



Developing and implementing innovative patient-centred care pathways for cancer patients

Project no. 101057514

Deliverable 1.3
Local, cultural, social and religion-related aspects report

Version 1

WP1 – CO-DESIGN – MyPath structure and contents

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Partner short names

Abbreviations	Details
accelCH	accelopment Schweiz AG
CUH	Copenhagen University Hospital - Rigshospitalet
DNV Imatis	DNV Imatis AS
EAPC	European Association for Palliative Care
ECPC	European Cancer Patient Coalition
ESMO	European Society for Medical Oncology
FINT	Fondazione IRCCS Istituto Nazionale dei Tumori
HCS	HOSPICE Casa Sperantei Foundation
INCLIVA	INCLIVA Biomedical Research Institute
LTHT	Leeds Teaching Hospitals NHS Trust
OUS	Oslo University Hospital
UEDIN	University of Edinburgh
UL	University of Leeds
UM	University of Maastricht
VUB	Vrije Universiteit Brussel

Abbreviations

Abbreviations	Details
D	Deliverable
WP	Work Package
PROMs	Patient-Reported Outcome Measures
PREMs	Patient-Reported Experience Measures
PCCPs	Patient-Centred Care Pathways
TPOM	Technology, People, Organizations, and Macroenvironmental factors

Executive Summary

This **Deliverable 1.3 (D1.3)** is **part of Work Package 1 (WP1): *MyPath structure and contents***, led by *UL*. The goal of WP1 is to develop and deliver the evidence-based content and structure for improved, individual patient-centred cancer treatment and care in Europe, to be configured in the electronic pathway, i.e. *MyPath* (WP2 by *DNV Imatis*). The **Lead Beneficiary of D1.3 is VUB**, being responsible for WP3: *Ethics, legal, socio-cultural and economic aspects* and collaborating closely with *UEDIN*, being responsible for WP4: *Large-scale implementation and validation of MyPath*. D1.3 describes (how to identify) the preconditions for a successful implementation of the electronic patient-centred care pathways (PCCPs) in cancer care in the hospital setting.

Need for the deliverable and objectives of the deliverable

D1.3 is an important deliverable in the development of the EU *MyPath* tool as a run-up to a formal implementation study. It includes important information and insights for the development of a highly suitable *MyPath* tool to be developed by WP1 (*MyPath structure and contents*) and WP2 (*Digital solution development and configuration*) as well as for maximizing the chances of a successful implementation of the electronic PCCPs at all participating sites. More specifically, the objective of this public deliverable is to:

- identify different stakeholders
- develop ethically sound methods in how to involve these stakeholders in the identification of existing practices and needs to achieve improved patient-centred care alongside tumour-centred care
- determine structural, social, ethical and cultural preconditions needed to achieve the desired integration and adoption of *MyPath*.

Outcomes

This report provides:

- The protocol for the qualitative pilot study to be conducted in all five pilot sites (Brussels, Edinburgh, Leeds, Oslo and Valencia)
- An overview of the first insights gained from the stakeholder meetings with organisational leaders and managers, medical and allied healthcare professionals at Brussels and Edinburgh

VUB and UEDIN are taking the joint lead in WP3/4 and have developed this deliverable D1.3. As only Brussels and Edinburgh finished most of their initial meetings with local stakeholders, this report is limited to the first insights from these two pilot sites. A final report, including qualitative findings from all pilot sites, will be worked on as the project progresses (cf. D3.2). However, through regular meetings with both WP1 and WP2, important findings will be timely exchanged between WP3-4 and WP1-2.

Next steps

In the coming months, the focus is on starting the qualitative data collection at the other pilot sites (Leeds, Oslo & Valencia) and continuing interviewing the stakeholders in Brussels and Edinburgh. The immediate concrete actions are :

- For Brussels & Edinburgh: developing instruction guides to support the other pilot sites in collecting qualitative data and performing qualitative data analysis (cf. D4.1), finalizing the stakeholder mapping exercise, recruiting selected stakeholders to be interviewed and performing qualitative individual semi-structured interviews with stakeholders and general unit observations (data-collection + -analysis)

- For Leeds, Oslo & Valencia: submitting and obtaining ethical approval, continuing the stakeholder mapping exercise, recruiting selected stakeholders to be interviewed and performing qualitative individual semi-structured interviews with stakeholders and general unit observations (data-collection + -analysis)
- Regular meetings with all pilot sites on data collection and data analyses of the pilot data
- Regular bilateral meetings with WP1 and WP2

1 Pilot study protocol

1.1 The content of the pilot study protocol

The WP3-4 developed a protocol for the pilot study (September 2022 - August 2024) with the aim of better understanding existing work practices and needs and tailoring the MyPath tool to achieve maximum impact in oncology care.

1.1.1 Study background

Successfully adopted and implemented Health Information Technology (HIT) Innovations are a means to provide better and more patient-centred cancer care by, for instance, incorporating electronic and routine assessments of patient-reported outcomes (PROMs) and experience measures (PREMs) into oncology care (1,2). In recent years, the use of PROMs and PREMs expanded to clinical practice to improve care at the population, service and individual levels (3). Although there is no shortage of HIT innovations in oncology practice, cancer care still has silos, and to this day, there is no technological support available that is suitable for different cultures, settings and environments. Moreover, many HIT systems fail to realise their potential in clinical practice due to several important barriers to system usability and adoption of (digital) PROMs and PREMs, including increasing workloads for healthcare staff, lack of training initiatives, the absence of implementation leads, risk of new HIT-induced errors, lack of clinician and patient pull, and potentially adverse consequences for clinician-patient relationships (2, 4-8). If HIT innovations are not effectively adopted and implemented, then they can create risks to safety, introduce new errors, and increase the burden on health and care staff. To conclude, prior to implementation, research is needed to understand current practices/needs and determine ethical, legal and sociocultural preconditions to develop a HIT that has maximum chances of being successfully implemented and adopted. By successfully, we mean that the MyPath tool is used.

1.1.2 Objectives

This protocol focuses on the first period of the MyPath study that aims to improve patient-centred care alongside tumour-centred care. The first period, i.e. the pilot study, functions as a run-up to the formal implementation study. Our principal research objective within this protocol is to conduct qualitative research to investigate how might the digital solution MyPath improve work efficiency and interdisciplinary communication among medical and allied healthcare professionals. In addition, the qualitative research will explore patients' perceptions of current gaps in patient-centred care and their thoughts on how MyPath may or may not address these gaps, in addition to their opinion of the acceptability of the current MyPath tool. Detailed discussions with ICT will be a necessary part of understanding the degree to which MyPath can be integrated with track-care.

- 1) In this pilot study, we aim to understand current practices/interests and determine ethical, legal, and sociocultural preconditions needed in order to develop a MyPath tool that has maximum chances of being successfully implemented and adopted across contexts as well to achieve the desired integration and adoption of MyPath in each pilot site (Brussels, Edinburgh, Oslo, Leeds & Valencia).
- 2) Next, we want to receive feedback on the MyPath prototypes, on the basis of an iterative and cyclical process. These prototypes are not available yet and are currently being developed by our technological MyPath partner *DNV Imatis*. These prototypes will stand alone and will be using synthetic patient data which will not be integrated into the hospital system yet.

The implementation of MyPath patient-centred care into routine cancer care (period 2) aims to considerably improve the delivery and quality of cancer care for people with cancer, their family members and caregivers, and it will facilitate the organisation of care for health and care providers at many levels.

Stakeholder feedback is needed to 1) further develop and optimize the **implementation strategy** and the **MyPath tool** (its functionality, user interface, usability, and content); and 2) identify what strategic and behavioural components are needed to support the implementation of the technological intervention (e.g., training initiatives). **Co-creation** with all key stakeholders during the development phase of MyPath will ensure that MyPath meets the specific stakeholders' requirements and that the elements are appropriate, engaging and effective across contexts and stakeholder groups.

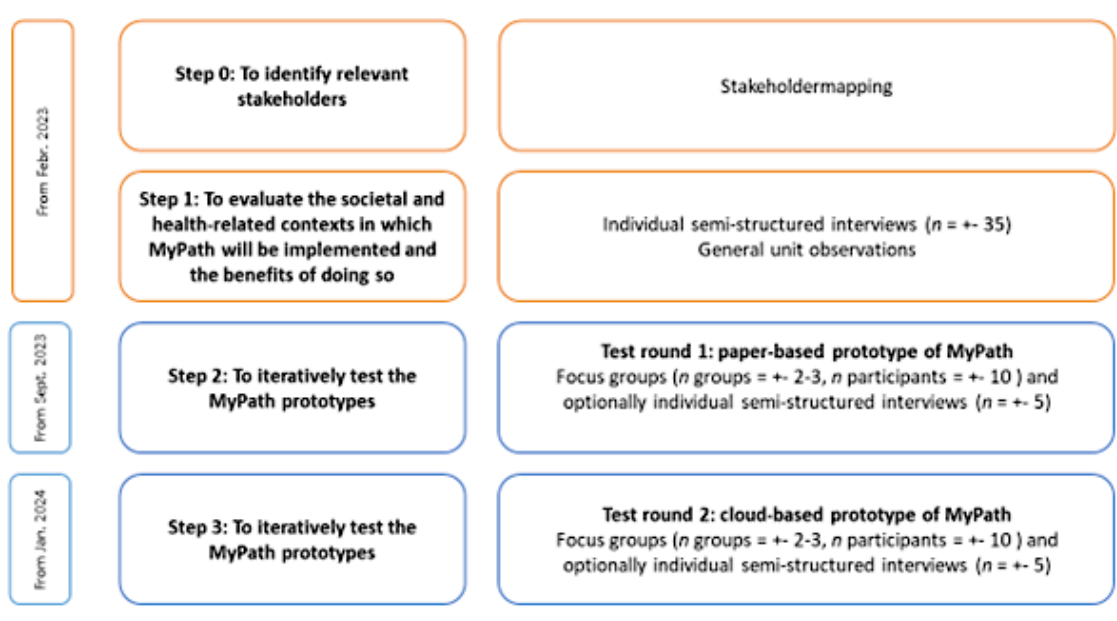
1.1.3 Methodology

The following methodology was applied:

- Stakeholder mapping exercise; using the Technology, People, Organizations and Macroenvironmental factors (TPOM)-framework developed by Kathrin Cresswell et al. for organizing the first insights from stakeholder meetings
- in-depth qualitative interviews with patients, family/carers and all people involved in the care for people with cancer in the hospital setting e.g. managers and organizational leaders, professional carers and social and healthcare workers; using the TPOM-framework developed by Kathrin Cresswell et al. for developing the interview guides
- interviews or focus group discussions to receive all stakeholders' feedback on the prototypes provided by Imatis
- general unit observations of meetings and practices

An overview of the methodology within this qualitative pilot study is illustrated in **Figure 1**.

Figure 1: Schematic overview and summary of the methodology



Study design

For this study protocol, we will conduct qualitative research.

Objective A involves the following steps:

- Step 0: We want to identify important and relevant stakeholders at all pilot sites (i.e., organisational leaders and managers, medical and allied healthcare professionals, patients with cancer and family caregivers). Therefore, we will have exploratory meetings. A stakeholder map will be formed that classifies stakeholders according to their level of power and level of interest, which, in turn, determines the appropriate engagement strategy for each stakeholder and the interview selection.
- Step 1: Second, through semi-structured interviews, we want to qualitatively explore stakeholders' needs and expectations of the MyPath tool, identify potential opportunities and barriers for using the MyPath tool, current work and organisational practices, existing technological/organisational infrastructures, and describe ethical, legal and sociocultural preconditions needed to achieve the desired integration of MyPath. We will also conduct general unit observations.

Objective B involves the following steps:

- Step 2: We will present the same stakeholders with a paper-based prototype of MyPath and gather feedback through heterogenous focus group discussions and if needed, additional individual interviews.
- Step 3: Next, a second iterative test round will be conducted by presenting a cloud-based prototype of MyPath and gathering stakeholders' feedback through heterogeneous focus group discussions and, if needed, additional individual interviews.

Setting

The qualitative research will be performed at five pilot sites (Brussels, Edinburgh, Leeds, Oslo and Valencia) in a hospital setting (e.g. Brussels: University Hospital of Brussels; Edinburgh: Edinburgh Cancer Cancer, St John's Hospital, Queen Margaret's in Dunfermline, Borders General). In addition to the hospital managers and organisational leaders, we will focus on one or two tumour sites selected at each hospital site. A tumour site is the (local) clinical site of the chosen diagnostic group(s) to implement MyPath in e.g. lung cancer and prostate cancer for Brussels and the tumour site breast cancer for Edinburgh. Consequently, we will mainly involve medical and allied healthcare professionals working at these sites, people diagnosed with these types of cancer and their carers. For a successful adoption and implementation of MyPath, it is important to select tumour sites strategically. For example, in Brussels, the research team work closely together with two medical oncologists (oncologist lung cancer + prostate cancer) who are willing to commit to MyPath. Furthermore, these tumour sites represent a well-diversified patient group.

Participants

The participants will be both adopters, implementers and the intended users of the MyPath tool sampling a diverse range of relevant organisational leaders (e.g., CEO), managers, health and social care professionals working with people with cancer (e.g., medical oncologist, nurse, psychologist, dietitian, pharmacologist etc.); with a range of varying levels of seniority and from a range of professional backgrounds. We will also involve people with the cancer types selected and their family carers with the patient and family carer group representing, for example, various age groups and culture. At the patient level, consenting patients with any stage of cancer, including patients with post-curative treatment symptoms, will be included in the study. For getting insight into the context and users' needs/expectations, we expect to approach approximately 20 people working at the hospital, 10 people with cancer and 5 family carers resulting in a total sample of approximately 35 participants. For receiving feedback on the prototypes, each focus group will be led by a moderator and will include 6 to 10 participants, which is considered to be large enough to gain a variety of perspectives and small enough not to become chaotic or fragmented (9). If needed, additional individual interviews will be conducted to gather more in-depth information. We estimate to perform two to three focus group discussions in total (max. 30 participants) and optionally, five extra individual interviews.

Eligibility criteria:

- Managers and organisational leaders, all healthcare professionals, patients and family carers to be interviewed should be able to understand and speak the native language.
- Health and social care professionals should provide care or support to patients from the selected tumour sites.
- General inclusion criteria for patients and family caregivers are:
 - Aged 18 years or older (≥ 18 years)
 - Being diagnosed with tumour type selected or being the primary family caregiver of a patient with tumour type selected in the relevant hospital
- General exclusion criteria for patients and family caregivers are:
 - Cognitive or communication difficulties that would make a semi-structured interview/focus group discussion impossible or substantially more difficult
 - Psychiatric disorders that would make a semi-structured interview/focus group discussion impossible or substantially more difficult

Recruitment procedures

In general, the stakeholder mapping will guide the selection of relevant interviewees (i.e., step 0). Organisational leaders, managers, and health care professionals will be recruited in person, via email or phone. By doing so, they will be informed about the goal and procedures of the study. Other relevant stakeholders will be recruited through the snowball sampling technique, in which participants will be asked to recommend other relevant stakeholders. With the help of healthcare professionals, patients will be recruited in the same hospital and will be informed in advance about the goal and procedures by the healthcare professional. The healthcare professionals will then provide the research team with contact details (after permission) of patients who are interested in participating in the study. Informal caregivers will be recruited through the patient or relevant family carer organisations. The patient is first asked for permission to interview his/her family caregiver if the family caregiver is recruited through the patient. If the patient agrees, she/he will provide the research team with the contact details of the informal caregiver. The research team will contact the informal caregiver to explain the goals and procedures of the study.

Participants will be informed in advance about the study goal and will be provided with an information letter in which the aims and the procedures will be outlined. Stakeholders are invited to participate in one to a maximum of three interviews and/or focus group discussions. Participants of the first individual interviews will be asked whether they are also willing to give feedback on the MyPath prototypes later on. Individuals who were interviewed individually first are not obliged to participate in the MyPath prototype testing. If needed, we will recruit new stakeholders when evaluating the prototypes.

The recruitment procedure may be slightly different from pilot site to pilot site. For example, for Edinburgh, recruitment will take place via the Breast care team, who will identify appropriate managerial/administrative (ICT)/clinical staff/PPI online, via email or in-person invitations. They will be approached via an email, letter or phone call if identified as acceptable. The interviews will be conducted either online via Teams or in relevant hospitals in Lothian, Fife or Borders.

Objective A (period I): to understand current practices, needs and interests and determine ethical, legal, and sociocultural preconditions for successful implementation (period II) - interviews will be conducted by qualitative researchers who are part of the team

Objective B (period I): Receive feedback on the digital tool MyPath prototypes, based on an iterative and cyclical process. The prototype is available in an early-stage format - Interviews will be conducted by qualitative researchers who are part of the team

Measuring tools and data collection procedures

- Stakeholder mapping

Stakeholder mapping will help to classify stakeholders according to their level of power and level of interest, which, in turn, determines the appropriate engagement/communication strategy for each stakeholder and the interview selection.

- Interviews

All interviews will follow semi-structured topic guides, drawing on Cresswell et al.'s Technology, People, Organizations, and Macroenvironmental factors (TPOM) framework (see **Appendix 1**) (10), but commencing with open questions to allow participants flexibility to talk about issues of greatest importance to them. The interview guides will be adapted to the target group (interviews can be found in **Appendix 2**). All interviews will be audio recorded and notes will be taken. A convenient time and location will be chosen for the interviewee or, in the case of the focus group discussion, for all participants invited. The individual interviews and focus group discussions can be held in-person or online. In any case, it is important that the participant feels comfortable and, therefore, the place should be relatively private, calm, and undisturbed. Both the individual interviews and focus group discussions will take approximately one to one and a half hour, depending on the type of stakeholder and the study phase. Before the start of the interview, the stakeholders that agreed to participate in the study will again be informed about the goal of the study. Written informed consent will be sought once the potential participants have had time to consider all the information provided. Possible questions of the participants about the study can be answered by the interviewer/moderator. Prior to the interviews/focus group discussions, we will ask participants for a few demographic details to collect data about the participant's age and sex. In the case of people working at the hospital, we will collect data related to their work (experience). In the case of patients and family carers, we will collect data related to the patient's cancer diagnosis and the relation between them (see **Appendix 3**).

When co-creatively developing an implementation strategy and MyPath tool, it is important to hear stakeholders' ideas and effectively apply these. Therefore, we will use tools to introduce the MyPath tool in the interviews and to explain in an easy way what it could look like. Awaiting the first prototype, we will let the stakeholders watch the MyPath video (15') developed by UOS prior to the interview and share a folder (see **Appendix 4**) and interview cards (see **Appendix 5**) developed by WP3-4 during the interview to support the stakeholders' understanding and interpretation of the MyPath tool.

- General unit observations

For the general unit observations, fieldnotes will be collected. Researchers will be observing the daily practice at the medical oncology sites (e.g., meetings and care activities) and will remain as inconspicuous as possible (e.g., in the waiting room). During and after non-participant observations, the researchers will write down the observations using a recording sheet of the types of activities observed.

Saturation (the point at which no significantly new insights into daily practices, barriers or opportunities emerge from data collection) will guide the volume of data collection, but we anticipate undertaking a combination of qualitative interviews, multidisciplinary focus groups and non-participant observations. We may also collect relevant local documents (e.g., brochures, flowcharts).

Data processing and analysis

Every site is collecting data at its own pace. At each site, stakeholder meeting notes will be collected via a recording sheet that we have developed. The individual interviews and focus group discussions will be recorded, transcribed verbatim and analysed. A first version of a codebook, in English, and built on the TPOM framework and literature review, will be used among all pilot sites. The first analysis will be done on the pilot site level, but integrated afterwards in one project in Nvivo. All sites will be invited to recurrent interactive analysis workshops to present findings emerging from local sites in English, to go through codes on coding framework and in the end to perform cross-case validation. Findings from the first interviews will be completed with the qualitative data from the recording sheets and field notes derived from the general unit observations. Findings will be tabulated and analysed to identify changes to the intervention and implementation processes required. We will also identify potential risks and propose mitigation strategies associated with implementation approaches and contextual differences across settings. We will provide participants with formative feedback and send emerging findings for checking participants. The interview data will help researchers develop digital PCCPs and provide feedback on PROMs and PREMs for shared decision-making between people with cancer and professional carers in hospital settings. The participants will have the opportunity to share their experiences and feedback on the digital tool which is designed to help them communicate their symptoms, psychological and social problems effectively to the oncology team in a systematic manner which the oncology team can use in routine clinical practice and address these issues with appropriate management plans.

1.2 The need for ethical approval

Prior to starting the qualitative interviews, ethical approval is needed with the aim of conducting ethically sound research and publishing scientific articles based on the results and insights obtained. This protocol can function as the basis for the ethical committee application but may require adjustments depending on the pilot site. Next to this protocol, the following documents may be needed for obtaining ethical approval at all pilot sites: a General Data Protection Regulation (GDPR) record, a data management plan, information letters and informed consent for all types of participants.

2 First insights from stakeholder meetings at Brussels (WP3) and Edinburgh (WP4)

The MyPath research teams at Brussels and Edinburgh have more or less completed the stakeholder mapping exercise regarding organizational leaders and managers and the medical and allied health professionals working with people with cancer. People with cancer and family carers were not heard so far. Below we would like to share the first insights gained from the initial stakeholders meetings in Brussels and Edinburgh.

The main challenges might be related to the **navigation of MyPath, ICT** and the need for **behavioural change** in medical and allied healthcare professionals within a care system to improve the multi-professional workflow and **behavioural change** in patients. In order to overcome these challenges, the design and implementation of MyPath need to be the outcome of a **co-creation process with all relevant stakeholders** involved in MyPath in the hospital, including professional caregivers, patients and their families. Based on the TPOM framework developed by Cresswell et al., we opted to categorize the first insights from meetings with stakeholders at Brussels and Edinburgh according to **questions, perceived barriers and opportunities** and link them to the following themes: digital solution (goal, content, design, flexibility, integration, data availability, sustainability), macroenvironment (culture, context, legal, ethics, economic, primary care), organisational (vision, care organisation, existing technology, resources, support), social/human (patient, caregiver, ICT, user input) and target group (patient group, language, primary care) (see **Table 1** for an overview of all insights).

Next to the meetings with local stakeholders, **we are in close liaison with *DNV Imatis*** and are having regular bilateral meetings aimed at information exchange. These bilateral meetings also offer a great opportunity to explain the complexities of the stakeholders and to understand the different settings and contexts in an early phase of the MyPath project. This is important to ensure the MyPath tool basics can be adapted to be suitable to all hospitals and tumour sites selected. Some of the questions, barriers/concerns/tensions, and opportunities below were already discussed with *DNV Imatis*. *DNV Imatis* was also involved in the final check of the interview guides to ensure all relevant questions are included. **The local ICT key person of each pilot site is in touch with *DNV Imatis*** to learn more about the specific needs of the local setups seeing these may vary in terms of organisation or technical setup.

Table 1: First insights from stakeholders' meetings by (sub)category

Questions			
Digital solution	Goal		<ul style="list-style-type: none"> - What are the concrete goals of the digital solution? - Is MyPath supposed to feel more clinical or more personal for patients? Learnings from our conversations in cancer management have taught us that they have to be more personal, and not feel like another clinical evaluation, form, or collection of symptoms and clinical events - Is the goal related to the diagnosis? - Is the goal to commercialize the tool after 2027?
	Content	PROMs/PREMs	- Will other outcomes than PROMS & PREMs (e.g. experienced changes in health) be included?
		Language	<ul style="list-style-type: none"> - Will the MyPath tool detect the language used /narrative by the patient? This could be crucial. The language used by patients can change their narrative to a more positive one, and it takes a lot of courage to identify which areas patients would like to work on... - In what languages the tool will be available e.g. English, Dutch, French, Arabic?
		Guidelines	- What guidelines will be integrated into the care pathways?
		Length	- How many questions will be included in the patient questionnaire?
	Design	Interface	- How will the MyPath tool look like and work in real-life practice? Still hard to imagine now...
		Function	- Will a chat function to improve communication between patients and professional carers be included?
	Flexibility		- To what extent national or local customization options will be included (e.g., adding additional PROMs/PREMs if wished for, if changes in health care processes/sector/landscape)?
	Integration	Electronic health record	- What about the link with the electronic health record? Is it a one-way system?
	Sustainability		- Will the final tool still for the sites involved to use in practice after finishing the project in 2027 cf. user rights?
Data availability		<ul style="list-style-type: none"> - Will there be the possibility for patients to indicate with whom they want to share the data, and to change this at any time? Important that patients have control over this... - Will the data filled out by the patient be available for all professional carers; only for the professionals involved in the care for an individual patient? 	

			<ul style="list-style-type: none"> - Will other clinicians inside and outside the hospital from outside the oncology ward, e.g. in case of comorbidities also be able to see the data? - Will MyPath create any optional outputs/summary reports/printouts? - Will data be available to the primary care settings (GPs)?
Macroenvironment	Legal		<ul style="list-style-type: none"> - Is MyPath a medical device e.g. who is responsible for the development of MyPath? What is the intended goal? - Where will data be stored? In what type of clouds? - Data protection: how is patient confidentiality or information about treatment going to be protected? - Will data also be stored within the hospital centre? Will data be used outside of the hospital centre?
	Ethics		<ul style="list-style-type: none"> - Will the tool include a two-factor authentication to ensure the security of each patient account? - Might be dangerous if the system is easily accessible to others. For example, will it be easy for patients to share their login and password with others? - What are the consequences of system malfunction? - Will anyone be able to access the patient's psychosocial (sensitive) data? - What measures will be taken if there are urgent needs that require follow-up?
Organisational	Care organisation	Introduction of MyPath	<ul style="list-style-type: none"> - Who will introduce the MyPath tool to the patient (e.g. the onco-coach)? - When will the MyPath tool be introduced eg after the first consultation with the oncologist?
		Clinician access to MyPath	<ul style="list-style-type: none"> - Suppose a caregiver has acted on a signal/need from a patient, can this be indicated so that it is visible to other caregivers?
		Consultation	<ul style="list-style-type: none"> - Besides the oncologist, what other professional carers could play a role in using the MyPath tool during the consultation with the patient? - Will a translator-interpreter still be necessary e.g. in case of Arabic language?
	Existing technology		<ul style="list-style-type: none"> - Can the onboarding process be linked to a local existing patient portal?

	Support		<ul style="list-style-type: none"> - To what extent does Imatis provide the clinical centres with support during implementation and after implementation?
Social/human	Patients	Filling out the questionnaire	<ul style="list-style-type: none"> - When and where would patients need to fill out the PROMs and PREMs? - What happens, ie what are the consequences, when patients do not fill out the PREMs and PROMs? - What if people do not answer questions honestly?
		Digital literacy	<ul style="list-style-type: none"> - Would it be possible to also provide a tablet from the hospital to patients who do not have a computer or phone? - Do you also provide an alternative if patients are unable to work with a digital tool/do not have a smartphone e.g. paper version?
	Caregivers	Workload	<ul style="list-style-type: none"> - What will be the exact workload for care staff?
		Engagement	<ul style="list-style-type: none"> - How can we make sure that professional carers use MyPath?
	Attitudes and expectations	<ul style="list-style-type: none"> - What are the expectations towards non-physician staff during the MyPath project e.g. Nursing Staff? 	
ICT	Workload	<ul style="list-style-type: none"> - How many ICT personnel is needed for the actual implementation? 	
Target group	Patient group		<ul style="list-style-type: none"> - Do only new patients qualify for using the tool in the implementation phase? - Why were those specific tumour sites selected? - Will the MyPath tool be functional for multiple cancer types? For example, will it be relevant for patients with prostate or urogenital cancer who mostly use primary care and only visit the hospital every 6 months or when problems occur? - What can the tool mean for people with cancer suffering from comorbidities (eg cancer patients with diabetes?)
	Primary care: GPs		<ul style="list-style-type: none"> - Will GPs be involved in the project?
Perceived barriers/concerns/tensions			
Digital solution	Content	PROMs/PREMs	<ul style="list-style-type: none"> - PROMs/PREMs: focus on symptomatology and needs; not each symptom in patients with chronic diseases can be 'solved'
		Underlying meaning	<ul style="list-style-type: none"> - Underlying meanings of symptoms seem not to be measured (e.g. meaning of pain: pain can be considered as an indicator of an underlying problem)
		Language	<ul style="list-style-type: none"> - Language barriers (e.g. Arabic language)
		Feedback	<ul style="list-style-type: none"> - Patients should receive feedback after completing the questionnaire, even when things are going well

	Design	Interface	- A not user-friendly tool will negatively affect its use
	Accessibility	Login	- Logging in to a different system than the easily accessible electronic health record
	Data availability		- Primary care e.g. GPs do not have access to the Electronic Medical Record / Electronic Patient Database including all the important and relevant information collected by the MyPath tool
Macroenvironment	Culture		- The large diversity in terms of languages, cultures, belief systems and religions - When translating the care pathways we should also consider the underlying meaning of language
	Legal		- Checking/ensuring that the name MyPath has not been patented or trademarked yet - Data Ownership - Limited (re) use of collected data - Processing/analysing data that was not inputted by patients themselves
	Ethics		- The tool must meet local ethical codes and guidelines which may differ depending on the country (GDPR, MDR,...) - User cannot be aware of other applications that are hidden in MyPath - Risk of inequality between patients that do and do not fill out PROMs and PREMs (possible consequence: too little/insufficient data for identifying an appropriate care pathway) - No/insufficient monitoring of patients in case of deviating scores/abnormal scores e.g. that are reported by patients at home/during the weekend/at night - What in case of misinterpretation of signal scores - Asking questions about psychological well-being could potentially trigger patients - Important not to label patients in terms of psychosocial well-being
	Economics		- Limited local financial resources (ICT/DPO) and personnel resources (ICT) to implement MyPath as well as to maintain the (sustainable) use of MyPath (e.g. workload ICT department) - ICT needs must be clearly mapped out, in function of financing
	Primary care		- Primary care may miss important and relevant information
Organisational	Vision		- The current care vision is not person/patient centred
	Care organisation		- A large and inefficient department

			<ul style="list-style-type: none"> - Important to have insight into the research load within a tumour group and what other clinical studies are either ongoing or planned within the timescale of the study and identify any conflicts
Social/human	Patients	Filling out the questionnaire	<ul style="list-style-type: none"> - If the patient fills the questionnaire out at home they might expect immediate follow-up on the score as well but there might be a bigger chance of no immediate follow-up
		Digital literacy	<ul style="list-style-type: none"> - Digital (health) literacy is an important prerequisite of using the tool by patients - The mean age of cancer patients is 65 (e.g. lung cancer and prostate cancer patients are even older) who are not comfortable using digital tools such as a smartphone
		Difficulties with expressing needs	<ul style="list-style-type: none"> - Patients that are less articulate might find it difficult to express their needs - Patients sometimes experience a sense of shame when expressing psychosocial needs
		Motivation/engagement	<ul style="list-style-type: none"> - Patients already get a lot of demand for completing questionnaires - Using the MyPath tool might be too burdensome for patients if they have to report outcomes measures too frequently - Low motivation in patients to use the tool (submitting data, interpretation of data, performing actions) - Fatigue may complicate wanting to complete a questionnaire in patients with cancer - Patient dropout during the implementation phase - It might be possible that the patient considers the MyPath invitation per SMS as insufficiently confidential, therefore it is important to provide sufficient context and information in advance eg a flyer with a clear step-by-step plan with one of the steps referring to the SMS - It might be confronting if a patient is recently confronted with the diagnosis of cancer and then receives information about patient-centred care or palliative care immediately
	Caregivers	Workload	<ul style="list-style-type: none"> - Adjusting the tool to the healthcare staff's current workload - A lot of admin-related tasks for nursing staff already
		Attitudes and expectations	<ul style="list-style-type: none"> - Making a change in practice is sometimes difficult for staff (importance of emphasizing the benefits of the project)
		Follow-up	<ul style="list-style-type: none"> - False referral to a psychologist or other health care provider ('false positive')
Target group	Patient group		<ul style="list-style-type: none"> - Lung cancer patients (due to increased age) often show comorbidities (not only cancer-related symptoms)
Perceived opportunities			

Digital solution	Goal		<ul style="list-style-type: none"> - Digital communication between professional carers instead of face-to-face communication might improve interdisciplinary communication, work efficiency and patient-centred care
	Content	PROMs/PREMs	<ul style="list-style-type: none"> - MyPath motivates clinicians to address different health topics during the consultation and facilitates clinicians to provide more patient-centred care -
		Guidelines	<ul style="list-style-type: none"> - Use of evidence-based guidelines for clinical practice
	Design	Interface	<ul style="list-style-type: none"> - User-friendly interface created together with the target population and end-users
		Function	<ul style="list-style-type: none"> - We imagine the application will have the same layout for all cancers, and centres, and be available in multiple languages. It will have the same basic main menu, but depending on cancer type, it will have some additional sections/acknowledged challenges (breast pain (breast cancer); difficulty breathing (lung cancer, etc). Perhaps someone should create a spreadsheet of all cancers and create a list of common problems, in cells and rows for clear visualization of how we could integrate this. - Representation of evolutions in reported symptoms
	Flexibility		<ul style="list-style-type: none"> - The final toolkit can be easily adapted for use in other departments
	Integration	Electronic Health Record	<ul style="list-style-type: none"> - Integration into EPD - Own medical record system cf. Brussels, not dependent on commercial organizations
	Sustainability		<ul style="list-style-type: none"> - Use of implementation science research
Data availability		<ul style="list-style-type: none"> - Data is available for all care staff (referral is not only the oncologist's responsibility/referral as a shared responsibility) 	
Macroenvironment	Economics		<ul style="list-style-type: none"> - Submitting applications for extra local funding
	Legal Ethics		<ul style="list-style-type: none"> - The willingness of legal and ethical experts to help us with the MyPath preparation and implementation
Organisational	Vision		<ul style="list-style-type: none"> - The hospital's vision includes digital innovation and patient-centred care
	Care organisation		<ul style="list-style-type: none"> - Digital innovation is well-funded and organized - Oncology care is centralized (Brussels) - MyPath messages can be linked e.g. to the text message that patients receive to remind them of the appointment they have
	Existing technology		<ul style="list-style-type: none"> - Own medical record system, not dependent on commercial organizations (Brussels)

			<ul style="list-style-type: none"> - Existing platforms exist, which measure and give feedback on a person’s well-being (psychological, social, physical) (e.g., “87%” is a London-based company) whose model is tested. Would be used an existing model and include cancer-specific parts (e.g. managing fear, shock, and communication around psychological, social, financial, and practical aspects of living with and treating cancer). The common ones are denial (shock); managing fear of death (fear); supporting people’s communication around cancer to their loved ones (communication); anticipated grief (communication); managing new reality (shock); managing financial practicalities (fear).
Social/human	Patients	Filling out the questionnaire	<ul style="list-style-type: none"> - Important to emphasize the benefits of using the MyPath tool - MyPath can be completed when patients are in the waiting room prior to a consultation
		Motivation/engagement	<ul style="list-style-type: none"> - Might be facilitating if patients will be guided when using the MyPath tool (e.g. oncocoach), oncological coaches indicate to have time for doing this - MyPath can lower the threshold for patients who experience difficulties when expressing their needs
	Caregivers	Use	<ul style="list-style-type: none"> - Important to emphasize the benefits of using the MyPath tool
	User input		<ul style="list-style-type: none"> - Co-creation with the intended end-users and other relevant stakeholders and training/support will be really important for the adoption and implementation of the MyPath tool
	Primary care		<ul style="list-style-type: none"> - Health professional carers think that it might be interesting to explore options to involve primary care as well (eg family physician) e.g. by giving information sessions about MyPath

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4 Appendices



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4.1 Appendix 1 - Technology, People, Organizations, and Macroevironmental factors (TPOM) framework

Factor and dimension	Description
Technological factors	
Usability	What is the ease of use and learnability of the technology?
Performance	Does the technology function as intended by developers?
Adaptability and flexibility	Can system design be changed to suit emerging needs?
Dependability	Is the system reliable and stable?
Data availability, integrity, and confidentiality	Is data in the system available, accessible, and usable for those who need it?
Data accuracy	Is the data in the system accurate?
Sustainability	Is use of the technology sustainable?
Security	Is the system secure?
Social/human factors	
User satisfaction	Who are the users? Are users satisfied with the technology?
Complete/correct use	Are features and functionality implemented and used as intended?
Attitudes and expectations	What benefits do users expect from using the technology and how can these be measured?
Engagement	Are users actively engaged in implementation, adoption, and optimization?
Experiences	Do users have negative experience with previous technologies?
Workload/benefits	Are the benefits and efforts relatively equal for all stakeholders?
Work processes	Does the system change relationships with patients, patterns of communication, and professional responsibilities (eg, increase of administrative tasks)?
User input in design	Is there effective communication between designers, information technology staff, and end users, as well as between management and end users?
Organizational context	
Leadership and management	Are management structures to support the implementation adequate?
Communication	Are aims, timelines, and strategy communicated?
Timelines	Are implementation timelines adequate?
Vision	What benefits do organizations expect from implementing the technology and how can these be measured? Is a coherent and realistic vision driving developments?
Training and support	Is the training adequate and realistic?
Champions	Are champions and boundary spanners utilized?
Resources	Is implementation adequately resourced? (includes technology, change management, and maintenance)
Monitoring and optimization	Is system performance and use monitored and optimized over time? Are lessons learned captured and incorporated in future efforts?
Wider macroenvironment	
Media	How is the technology viewed by the media and by the public? How does the organization view/manage media relations?
Professional groups	How is the technology viewed by professional groups?
Political context	What benefits do policymakers expect from the technology and how can these be measured? What is the national approach to achieving interoperability and does the system align with this? Is there a coherent vision, consistent approach, and a clear direction of travel, allowing a degree of local input?
Economic considerations and incentives	Are there clear incentives for organizations and users to implement? (eg, improvements in quality of care) Is sufficient funding in place to support the initiative?
Legal and regulatory aspects	Have legal and regulatory frameworks been established?
Vendors	Is vendor management effectively organized?
Measuring impact	Are various stakeholders working together to define, validate, test, and refine outcome measures and measurement strategies? Are outcome measures important, clinically acceptable, transparent, feasible, and usable?

4.2 Appendix 2 – interview guides

4.2.1 People with cancer

Participant introduction and set-up

- **Introduction of researcher** to the participant
- We are currently developing a digital tool ‘**MyPath**’ with other researchers from Europe to improve care for patients with cancer. The tool aims to 1) allow persons with cancer to share data about their health and well-being (e.g., pain, nutrition, psychosocial) with healthcare professionals and 2) to translate this data into tailored care. In the development phase, we are undertaking **in-depth qualitative interviews** to explore the perceptions of healthcare providers, people with cancer and their family carers towards such digital solutions, to understand how current clinical practice in the hospital is organized, and what potential barriers/opportunities are perceived for implementing the digital tool.
- The interview will last up to approximately **one hour**, but can be as short as you like.
- We will **audiotape** this interview and in a next stage we will write up what you said word-for-word. When writing this up, we will take out anything that identifies you, or where you live or anyone else that you mention, so it will all be **pseudonymized**. Also, everything we talk about here will be **confidential**. We do this to be able to analyse in the group what all participants have said. Without doing this, we might forget important things you have said.
- There are **no right or wrong answers**, so please say any thoughts that spring to mind, even if you think they might not be important. Your views are really important so the more you can tell us about it the better.
- If you have **any questions** while we are going through, I will be very happy to answer them.
- We can take a **break** at any time you like, please just let know and I can pause the recording.
- Is there anything you would like to ask me at the moment? Do you have any questions about any aspects of the interview?
- Collect signed consent forms and survey.
- **If you are happy, I will start the interview recording now.**

Topic guide	Question & prompts
Patient-centered care (introduction)	<p>Questions:</p> <ol style="list-style-type: none"> 1. Can you tell me something more about you, your condition and care journey? <ul style="list-style-type: none"> ○ When do you come to the hospital and for how long? ○ With what professional carers do you have contact? ○ Which symptoms do you experience? What are specific needs? ○ In what ways do you express these needs/symptoms to healthcare professionals? <p>To whom?</p> <ul style="list-style-type: none"> ○ Which needs/symptoms are addressed/remain unaddressed? <p><i>In the MyPath project, the focus is on patient-centered care as an addition to anti-cancer care before, during, or after anti-cancer treatment. Patient-centred care means putting the patient with cancer in the center. Patient-centered means that specific attention is devoted to symptoms, functions, family, social, psychological, or existential issues. It also includes involving the patient and his/her needs and preferences in care decisions.</i></p> 2. What are your thoughts about the level of today’s patient-centered care? <ul style="list-style-type: none"> ○ If necessary, how do you think it can be improved?
Digital system (transition)	<p><i>The MyPath project aims to improve patients-centred care for people with cancer by means of technology. There will be a new digital system for people with cancer and we know from previous studies many have opinions about it.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 3. In what way are you currently using digital systems during your treatment? <ul style="list-style-type: none"> ○ Which systems do you use (e.g., website hospital, apps)? ○ For what purposes? ○ How do you use them? Individually? Together with someone? ○ What do you like/dislike about these digital tools? ○ Which ones are available but you don’t use (much)? ○ Benefits? Disadvantages?

<p>Digital outcome measures & care pathways (key)</p>	<p><i>To be specific, using an app on a mobile or computer, a patient with cancer can provide information about this/her health before a consultation with a healthcare professional. The patient is asked questions about pain, nutrition, anxiety, etc. This information automatically transfers to the hospital's electronic health record in which a report of the entered data will then be available for the healthcare providers. The person's information is intended to be visible to various healthcare providers in the hospital who are following up the person with cancer. During a consultation between a patient and a healthcare provider (e.g., oncologist), this information is further explored. In MyPath, such data will be incorporated into a customized treatment plan (care pathway) for each individual patient.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 4. What are your thoughts about it? <ul style="list-style-type: none"> ○ What do you think of measuring health among patients with cancer in a systematic way? It could be about pain, nausea, nutrition, anxiety, emotional well-being and so on. ○ What do you think of custom-made care plans? 5. In your case, how do you think the MyPath tool can impact your symptoms/needs? 6. How would you like to use this digital tool? When? How frequent? 7. Do you think you need support using the tool? If yes, which type of support? (e.g., guidance from healthcare professionals) 8. Why would you use this tool? Why not? <ul style="list-style-type: none"> ○ What might make using the tool more difficult or easier for you? 9. What would the system need to entail to be useful? 10. What are the expected implications for you? <ul style="list-style-type: none"> ○ Benefits/disadvantages?
<p>Ending</p>	<p><i>If possible: give summary of the most important points covered here, ask if they agree with it/would like to add anything.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 11. Any other comments? 12. Any questions?

Thank you for your participation.

4.2.2 Family carers

Participant introduction and set-up

- **Introduction of researcher** to the participant
- We are currently developing a digital tool 'MyPath' with other researchers from Europe to improve care for patients with cancer. The tool aims to 1) allow persons with cancer to share data about their health and well-being (e.g., pain, nutrition, psychosocial) with healthcare professionals and 2) to translate this data into tailored care. In the development phase, we are undertaking **in-depth qualitative interviews** to explore the perceptions of healthcare providers, people with cancer and their family carers towards such digital solutions, to understand how current clinical practice in the hospital is organized, and what potential barriers/opportunities are perceived for implementing the digital tool.
- The interview will last up to approximately **one hour**, but can be as short as you like.
- We will **audiotape** this interview and in a next stage we will write up what you said word-for-word. When writing this up, we will take out anything that identifies you, or where you live or anyone else that you mention, so it will all be **pseudonymized**. Also, everything we talk about here will be **confidential**. We do this to be able to analyse in the group what all participants have said. Without doing this, we might forget important things you have said.
- There are **no right or wrong answers**, so please say any thoughts that spring to mind, even if you think they might not be important. Your views are really important so the more you can tell us about it the better.
- If you have **any questions** while we are going through, I will be very happy to answer them.
- We can take a **break** at any time you like, please just let know and I can pause the recording.
- Is there anything you would like to ask me at the moment? Do you have any questions about any aspects of the interview?
- Collect signed consent forms and survey.

- [If you are happy, I will start the interview recording now.](#)

Topic guide	Question & prompts
Patient-centered care (introduction)	<p>Questions:</p> <ol style="list-style-type: none"> 1. What is your relation with the relative diagnosed with cancer and how are you involved in caring for him/her? 2. In what way do you help him/her in processing information and communicating with professional carers? <p><i>In the MyPath project, the focus is on patient-centered care as an addition to anti-cancer care before, during, or after anti-cancer treatment. Patient-centred care means putting the patient with cancer in the center. Patient-centered means that specific attention is devoted to symptoms, functions, family, social, psychological, or existential issues. It also includes involving the patient and his/her needs and preferences in care decisions.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 3. What are your thoughts about the level of today’s patient-centered care? <ul style="list-style-type: none"> ○ If necessary, how do you think it can be improved?
Digital system (transition)	<p><i>The MyPath project aims to improve patients-centred care for people with cancer by means of technology. There will be a new digital system for people with cancer and we know from previous studies many have opinions about it.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 4. In what way are you currently using digital systems related to the treatment of your family member? <ul style="list-style-type: none"> ○ Which systems do you use (e.g., website hospital, apps)? ○ For what purposes? ○ How do you use them? Individually? Together with someone? ○ What do you like/dislike about these digital tools? ○ Which ones are available but you don’t use (much)? ○ Benefits? Disadvantages?
Digital outcome measures & care pathways (key)	<p><i>To be specific, using an app on a mobile or computer, a patient with cancer can provide information about this/her health before a consultation with a healthcare professional. The patient is asked questions about pain, nutrition, anxiety, etc. This information automatically transfers to the hospital’s electronic health record in which a report of the entered data will then be available for the healthcare providers. The person’s information is intended to be visible to various healthcare providers in the hospital who are following up the person with cancer. During a consultation between a patient and a healthcare provider (e.g., oncologist), this information is further explored. In MyPath, such data will be incorporated into a customized treatment plan (care pathway) for each individual patient.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 5. What are your thoughts about it? <ul style="list-style-type: none"> ○ What do you think of measuring health among patients with cancer in a systematic way? It could be about pain, nausea, nutrition, anxiety, emotional well-being and so on. ○ What do you think of custom-made care plans? 6. How do you think the MyPath tool can be used? When? How frequent? <ul style="list-style-type: none"> ○ What could be your role? 7. Do you think your family member will need support? If yes, which type of support? 8. Do you think your family member will use the tool? Why (not)? <ul style="list-style-type: none"> ○ In your opinion, what might make using the tool easier or more difficult? 9. What would the system need to entail to be useful? 10. What are the expected implications for you/your family member? <ul style="list-style-type: none"> ○ Benefits/disadvantages?
Ending	<p><i>If possible: give summary of the most important points covered here, ask if they agree with it/would like to add anything.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 11. Any other comments? 12. Any questions?

Thank you for your participation.

4.2.3 Medical and allied health professionals working with people with cancer

Participant introduction and set-up

- **Introduction of researcher** to the participant
- We are currently developing a digital tool ‘**MyPath**’ with other researchers from Europe to improve patient-centred care for patients with cancer. The tool aims to 1) allow individuals with cancer to share information about their health and well-being (e.g., pain, nutrition, psychosocial) and 2) to translate this data into digital patient-centred care pathways and interventions. In the development phase, we are undertaking **in-depth qualitative interviews** to explore attitudes towards digitally-enabled patient-centred care pathway, to understand how current clinical practice in the hospital is organized, and what potential barriers/opportunities for implementation of digital patient-centred care pathways are perceived.
- The interview will last up to approximately **one to one and a half hour**, but can be as short as you like.
- We will **audiotape** this interview and in a next stage we will write up what you said word-for-word. When writing this up, we will take out anything that identifies you, or where you live or anyone else that you mention, so it will all be **pseudonymized**. Also, everything we talk about here will be **confidential**. We do this to be able to analyse in the group what all participants have said. Without doing this, we might forget important things you have said.
- There are **no right or wrong answers**, so please say any thoughts that spring to mind, even if you think they might not be important. Your views are really important so the more you can tell us about it the better.
- If you have **any questions** while we are going through, I will be very happy to answer them.
- We can take a **break** at any time you like, please just let know and I can pause the recording.
- Is there anything you would like to ask me at the moment? Do you have any questions about any aspects of the interview?
- Collect signed consent forms and survey.
- If you are happy, I will start the interview recording now.
- Can you tell me something more about your background and role in the hospital?

Topic guide	Question & prompts
Patient-centered care (introduction)	<p><i>Were you able to watch the video? In the MyPath project, the focus is on patient-centered care as an addition to anti-cancer care before, during, or after anti-cancer treatment. Patient-centred care means putting the patient with cancer in the center. Patient-centered care is related to the person having cancer, with specific attention to symptoms, functions, family, social, psychological, or existential issues. It also includes involving the patient and his/her needs and preferences in care decisions.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 1. Can you tell me something more about your work related to providing patient centred care for people with cancer? <ul style="list-style-type: none"> ○ If your patient has e.g., pain/depressive symptoms etc., what do you do? ○ What is facilitating your work? What works well? ○ What is hindering your work? What is challenging? 2. What are your thoughts about the level of today’s patient-centered care? <ul style="list-style-type: none"> ○ If necessary, how do you think it can be improved?
Digital system (transition)	<p><i>The MyPath project aims to improve patient-centred care for people with cancer by means of technology. There will be a new digital system for people with cancer and we know from previous studies many have opinions about it.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 1. In what way are you currently using digital systems in your work to promote patient centred oncology care? <ul style="list-style-type: none"> ○ Which systems do you use (e.g., EHRs)? ○ For what purposes? ○ How do you use them? Individually? Across multi-disciplinary teams? With patients? ○ Which ones are available but you don’t use (much)? ○ Benefits/disadvantages?

	<p>2. How is the current culture/working environment regarding changing practices and implementing new systems where you work?</p>
Digital outcome measures & care pathways (key)	<p><i>We will develop a digital tool through which we will survey so-called digital patient-reported outcome measures (PROMs)/patient-reported outcome measures (PREMs). To be specific, using an app on a mobile or computer, a patient with cancer can provide information about his/her health status before a consultation. The patient is asked questions about pain, nutrition, anxiety, etc. The plan is to automatically transfer that data to your workstation (EHR) from the hospital. A dashboard showing a report of the entered data will then be available for the healthcare providers/for you, showing both current status and changes over time. During a consultation between a patient and a healthcare provider (e.g., oncologist), this information is further explored. In MyPath, such digital data and clinical data will be incorporated into a treatment plan (care pathway) based on algorithms to tailor each individual patient's plan (pathways). These algorithms will be linked to suggested evidence-based measures based on the most recent guidelines.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 3. What are your thoughts about it? <ul style="list-style-type: none"> ○ What do you think of digital PROMs/PREMs and/or measuring these in a systematic way? ○ What do you think of getting such custom-made plans for your patients? 4. How could it be integrated within your workflow? <ul style="list-style-type: none"> ○ How could you use such data (in the consultation)? How do you envisage using this new system (in the consultation)? ○ How could other healthcare providers be involved? 5. Why would you use this tool? Why not? <ul style="list-style-type: none"> ○ In your opinion, what are the barriers and facilitators? 6. What would the pathways & digital PROMs/PREMs need to entail to be useful? 7. What are the expected implications for you/patients? <ul style="list-style-type: none"> ○ Benefits/disadvantages? 8. What conditions/resources are needed for this tool to be used/implemented? (e.g., practical training, implementation leaders)
Ending	<p><i>If possible: give summary of the most important points covered here, ask if they agree with it/would like to add anything.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 9. Any other comments? 10. Any questions? 11. Is there anyone else we can speak to?

Thank you for your participation.

4.2.4 Organisational leaders and managers

Participant introduction and set-up

- **Introduction of researcher** to the participant
- We are currently developing a digital tool 'MyPath' with other researchers from Europe to improve patient-centred care for patients with cancer. The tool aims to 1) allow individuals with cancer to share data about their health and well-being (e.g., pain, nutrition, psychosocial) and 2) to translate this data into digital patient-centred care pathways and interventions. In the development phase, we are undertaking **in-depth qualitative interviews** to explore attitudes towards digitally-enabled patient-centred care pathway, to understand how current clinical practice in the hospital is organized, and what potential barriers/opportunities for implementation of digital patient-centred care pathways are perceived.
- The interview will last up to approximately **one to one and a half hour**, but can be as short as you like.
- We will **audiotape** this interview and in a next stage we will write up what you said word-for-word. When writing this up, we will take out anything that identifies you, or where you live or anyone else that you mention, so it will all be **pseudonymized**.
- Also, everything we talk about here will be **confidential**. We do this to be able to analyse in the group what all participants have said. Without doing this, we might forget important things you have said.

- There are **no right or wrong answers**, so please say any thoughts that spring to mind, even if you think they might not be important. Your views are really important so the more you can tell us about it the better.
- If you have **any questions** while we are going through, I will be very happy to answer them.
- We can take a **break** at any time you like, please just let know and I can pause the recording.
- Is there anything you would like to ask me at the moment? Do you have any questions about any aspects of the interview?
- Collect signed consent forms and survey.
- If you are happy, I will start the interview recording now.
- Can you tell me something more about your background and role in the hospital?

Topic guide	Question & prompts
Patient-centered care (introduction)	<p><i>Were you able to watch the video? In the MyPath project, the focus is on patient-centered care as an addition to anti-cancer care before, during, or after anti-cancer treatment. Patient-centred care means putting the patient with cancer in the center. Patient-centered care is related to the person having cancer, with specific attention to symptoms, functions, family, social, psychological, or existential issues. It also includes involving the patient and his/her needs and preferences in care decisions.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 1. If applicable: Can you tell me something more about your work (or the work of your team) related to providing patient centred care for people with cancer? <ul style="list-style-type: none"> ○ If a patient has e.g., pain/depressive symptoms etc., what do you/does your team do? ○ What is facilitating your work? What works well? ○ What is hindering your work? What is challenging? 2. What are your thoughts about the level of today’s patient-centered care? <ul style="list-style-type: none"> ○ If necessary, how do you think it can be improved?
Digital system (transition)	<p><i>The MyPath project aims to improve patient-centred care for people with cancer by means of technology. There will be a new digital system for people with cancer and we know from previous studies many have opinions about it.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 3. If applicable: In what way are you (or the team you are managing) currently using digital systems in your work to promote patient centred oncology care? <ul style="list-style-type: none"> ○ Which systems do you use (e.g., EHRs)? ○ For what purposes? ○ How do you use them? Individually? Across multi-disciplinary teams? With patients? ○ Which ones are available but you don’t use (much)? ○ Benefits? Disadvantages? 4. How is the current culture/working environment regarding changing practices and implementing new systems where you work?
Digital outcome measures & care pathways (key)	<p><i>We will develop a digital tool through which we will survey so-called digital patient-reported outcome measures (PROMs)/patient-reported outcome measures (PREMs). To be specific, using an app on a mobile or computer, a patient with cancer can provide information about his/her health status before a consultation. The patient is asked questions about pain, nutrition, anxiety, etc. The plan is to automatically transfer that data to your workstation (EHR) from the hospital. A dashboard showing a report of the entered data will then be available for the healthcare providers/for you, showing both current status and changes over time. During a consultation between a patient and a healthcare provider (e.g., oncologist), this information is further explored. In MyPath, such digital data and clinical data will be incorporated into a treatment plan (care pathway) based on algorithms to tailor each individual patient’s plan (pathways). These algorithms will be linked to suggested evidence-based measures based on the most recent guidelines.</i></p> <p>Questions:</p> <ol style="list-style-type: none"> 5. What are your thoughts about it? <ul style="list-style-type: none"> ○ What do you think of digital PROMs/PREMs and/or measuring these in a systematic way? ○ What do you think of getting such custom-made plans for patients? 6. If applicable: How could it be integrated within your workflow (or that of your team)?

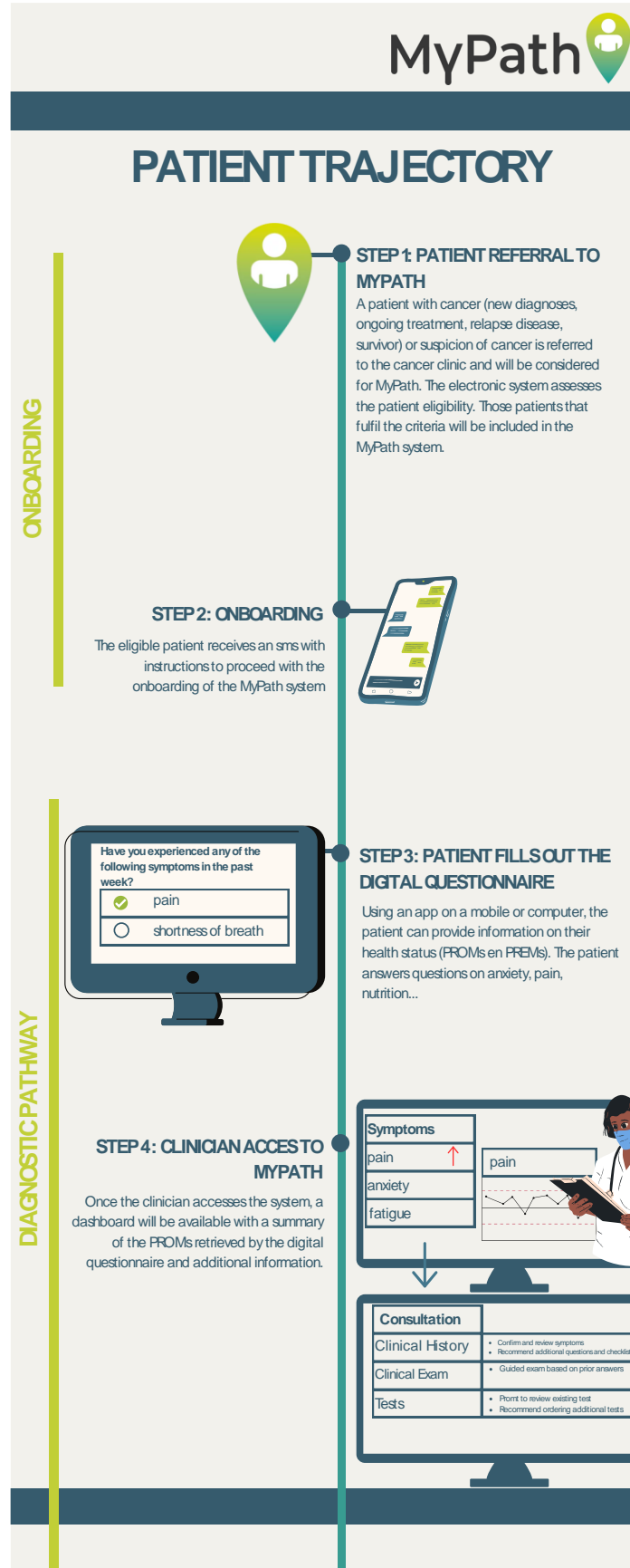
	<ul style="list-style-type: none"> ○ How could you use such data (in the consultation)? How do you envisage using the new system (in the consultation)? ○ How could other healthcare providers be involved? <p>7. If applicable: Which legal/political/ethical/financial aspects might influence the adoption/implementation/maintenance of MyPath?</p> <p>8. If applicable: Why would you (your team) use this tool? Why not?</p> <ul style="list-style-type: none"> ○ In your opinion, what are the barriers and facilitators? <p>9. If applicable: What would the pathways & digital PROMs/PREMs need to entail to be useful?</p> <p>10. What are the expected implications for patients/healthcare professionals?</p> <ul style="list-style-type: none"> ○ Benefits/disadvantages? <p>11. If applicable: What is needed for using the tool at your hospital/ward? (e.g., practical training, implementation leaders)</p>
Ending	<p><i>If possible: give summary of the most important points covered here, ask if they agree with it/would like to add anything.</i></p> <p>Questions:</p> <p>12. Any other comments?</p> <p>13. Any questions?</p> <p>14. Is there anyone else we can speak to?</p>

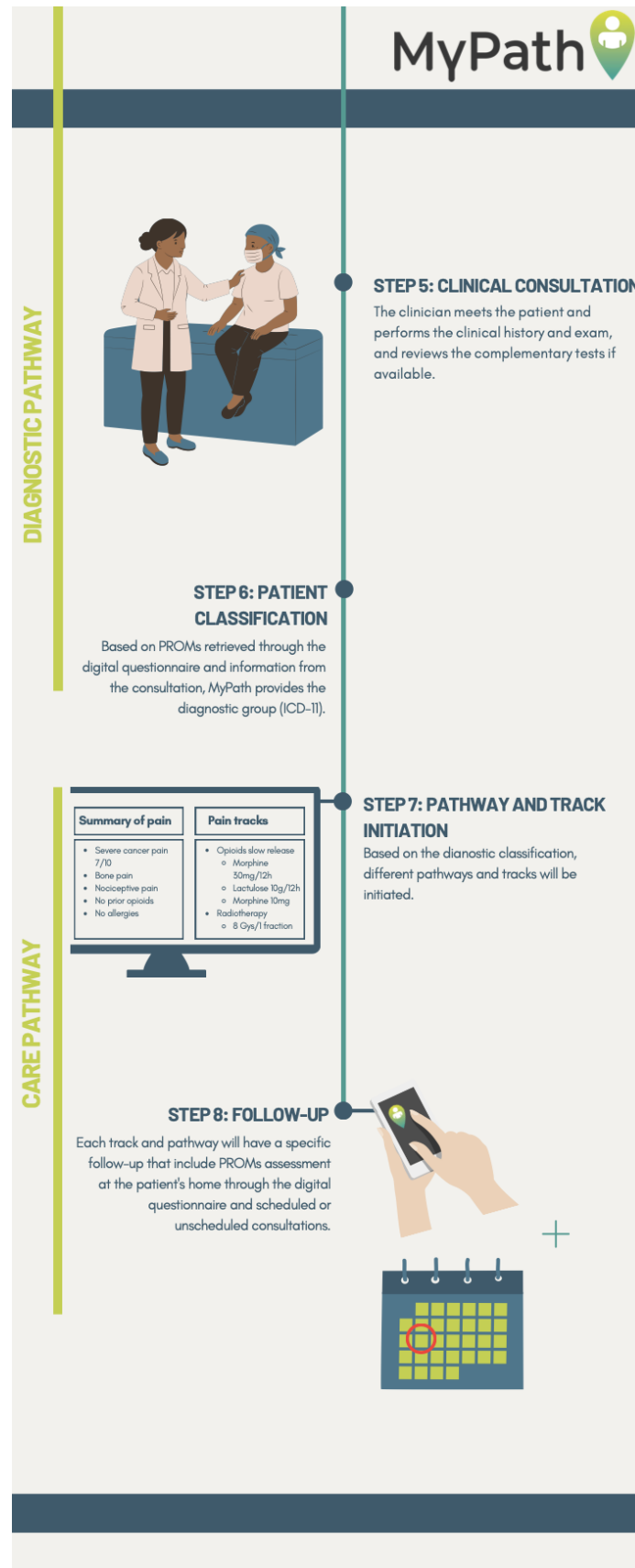
Thank you for your participation.

4.3 Appendix 3 – sociodemographic survey

Date	
Code participant	
Ageyears
Sex	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> X
Involved as...	<input type="checkbox"/> Person with cancer Cancer diagnosis: <input type="checkbox"/> Family carer Relation with your family member: Cancer diagnosis of your family member: <input type="checkbox"/> Management/organisational leader in the hospital Specify: Years of working experience: <input type="checkbox"/> Medical health professional: Specify: Years of working experience with people with cancer: <input type="checkbox"/> Allied health professional: Specify: Years of working experience with people with cancer: <input type="checkbox"/> Other (specify): Years of working experience with people with cancer:

4.4 Appendix 4 – interview folder





4.5 Appendix 5 – interview cards

Patient-centred care

- Putting **patients at the center**
- Specific attention to **symptoms, functions, family, social, psychological, or existential issues**
- Involving the **patient and his/her expressed needs and preferences** in care decisions



Digital system

- Goal MyPath: to **improve patients-centred care** for people with cancer by means of **technology**
- A new digital system for **people with cancer** (app on a mobile or computer)



PROMS/PREMS

- **PROMS** = patients' perception of their own health
 - E.g. pain, anxiety, nutrition...
- **PREMS** = patients' perception of their experiences with care
 - E.g. satisfaction, subjective experiences ...
- Transfer of data to the workstation (electronic health record)
- Exploration during **consultation with a healthcare professional**



Care Pathways

- Digital data and clinical data will be incorporated into **care pathways**
- On the basis of **algorithms** for each individual
- **Evidence-based** guidelines

