.

Date:

ID-number patient (*Flycatcher*):

Patient, letter:

**General information** (study population characteristics, sub-question 3 and 5):

GP (*cover page assessment/ 'Pseudonimisatiebestand'*):

Care coordinator (*cover page assessment*):

Marked by (GP or medical specialist) (*'Pseudonimisatiebestand' / 'Overzicht geïnccludeerde patiënten week 19'*):

**Patient information** (study population characteristics, sub-question 5):

- Date of birth: (*MTM registration form/ cover page of the assessment form/ 'Pseudonimisatiebestand'*):
- Gender (*MTM registration form/ cover page of the assessment form/ 'Pseudonimisatiebestand'*):
- Diagnose of the patient (*MTM registration form/ advice form MTM*):
- Medical history (*MTM registration form*):
- Medication (*MTM registration form*):
- Type of relationship with the informal caregiver (e.g. mother/ brother (*Cover page assessment/ 'Pseudonimisatiebestand'*)):

**A time-path of the TZPZ of the patient** (sub-question 4):

- Date of marking (*MTM registration form*):
- Date of consultation about the marking as a palliative patient:
- Date of assessment (*cover page of the assessment form*):

- Date of registration for the MTM:
- Date of MTM (*advice form MTM*):
- Date of composing a care plan (*care plan, but there are only dates written down before a certain problem/ goal; the earliest date is considered during the current study*):
- Date of death:
- Date of evaluation (between the relatives of the patient and the main practitioner and/or care coordinator):

#### Short explanation of the table:

The column ‘‘form/ document used’’ within the table means the form which are used to assess the implementation of that element of the TZPZ.

Whether forms are filled in as intended (e.g. completely filled in), depends on the form itself. In the column of the intended (‘‘Should be’’) situation, a more detailed description is given of ‘‘how the form should be filled in’’.

| Element of the TZPZ            | Form/ document used | Checkpoints                                                                                        | Intended (‘‘Should be’’) situation (based on Appendix 2)                                                                                                                                                        | Answer                                                                                                                                                                                       |
|--------------------------------|---------------------|----------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Full-length of the TZPZ</b> | All forms           | - Are the different elements of the TZPZ implemented/ which forms are filled in? (sub- question 1) | The following forms should be filled in:<br>- Assessment form (should include both the cover page and the questionnaire)<br>- EDIZ questionnaire<br>- MTM registration form<br>- MTM advice form<br>- Care plan | - Assessment form (the cover page and the questionnaire): yes/ no<br>- EDIZ questionnaire: yes/ no<br>- MTM registration form: yes/ no<br>- MTM advice form: yes/ no<br>- Care plan: yes/ no |

|                                                                                  |                                                                      |                                                                                                                          |                                                                                                                                                                                                                                                 |                                                                                                                                                                           |
|----------------------------------------------------------------------------------|----------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Assessment (excl. EDIZ)</b>                                                   | Assessment form (consisting of the cover page and the questionnaire) | - Is the form (both the questionnaire and the cover page of the assessment form) filled in as intended? (sub-question 2) | - The cover page (contains general information about the care coordinator, patient and the contact person) and the questionnaire (with a part completed in collaboration with the patient, and a part completed by the care coordinator itself) | - Cover page: is there information missing?: yes/ no, if yes, what information?<br><br>- Questionnaire: is there information missing?: yes/ no, if yes, what information? |
|                                                                                  |                                                                      | - Is the form filled in by the person as intended? (sub-question 3)                                                      | - The assessment form should be filled in by the care coordinator                                                                                                                                                                               | - The assessment form is filled in by the care coordinator: yes/ no, if no, by who?                                                                                       |
| <b>Questionnaire regarding the pressure experience by the informal caregiver</b> | The Ervaren Druk Informele Zorg (EDIZ)                               | - Is the form filled in as intended? (sub-question 2)                                                                    | - All the questions should be answered                                                                                                                                                                                                          | - Questionnaire: is there information missing?: yes/ no, if yes, what information?                                                                                        |
|                                                                                  |                                                                      | - Is the form filled in by the person as intended? (sub-question 3)                                                      | - The questionnaire should be filled in by the informal caregiver                                                                                                                                                                               | - The EDIZ questionnaire is filled in by the informal caregiver: yes/ no, if no, by who?                                                                                  |

|            |                       |                                                                            |                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                    |
|------------|-----------------------|----------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>MTM</b> | MTM registration form | - Is the form filled in as intended? (sub-question 2)                      | - The form should include the information regarding the marking of the patient, general information of the patient, diagnose of the patient, medical history (not obligated), medication (not obligated), a summary and the scores of the assessment and a question for the MTM | - Registration form: is there information (e.g. scores of Lastmeter/ HAST/ CAM/ pain measurement/ EDIZ, question for the MTM) missing?: yes/ no, if yes, what information?                         |
|            |                       | - To what extent are patients marked as intended? (sub-question 2)         | - The marking should be based on, at least, the surprise question. If necessary, the RADPAC+ criteria can be used.                                                                                                                                                              | - The marking is based on: <ul style="list-style-type: none"> <li>• Surprise question: yes/ no</li> <li>• RADPAC+: yes/ no</li> </ul>                                                              |
|            |                       | - Is the form filled in by the by the person as intended? (sub-question 3) | - The registration form should be filled in by the care coordinator                                                                                                                                                                                                             | - The registration form is filled in by the care coordinator: yes/ no, if no, by who?                                                                                                              |
| <b>MTM</b> | Advice form MTM       | - Is the form filled in as intended? (sub-question 2)                      | - The form should include general information of the patient, the potential problems, an advice, a summary of the MTM, and the complexity/ severity of the patient's disease/ situation (by using colors)                                                                       | - Advice form MTM: is there information missing?: yes/ no, if yes, what information?<br><br>- Is the complexity/ severity of the patient's disease/ situation assessed by using colors?<br>yes/ no |

|                  |           |                                                                          |                                                                                                                                                                                                                                                                                                                           |                                                                                                                     |
|------------------|-----------|--------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------|
|                  |           |                                                                          |                                                                                                                                                                                                                                                                                                                           | - Does the advice form give an answer to the MTM question as formulated on the registration form?                   |
|                  |           | - Is the form filled in by the person as intended? (sub-question 3)      | - The advice form should be filled in by the care pathway coordinator                                                                                                                                                                                                                                                     | - The advice form is filled in by the care pathway coordinator: yes/ no, if no, by who?                             |
| <b>Care plan</b> | Care plan | - Is the care plan filled in as intended? (sub-question 2)               | - Care plan should be based on both the assessment and the MTM, and should include general information about the patient, general information of the contact person, the problems/ questions/ wishes on the several domains (somatic, psychological, functional, social) and the potential future problems of the patient | - Care plan: is there information missing (e.g. are all the domains filled in)?: yes/ no, if yes, what information? |
|                  |           | - Is the care plan filled in by the person as intended? (sub-question 3) | - The care plan should be filled in by the care coordinator                                                                                                                                                                                                                                                               | - The care plan is filled in by the care coordinator: yes/ no, if no, by who?                                       |

Additionally, the following information is assessed:

- Did the GP and the medical specialist align regarding the marking and who will be the main practitioner? (sub-question 1, 2, 3):

- Does the consultation to inform the patient about the marking (as a palliative patient) by the GP take place? (sub-question 1, 2, 3):
- If (some of) the scores of the assessment are high (Lastmeter:  $\geq 5$ , HADS:  $> 8$  for fear and/or depression, CAM: yes, EDIZ: score between 7 and 9, NRS (pain):  $> 4$ ), did health care professionals (e.g. the care coordinator) undertake action (by discussing it in the MTM and, subsequently, give advice; by writing down, in the care plan, how action (should be) undertaken)? (sub-question 2):
- Is the medication review executed by the pharmacist? (sub-question 1, 2, 3):
- Is the coordination of the multidisciplinary care executed by the care coordinator? (e.g. whether health professionals have undertaken action emerging from the problems written down in the care plan) (sub-question 1, 2, 3):
- Has the evaluation (between the relatives of the patient and the main practitioner and/or care coordinator) taken place? (sub-question 1, 2, 3):

## Appendix 4: Topic list for the focus group (in Dutch)

Datum: 09-06-2016

Locatie: Meditta, Milaanstraat te Sittard

Duur:

Geïnterviewden (en ♂ or ♀):

Interviewster: Dr. V. Braeken (researcher at Zuyderland Hospital)

### Introductie

- Introduceren door de projectleider, o.a. van het onderzoek en de voortgang van de implementatie van het TZPZ
- Uitleggen van doelstelling focusgroep (inhoudelijk van gedachten wisselen over de eerste ervaringen met het TZPZ en behoeften aan ondersteuning)
- Vragen om goedkeuring voor het auditief opnemen van het interview
- Er wordt gestart met een rondje waarbij de huisartsen hun ervaring met het TZPZ kunnen delen

### Markering

- Welke meerwaarde heeft het markeren van palliatieve patiënten voor u? (H1.2.) (*opinion/ motivation/ attitude (characteristics of the GP)/ benefit (characteristics of the innovation itself)*)?
- Ervaart u belemmeringen in het markeren van patiënten? (H1.3.) (*barrier*)
- Welke oplossingsrichtingen ziet u om deze belemmeringen op te lossen? (H1.4.) (*potential solutions/ recommendations*)
- Gaat u het gesprek aan met de patiënt over zijn/ haar markering? (S1.3) (*sub-question 1*)
- Hoe verlopen deze gesprekken tussen u en de patiënten? (S1.4) (*sub-question 1, 2*)
- Ervoer u bij het vroegtijdig bespreken van het naderende levenseinde een drempel? (S1.6) (*barrier*)
- We zien nu dat patiënten in een late fase worden geïncludeerd. Liever zouden we dit in een eerder fase willen zien. Hoe komt dit en wat voor ondersteuning kunnen we hiervoor bieden? (*potential solutions*)
- Hoe verloopt de afstemming met de tweede lijn? (*sub-question 1/ potential solutions/ recommendations*)

### Assessment

- Rondje: wie heeft het assessment uitgevoerd? (GP/ POH/ assistent) (*sub-question 3*)

- Welke meerwaarde heeft het assessment voor u (H2.2.)? (*opinion/ motivation/ attitude (characteristics of the GP)/ benefit (characteristics of the innovation itself)*)
- Ervaart u belemmeringen in (het uitvoeren van) het assessment? (H2.3.) (*barrier*)
- Welke oplossingsrichtingen ziet u om deze belemmeringen op te lossen? (H2.4.) (*potential solutions/ recommendations*)
- Wat vindt u van het assessment (lengte, volledigheid, inhoud) van het assessment? (S2.2.) (*mogelijke barrier, characteristics of the innovation itself or characteristics of the organizational context; availability and quality of resources; equipment to use*)
- Wat is volgens u het doel van het assessment en wordt dit doel bereikt met de huidige vragen? (S2.3) (*opinion/ motivation/ attitude (characteristics of the GP)*)

## **MTM**

- Wat is jullie ervaring met het MTM? (H2.5.) (*opinion (characteristics of the GP)*)
- Welke meerwaarde heeft het MTM voor u? (H2.6.) (*opinion/ motivation/ attitude (characteristics of the GP)/ benefit (characteristics of the innovation itself)*)
- Ervaart u belemmeringen in het MTM? (H2.7.) (*barrier*)
- Welke oplossingsrichtingen ziet u om deze belemmeringen op te lossen/ hoe zouden we de meerwaarde voor het MTM kunnen vergroten? (H2.8.) (*potential solutions/ recommendations*)
- Wat vindt u ervan dat alle gemarkeerde patiënten op het MTM besproken worden? (S2.10.) (*opinion/ motivation/ attitude (characteristics of the GP)/ benefit (characteristics of the innovation itself)*)
- Bent u tevreden over het bijwonen van het MTM via communicatie kanalen zoals facetime/ skype? (S2.11) (*opinion (characteristics of the GP)*)

## **Zorgplan**

- Wordt er een zorgplan gemaakt, en zo ja, welk format wordt er gebruikt? (H2.9.) (*sub-question 1, 2*)
- Draagt het advies van het MTM iets bij aan het opstellen van het zorgplan? (S2.12) (denk aan waarde, leesbaarheid, tijdigheid en hanteerbaarheid) (*sub-question 2/ opinion (characteristics of the GP)*)
- Wat is uw mening betreffende de meerwaarde van het zorgplan? (*opinion/ motivation/ attitude (characteristics of the GP)/ benefit (characteristics of the innovation itself)*)
- Ervaart u belemmeringen in het maken van het zorgplan? (H2.10) (*barrier*)
- Welke oplossingsrichtingen ziet u om deze belemmeringen op te lossen? (H2.11.) (*potential solutions/ recommendations*)

**De volgende elementen zullen (i.v.m. de tijd en de verwachting dat veel huisartsen nog niet bij deze onderdelen zijn ‘aangekomen’) minder/ geen aandacht krijgen.**

#### **Monitoring/ coördinatie multidisciplinaire zorg**

- Hoe wordt het proces cq. de acties naar aanleiding van MTM en maken van zorgplan opgevolgd? (H3.1.) (*sub-question 2 en 4*)
- Wie pakt welke rollen, taken en verantwoordelijkheden in de uitvoering van het zorgplan op? (S3.1.) (*sub-question 4*)
- Wat zijn volgens u de randvoorwaarden om het zorgplan en de begeleiding daarvan goed uit te kunnen voeren? Wordt hieraan voldaan? (S3.2.) (*kan behulpzaam zijn in het identificeren van zowel barriers als facilitators*)
- Hoe verloopt het contact/ begeleiding patiënten? (S3.8.) (*sub-question 2*)
- Hoe verloopt het betrekken van de informele zorgverleners? (S3.8.) (*sub-question 2*)
- Ervaren jullie belemmeringen bij het monitoren van deze acties? (H3.2.) (*barrier*)
- Welke oplossingsrichtingen zien jullie om deze belemmeringen op te lossen? (H3.3.) (*potential solutions/ recommendations*)

#### **Evaluatie**

- Zijn er gesprekken met de nabestaanden gevoerd? (*sub-question 1*)
- Hoe ervaart u, als professional, het gesprek met de nabestaande te voeren 6 weken na het overlijden van de cliënt? (4.1.) (*opinion (characteristics of the GP)*)
- Ervoert u in dit gesprek een drempel? Waarom? (4.2.) (*barrier*)
- Heeft u het idee dat u voldoende handvaten heeft aangereikt gekregen om dit gesprek goed uit te voeren? (4.3.) (*sense of competence/ knowledge of the TZPZ (characteristics of the GP)*) Zo nee, hoe zou dit verbeterd kunnen worden? (*potential solutions/ recommendations*)
- Zou u wat willen veranderen aan dit gesprek? (4.4.) (*potential solutions/ recommendations*)

**Als laatste zullen er nog een aantal algemene vragen betreffende het TZPZ gesteld worden.**

#### **Algemene vragen met betrekking tot het TZPZ**

- Rondvraag: wat is op dit moment de grootste belemmering om te includeren? (financieel, ICT ondersteuning, kennis, tijd) (*barrier*)
- Bent u voldoende voorbereid en gefaciliteerd om te werken met het zorgpad? (*sense of competence/ knowledge of the TZPZ (characteristics of the GP)*)

- Tijdens het proces is de medicatie review toegevoegd, heeft dit meerwaarde voor u? (*opinion/ motivation/ attitude (characteristics of the GP)/ benefit (characteristics of the innovation itself)*)?
- Welk effect verwacht u van het TZPZ? (*benefit (characteristics of the innovation itself)*)
- Zou u iets willen veranderen aan het zorgpad? (5.2.) (*potential solutions/ recommendations*)
- Heeft u nog adviezen voor verdere uitrol van het TZPZ? (5.13.) (*potential solutions/ recommendations*)
- Welk cijfer zou u het gehele zorgpad willen geven? (Cijfer 1 tot 10)

#### **Eventueel nog:**

- De formulieren moeten momenteel naar verschillende e-mailadressen verstuurd worden. Maakt dit voor jullie het toepassen van het TZPZ extra ingewikkeld? (*factors of the organizational context; availability and quality of resources; equipment to use the TZPZ*)
- Zou het helpen om regelmatig een bijeenkomst (met huisartsen/ specialisten) plaats te laten vinden om ervaringen te delen? (*potential solutions/ recommendations*)
- Vindt u het TZPZ te complex? Zo ja, wat zou er veranderd kunnen worden om de toepassing van het TZPZ te vergemakkelijken? (*characteristics of the TZPZ itself; complexity*)
- Als u zo terugkijkt, wat had u graag anders gezien in het uitrollen van het TZPZ (bijv. meer stapje voor stapje)? (*potential solutions/ recommendations*)

#### **Focusgroep**

- Wat vindt u van deze focusgroep en de opzet daarvan?

## Appendix 5: Coding form for analysis of the transcripts of the focus group and the interview

Codes barriers / Facilitators

Table 2: Possible facilitators and/ or barriers during the implementation of the TZPZ

| Category of potential facilitators and/ or barriers | Factors within these categories which can facilitate and/ or hinder the implementation of the TZPZ                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-----------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Main → <b>Characteristics of the GP and/ or POH</b> | Sense of competence to use the TZPZ, knowledge of the TZPZ, opinion regarding the TZPZ, motivation to use the TZPZ and attitude towards the TZPZ (e.g. regarding the effectiveness of the TZPZ and the applicability of the TZPZ to a specific patient), sense of urgency, conventional routines concerning the care of a palliative patient, awareness and familiarity with the TZPZ and the willingness to innovate and change of the GP and/ or POH.                                                                                                                                                                                    |
| <b>Factors of the organizational context</b>        | Availability and quality of resources (e.g. knowledgeable staff within the GP practice, and equipment to use the TZPZ such as forms to fill in and the ICT system), clear task division between the GP and the POH, time constraints of the GP and/ or the POH, and dissemination of clear information about the use of the TZPZ by the organization of the TZPZ, which is "Anders Beter" and its collaborative partners. Something which is not mentioned in the literature, but which can be an important factor influencing the implementation of the TZPZ, is the level of feedback to the GP and/ or POH about their use of the TZPZ. |
| <b>Factors of the economic and legal context</b>    | The degree of reimbursement, financial incentives (e.g. financial incentives for the GPs executing the TZPZ can increase motivation to achieve successful implementation) and certain legislation (e.g. contracts of GPs with certain health insurers).                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Factors of the social context</b>                | Culture (e.g. culture of the collaboration between the different health care professionals involved in the pilot), leadership from the organization of the TZPZ concerning stimulation and support regarding the use of the TZPZ by the GPs/ POHs, attitude and behaviour of other GPs/ POHs concerning the TZPZ, the degree of support and pressure from other GPs/ POHs and the quality of the relationship with the palliative patient.                                                                                                                                                                                                 |
| <b>Factors related to the TZPZ itself</b>           | The degree of benefit, compatibility, complexity, triability and visibility of the TZPZ.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |

sub-codes

inged eeld per element.

Per related

Codes potential solutions

↳ per element: marking, assessment, MDO, zorgplan, coördinatie multidisciplinair zorg, evaluatie

En: documentatie

Overig

## Appendix 6: Design of a digital system

The forms and/or information which currently have to be filled during the execution of the TZPZ should be adapted for the following reasons. At first, the GPs participating in the focus group and the interview indicate that some information has to be filled in multiple times. Secondly, some information necessary to execute an accurate process evaluation was missing. The digital system should include the following forms and/or information (the adapted or added forms and/or information are colored yellow):

- Information of the patient and the informal caregiver (BSN, name, date of birth, ♀/ ♂, address, telephone number, e-mail address), the (name of the) GP (and medical specialist, if the patient is still treated in secondary care), and the information of the care coordinator (name, e-mail address, telephone number and function, e.g. GP or POH). This information previously had to be filled in multiple times, i.a. on the cover page of the assessment, the registration form of the MTM, the advice form of the MTM and the care plan. Therefore, on these forms, this information can be left out. The cover page can even be completely abandoned.
- Date of marking, by whom and the basis of marking (Surprise question, RADPAC, SPICT indicators). As the date of marking is currently multi-interpretable, the date of marking is defined as the date at which the GP (or medical specialist) considers the patient as palliative. The marking can be supported by the use of a digital surprise question, digital RADPAC indicators and digital SPICT indicators. A study in Scotland used a digital form of the RADPAC indicators, which was found to be successful in timely identification of palliative patients (Mason et al., 2015).
- Whether there was alignment between the GP and the medical specialist about the marking of the patient and who (the GP or the medical specialist) becomes the main practitioner. The date of the alignment should also be recorded.
- Whether the consultation about the marking has taken place (including the date)
- Informed consent form for sharing medical information with other health care professionals
- The declaration of intention ('wilsverklaring')
- Regarding the assessment:
  - o Who performed the assessment (and his- or her function)
  - o Date of the assessment
  - o The questionnaire and the EDIZ (including the person who fills in the EDIZ, and the relationship of that person pertaining to the patient). To facilitate the creation of the care plan, the questionnaire might be classified in the four domains. Also, the GP should be instructed that, if he or she do not want to or cannot fill in a question, the reason why the question is not filled in has to be written down. The digital system should, after saving the questionnaire and the EDIZ, calculate the scores of the different tools used in the assessment automatically. This saves time for the secretary and the GP, and the GP immediately has the scores.

- MTM registration form: the sections ‘aanmeldgegevens’ en ‘patientgegevens’ can be left out. The date of registration and who registered the patient for the MTM should be added to the registration form. The scores of the assessment do not have to be attached to the registration form anymore, as the scores are calculated and saved in the digital system. If the MTM registration form is filled in by the GP/ care coordinator, the care pathway coordinator should receive an e-mail that a patient is registered for the MTM. In this way, the care pathway coordinator can plan this patient for the MTM as soon as possible, and it decreases the chance not discussing patients at the MTM. If the new, combined ‘MTM advice form/ care plan’ (see further on) is not uploaded within two weeks after registration for the MTM, the care pathway coordinator should receive a reminder (via e-mail) that he or she has to plan this patient for the MTM.
- The pharmacist should receive a notification (after the assessment has been conducted) by e-mail that a patient of his or her pharmacy is marked. The pharmacist should also be able to upload the medicine review into the digital system.
- The new, combined ‘MTM advice form/ care plan’: to ease the creation of a care plan, the care pathway coordinator immediately, after the MTM, incorporates the advice of the MTM in the care plan (by using the four domains). An advice form will not be completed anymore, but the following information is added to the care plan:
  - Date of the MTM and who was present at the MTM
  - Answer on the MTM question
  - Further advice emerged from the MTM (in short)
  - Color coding of the patient
  - Date of the (start of the) creation of the care plan
 The information of the patient and the informal caregiver can be left out in the care plan.
- Whether the patient has deceased or not (and on what date): the digital system should automatically send an e-mail to IQ health care that the patient has deceased (including the (e-mail) address of the informal caregiver and the GP/ medical specialist). In this way, the evaluation forms can be send to the GP/ medical specialist and informal caregiver.

A consequence of adapting the forms and using a digital system is that the toolkit, which functions as a guideline for health care professionals of ‘how to execute the TZPZ’, should be changed. This can be confusing for GPs and medical specialists currently participating in the pilot. However, it is expected that the benefit outweighs this disadvantage (on the long-term).

As long as the digital system is not yet constructed, it is important that the GPs can send their forms to one e-mail address. Currently, the forms should be sent to several e-mail addresses, depending on what form it is, which is confusing for the GPs and a barrier to deliver the forms. In addition, as the results of the focus group and the interview show, some patients were not discussed at the MTM. Therefore, the lists of the participating patients of the secretary and the care pathway coordinator should

be compared to ensure that all patients are discussed in the MTM. Furthermore, when information on the forms is not filled in, an e-mail should be sent to the GP practices (instead of calling).