



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

Project no. 101057514

**Deliverable D1.1
Stakeholder requirement report**

Version 01

WP1 – CO-DESIGN – MyPath structure and contents

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Contents

Revision history	2
Contents	3
List of Figures.....	4
List of Tables	4
Partner short names.....	5
Abbreviations.....	6
Executive Summary	7
1 Background and objective	8
1.1 Objectives of Stakeholder requirement report.....	8
2 Examples from existing ePROMs solutions: what can we learn for developing MyPath?	9
2.1 Example 1 eRAPID: Towards safer delivery and monitoring of cancer treatments. Electronic patient self-Reporting of Adverse-events (AE): Patient Information and aDvice.....	9
2.1.1 Overview of eRAPID.....	9
2.1.2 Summary of eRAPID approach and methods	9
2.1.3 Key learning points from eRAPID.....	11
2.2 Example 2: Eir: A Computer-Based Tool for Patient-Reported Outcome Measures in Cancer.....	12
2.2.1 Overview of Eir	12
2.2.2 Summary of Eir development.....	12
2.3 Example 3: Cancer Care Ontario (CCO) Patient-Reported Outcomes and Symptom Management Program	13
2.3.1 Overview of CCO PROMs program	13
3 Developing MyPath pathways: The story so far	14
3.1 Definitions and terminology	14
3.1.1 Standardized Care Pathways (SCP).....	14
3.1.2 Patient-centered care pathways (PCCPs)	15
3.1.3 MyPath- digital Patient Centred Care Pathways (dPCCP).....	15
3.2 Developing MyPath dPCCP – A step wise approach exemplified with the pain pathway.....	17
4 Summary and plans for next steps	19
References	20

List of Figures

Figure 1: Overview of eRAPID system for remote monitoring of patients during cancer treatment	10
Figure 2: Key components that make eRAPID a complex intervention.....	10
Figure 3: The EIR patient and Health Care Professional modules	13
Figure 4: Examples from MyPath launch meeting brainstorming activity on the design and structure of digital Patient Centered Care Pathways (dPCCPs)	16
Figure 5: Overview of MyPath dPCCP elements.....	17
Figure 6: Overview of MyPath pipeline to pathway development	18

List of Tables

Table 1: Summary of eRAPID main findings and considerations for MyPath	11
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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
ASCO	American Society of Clinical Oncology
CCO	Cancer Care Ontario
dPCCP	digital Patient Centred Care Pathway
EMA	European Medicines Agency
ESAS	Edmonton Symptom Assessment Scale
ePROMs	Electronic Patient-Reported Outcome Measures
eRAPID	Electronic patient self-Reporting of Adverse Events: Patient Information and aDvice
ESMO	European Society for Medical Oncology
FDA	Food and Drug Administration
HCP	Health Care Professional
ICT	Information and Communications Technology
PCC	Patient-Centred Care
PCCP	Patient-Centered Care Pathway
PROMs	Patient-Reported Outcome Measures
RCT	Randomised Controlled Trial
SCP	Standardized Care Pathways
WHO	World Health Organisation

Executive Summary

This report presents deliverable D1.1, an initial Stakeholder Requirement Report prepared as part of MyPath Work Package 1.

Need for the deliverable

In oncology practice the routine use of systematic pathways to aid the assessment and management of pain, fatigue, nutrition, physical and social function, and psychological distress are lacking. Electronic approaches offer a solution to assist the delivery of these pathways in clinical practice. There is a growing evidence base supporting the value of incorporating the use of electronic or digital solutions and patient reported outcome measures into the care of people living with and beyond cancer. However, in practice:

- few cancer centres and services internationally have successfully adopted electronic approaches as part of everyday practice;
- there is considerable variation in how digital interventions have been designed and the features and functionality they provide (from both the patient and care professionals' perspectives);
- the majority of platforms have focussed on assessing symptoms and toxicity related to cancer and treatment;
- no known digital solutions are currently available that provide a dynamic and comprehensive patient centred approach (that adapts assessments, management guidance and ongoing monitoring pathways based on the needs and problems experienced by patients).

This report provides an overview of how key methodology and learning points from previous ePROMs projects for cancer patients are being built upon to support the evolution of content and functionality of MyPath digital Patient Centred Care pathways (dPCCPs). MyPath dPCCPs will be designed with aim of improving the routine assessment and dynamic management of pain, fatigue, nutrition, physical and social function, and psychological distress throughout the cancer trajectory and in parallel to anti-cancer and cancer-related treatment processes.

The initial framework and guidance for MyPath pathway development are summarized in this report (using the pain pathway as an exemplar) along with the proposed plans for further pathway development and stakeholder input.

Objectives of the deliverable

This report outlines the foundations of the MyPath consortium's approach to designing the structure and content of digital Patient Centred Care pathways.

Outcomes

The report provides a:

- top level overview of how existing evidence and knowledge from the development and implementation of previous patient centred ePROMs solutions is informing the creation of MyPath dPCCPs;
- summary of the guiding framework underpinning the development MyPath pathways.

Next steps

In the coming months, our focus will be to complete the initial prototypes of each pathway. Further work with MyPath stakeholders and collaborators will be conducted to determine how pathway structure and the content will require refinement to meet the specific needs of the project pilot centres across cancer groups and service types. Results and feedback from pilot testing will use multi-professional health care providers, researchers, and ICT experts locally and within MyPath, as well as synthetic and real patients, as the data sources. All these are regarded as stakeholders in the development and subsequent use of the pathways.

1 Background and objective

Patient-reported outcome measures (PROMs) constitute the mainstay of patient-centred care. PROMs denote all information that comes directly from the patients, with wellbeing, prevalence and intensity of symptoms, level of functioning, preferences and wishes for care being particularly relevant in health care. As such PROMs supplement clinician observations and objective findings. Major stakeholders, e.g., European Medicines Agency (EMA) and Food and Drug Administration (FDA) require the use of PROMs in clinical studies, while European Society for Medical Oncology (ESMO), American Society of Clinical Oncology (ASCO) and World Health Organisation (WHO) recommend systematic use of PROMs in all phases of a cancer trajectory.

In oncology practice the routine use of PROMs as part of systematic pathways to aid the assessment and management of pain, fatigue, nutrition, physical and social function, and psychological distress are lacking. Electronic approaches offer a potential solution to assist the delivery of these pathways into clinical practice. There is a growing evidence base supporting the value of incorporating the use of electronic or digital solutions and patient reported outcome measures into the care of people living with and beyond cancer. However, in practice:

- few cancer centres and services internationally have successfully adopted electronic approaches as part of everyday practice (1);
- there is considerable variation in how digital interventions have been designed and the features and functionality they provide (from both the patient and care professionals perspectives) (2);
- the majority of platforms have focussed on assessing symptoms and toxicity related to cancer and treatment;
- no known digital solutions are currently available that provide a dynamic and comprehensive patient centred approach (that adapts assessments, management guidance and ongoing monitoring pathways based on the needs and problems experienced by patients).

The MyPath project brings together an experienced consortium of clinical, academic, patient, public and IT stakeholders. Collectively the consortium will design and implement a dynamic and adaptive system to support the use of digital Patient Centred Care Pathways (dPCCP) to improve the routine assessment and management of pain, fatigue, nutrition, physical and social function, and psychological distress throughout the cancer trajectory. In this context, the digitally supported pathway is defined as the systematic assessment and plan for individual patient-centred care and follow-up. The basic premise is that PROMs guide the selection and content of patient-centred care pathways which will function in parallel along side cancer treatment pathways.

This report provides an overview of how key methodology and learning points from previous ePROMs projects for cancer patients are being built upon to support the evolution of content and functionality of MyPath dPCCPs. The initial framework and guidance for pathway development are summarized (using the pain pathway as an exemplar) along with the proposed plans for further pathway development and stakeholder input.

1.1 Objectives of Stakeholder requirement report

This report outlines the foundations of the MyPath consortium's approach to designing the structure and content of novel digital Patient Centred Care pathways for future implementation across the project's participating cancer sites. In the following sections we provide an overview of how previous examples of digital patient centred care approaches are being used to help guide the methods and work being undertaken.

2 Examples from existing ePROMs solutions: what can we learn for developing MyPath?

As evidenced in MyPath Deliverable 1.2 a range of electronic platforms and digital approaches for supporting the assessment and care of patients have been developed internationally to date. The field continues to grow with the increasing availability of software solutions, patient facing mobile apps and interest in the collection and use of patient reported data. Expertise and knowledge available from within the MyPath consortium and other international cancer projects can be used as valuable building blocks in MyPath. In this section examples from three such projects are described to highlight how information and methods can be taken forward in MyPath pathway design.

2.1 Example 1 eRAPID: Towards safer delivery and monitoring of cancer treatments. Electronic patient self-Reporting of Adverse-events (AE): Patient Information and aDvice

2.1.1 Overview of eRAPID

The eRAPID research programme was funded in the UK by the National Institute for Health and Care Research (NIHR) between 2013-2019. The aim of this work was to design and evaluate an electronic system to better support the monitoring and management of adverse events experienced by patients during cancer treatment. (3)

2.1.2 Summary of eRAPID approach and methods

Figure 1 provides a visual overview of how the eRAPID system was designed to function. In summary patients are given access to an online/web-based platform where they can complete regular self-assessments of their symptoms and side effects during treatment (items based on the Common Toxicity Criteria for Adverse Events). An underlying scoring algorithm determines the level of advice patients receive on completing the self-report.

In addition, eRAPID was also designed so that:

- patient reports were available to review in the patients' individual electronic hospital records;
- email alerts for severe symptoms/adverse events could be sent to selected health professionals;
- patients were able to review and view their symptom report profiles and management advice over time.

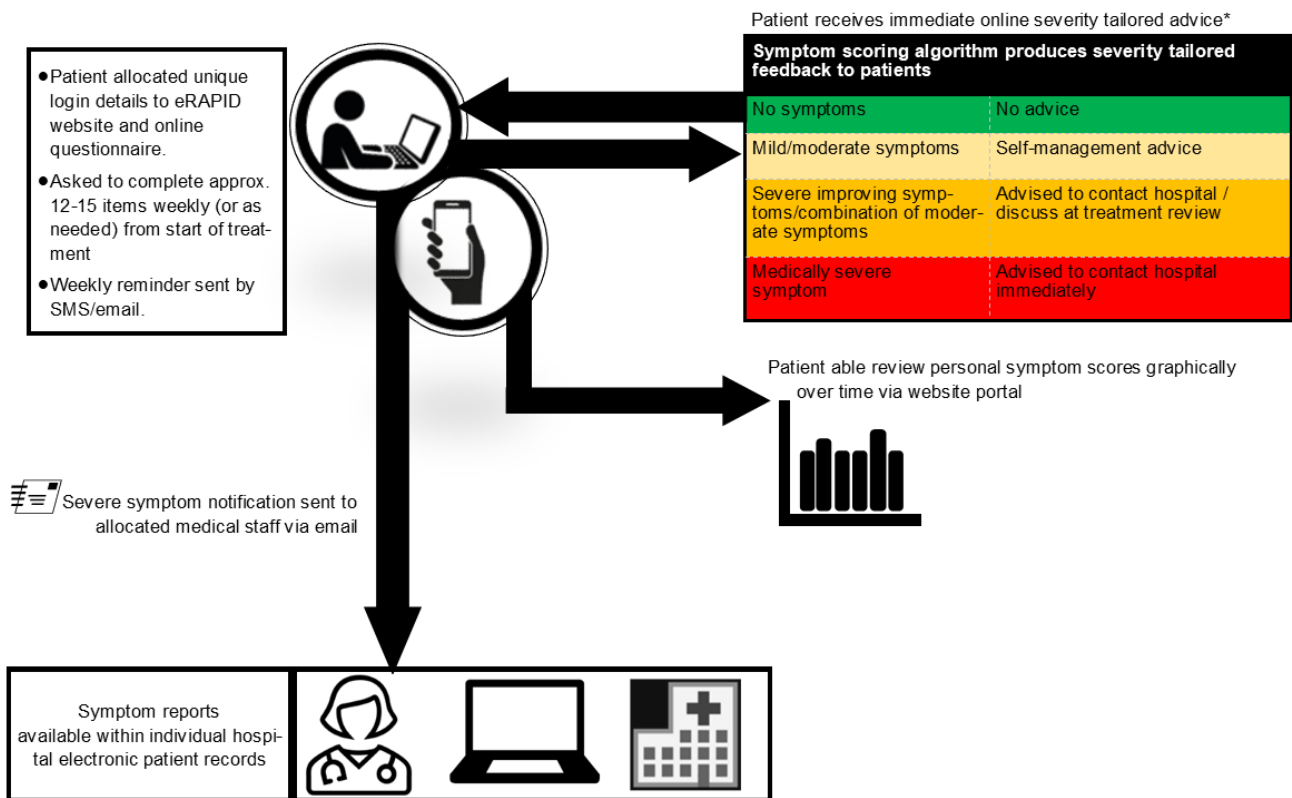


Figure 1: Overview of eRAPID system for remote monitoring of patients during cancer treatment

The developmental work leading to the final eRAPID system recognised that the system and its use in routine care needed to be considered a complex intervention requiring in depth co-design with patients, health care professionals and wider stakeholders including informatics. Overall, four main components of the intervention were identified (see Figure 2).

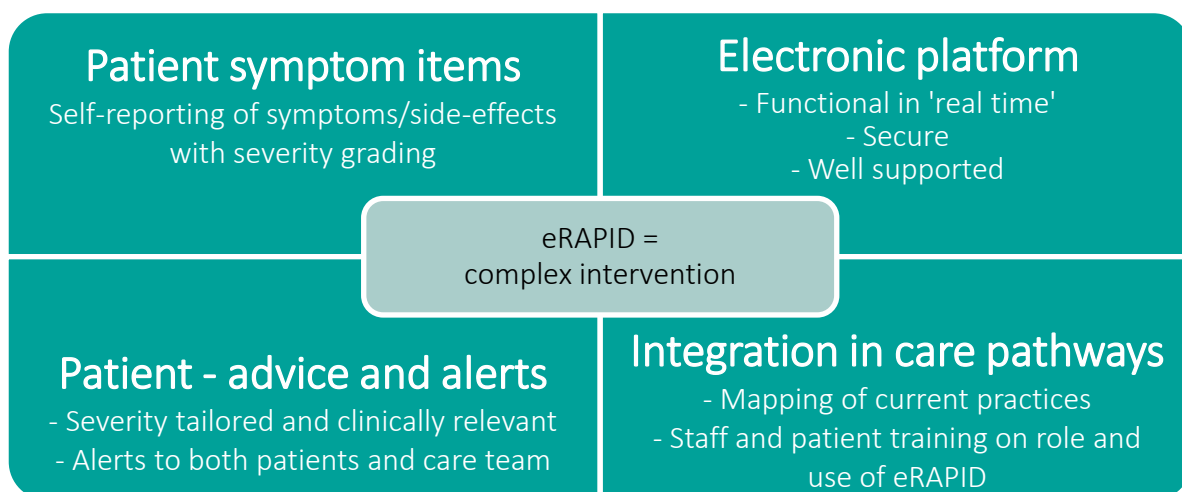


Figure 2: Key components that make eRAPID a complex intervention

The preliminary eRAPID development work, across the 4 areas mentioned in Figure 2, is described in a number of publications (2, 4-8). Across the programme five mixed-methods work packages were delivered, incorporating co-design with patients and health-care professionals:

- 1 Development and implementation of the electronic platform across hospital centres;
- 2 Development of patient-reported adverse event items and advice (systematic and scoping reviews, patient interviews and Delphi exercise);
- 3 Mapping health-care professionals and care pathways (thorough auditing and process mapping);
- 4 Feasibility pilot studies to assess patient and clinician acceptability;
- 5 Randomised controlled trial (RCT) within the systemic treatment setting (with a health economic assessment).

2.1.3 Key learning points from eRAPID

Key findings from the eRAPID developmental phases, the pilot trial and RCT are summarised below in Table 1 along with accompanying considerations for the design (and implementation) of MyPath.

Table 1: Summary of eRAPID main findings and considerations for MyPath

eRAPID stage	Key findings	Considerations for MyPath
Developmental work	<ul style="list-style-type: none"> - The content of eRAPID focuses on assessment of treatment related toxicity/adverse events (covering 12-15 items) with programmed scoring to guide patient self-management or prompt to seek medical advice - Digital clinically embedded interventions are complex and multi-faceted - Essential to design interventions that complement existing care guidance/care pathways - Co-design is vital 	<ul style="list-style-type: none"> - The digital structure and content will be dynamic and comprehensive, providing condition specific pathways and sub pathways (or tracks) to guide management (from both the HCPs and patients' perspective) and ongoing follow-up assessment of problems as needed - Provision of sufficient time to design and test pathways and refine these for each setting/site is needed - A definitive 'one size fits all' approach to the design, structure and content of pathways will not be possible – but use of existing PROMs measures and national/international cancer guidance is essential
Pilot and RCT evaluation (9, 10)	<p><u>Patient perspective:</u></p> <ul style="list-style-type: none"> - Digitally supported care acceptable to many patients - but eRAPID participants were younger and required remote internet access - Remote assessments, ability to review symptoms over time receive tailored management advice was valued and provided reassurance. - Better adherence to regular online PROMs/eRAPID symptom reports was associated with HCP use of the reports - Non-completion of online reports was associated with patients being very unwell, or feeling as though they did not have any issues to report - Patients disliked the repetitive nature of symptom reporting/management advice 	<ul style="list-style-type: none"> - How can uptake across patient/demographic groups be widened? <ul style="list-style-type: none"> - E.g., consider burden of routine assessments, access to internet/computer devices - Include patient directed management guidance and self-management advice as part of pathway - Encourage HCP's explicit use of MyPath assessments/advice in clinical assessments - Ensure baseline and ongoing PROMs assessments are relevant and appropriate to patient needs/experience

	<p>- Patients wanted the ability to add more detail on additional issues or wider context to assessments/functioning</p> <p><u>HCP perspective</u></p> <p>- HCPs recognised the potential value of the system</p> <p>- Few professionals gained significant experience with using eRAPID patient reports (due to the trial design)</p>	<p>- MyPath will be designed with a hierarchical and dynamic structure. Items/problems not endorsed by patients will not be subject to further in-depth follow-up</p> <p>- MyPath Educational and promotional strategies are being planned</p> <p>- MyPath team will develop thorough targeted, iterative training sessions</p>
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2.2 Example 2: Eir: A Computer-Based Tool for Patient-Reported Outcome Measures in Cancer

2.2.1 Overview of Eir

The development of Eir (11, 12) stemmed from collaborations between the European Association of Palliative Care (EAPC) Research Network and the European Palliative Care Research Centre to develop an electronic symptom assessment tool. The aim of EIR was to facilitate the integration of PROMs and clinical data in a user-friendly digital platform to support the treatment of adult patients with cancer. EIR version 3 (EirV3) is an electronic assessment tool initially developed for use in cancer, with emphasis on content and user-friendliness.

2.2.2 Summary of Eir development

Between 2013-2016 EirV3's specifications and content were developed through multi-professional, stepwise, and iterative processes. Literature reviews of traditional and electronic assessment and classification methods were conducted along with iterative usability tests with multi-professional end-users, both within and outside hospitals.

Prior to the software development, several national and international workshops were conducted assessing the needs and preferences of the end-users: patients, health care personnel, ICT experts/designers, and researchers.

Decisions were made regarding content, structure, concept and design. Specifically, it was decided that EIR should:

- include content based on evidence or consensus assessment methods;
- have a hierarchical structure, with an introductory question about the patient's well-being today prior to a screening section on symptoms, followed by a section on symptom intensity and another section for characterization and more detailed assessments of the endorsed symptoms;
- have a registration process with information immediately transferred and visually presented;
- be user-friendly and relevant for heterogeneous cancer populations;
- be easy to adapt to other languages and cultural and clinical preferences.

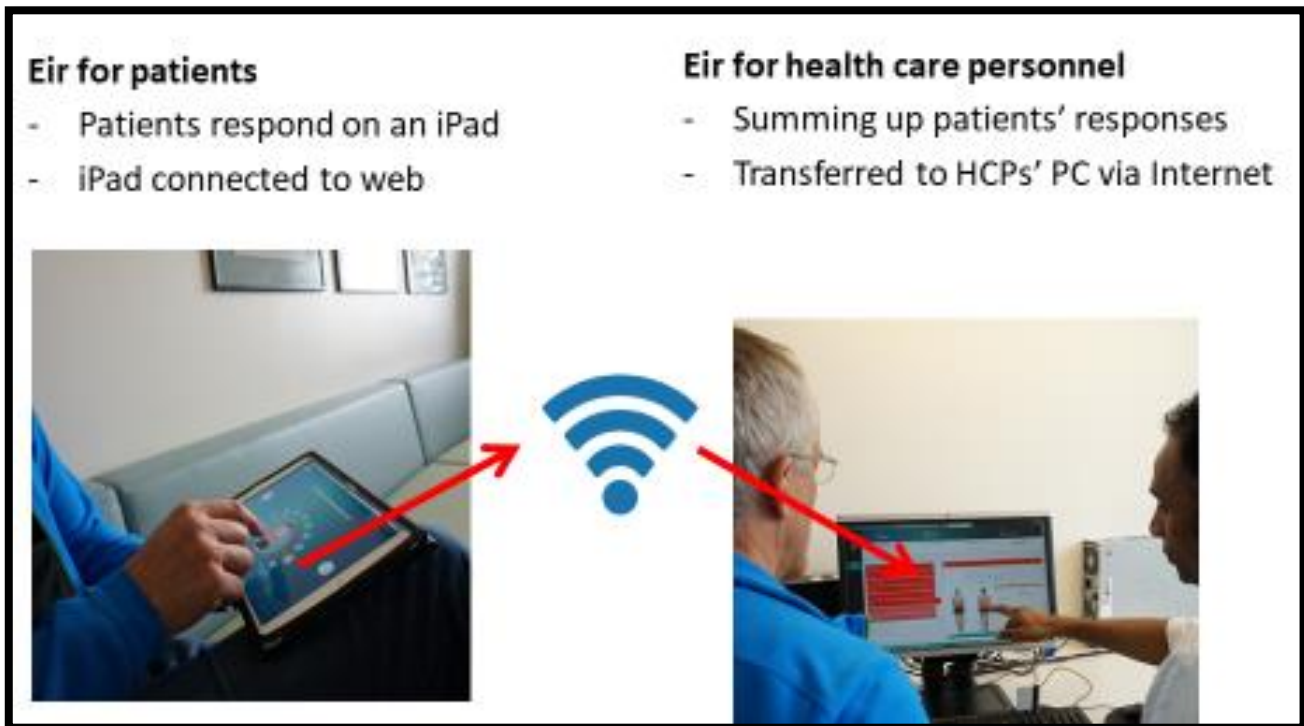


Figure 3: The EIR patient and Health Care Professional modules

Eir consists of two modules:

- Eir-Patient is for patient completion of PROMs on tablets or computers.
- Eir-Doctor allows health care professionals to view EIR PROM registrations via their computer with information being wirelessly transferred and transformed to a format designed for immediate use in clinical consultations (see Figure 3).

Usability testing of EIRV3 with patients and clinicians (11) helped to guide the refinement of the content and visual presentation of question items and data displays across the patient facing and health professional portals. Ultimately both patients and professionals (representing a range of cancer settings) reported finding EirV3 easy to use. EirV3 has subsequently been used within, PALLiON - a cluster-randomized control trial investigating the early integration of palliative care within oncology in Norway (13).

2.3 Example 3: Cancer Care Ontario (CCO) Patient-Reported Outcomes and Symptom Management Program

2.3.1 Overview of CCO PROMs program

Since 2007 Cancer Care Ontario (CCO) has undertaken a program of work to integrate Patient-Reported Outcomes into routine clinical practice to improve cancer symptom screening and management across the Canadian province (14). The purpose of this approach has been to:

- facilitate conversations with care providers;
- increase patient involvement in their care;
- help patients to focus on issues most relevant to their experience;
- identify issues early, track symptoms;
- improve patient outcomes.

The activity has been well documented in the CCO's Patient-Reported Outcomes and Symptom Management Program Strategic Framework (15).

In summary the CCO developed a digital platform called the Interactive Symptom Assessment and Collection tool which has been adopted across the majority of hospitals providing cancer care in Ontario (16). The Edmonton Symptom Assessment System Revised (ESAS-r) (17, 18) has been selected as the initial symptom screening tool with the patient reported version of the Eastern Cooperative Oncology Group performance status tool being included since 2013. In 2019 it was reported that over 40,000 symptom screens were being conducted per month across the province of Ontario (19) demonstrating the feasibility of implementing standardised symptom screening at scale.

A number of useful publications and outputs describing CCO's approach and learnings from their wide scale PROMs assessment program are available (14, 16). Montgomery et al., (16) described processes developed to guide the selection and implementation of additional PROMs for specific patient groups and settings. The concept of a 'PROs pipeline' (20) has been used by the team to convey the steps involved which include:

- Prioritisation (of the area of focus- disease or symptom type)
- Identification (identifying relevant PROMs/literature reviewing)
- Selection (based on agreed criteria)
- Piloting (in single then multiple sites)
- Implementation (site readiness assessment and including development of 1) guidelines and toolkits 2) patient education strategy 3) change management and communication plan
- Evaluation/refinement

In addition, the challenges in PRO selection and utilisation as part of the routine clinical setting have been well described along with strategies and solutions to address them (20, 21).

Encouragingly evaluation work to assess the impact of CCO's routine use of PROMs (and projects that have extended and refined the intervention further) have indicated positive benefits for screening on reducing emergency room, psychosocial-oncology and palliative care visits and increased opioid and antidepressant prescription rates (22) and survival (23).

3 Developing MyPath pathways: The story so far

This section summarises the approach taken within the project to create a shared understanding and framework for developing the MyPath digital patient centred care pathways (dPCCPs). First, we consider the standard definitions of care pathways used in the cancer setting and how MyPath dPCCPs build upon and complement these concepts.

3.1 Definitions and terminology

3.1.1 Standardized Care Pathways (SCP)

A fundamental starting point of the project has been the discussion and agreement of the term 'pathway' in the context of MyPath and wider oncology practice. Within cancer care "Standardized Care Pathways" (SCP) are detailed care plans that includes all the specific steps which guide decision making, provision and organisation of multidisciplinary care procedures for a well-defined group of patients during a specific period of time (24), thus, an organization and structure for patient care. SCPs enable the standardization of care for specific patient populations and support the integration of clinical guidelines into local protocols and clinical practice. Patients progress or move through the pathway according to time or criteria-based progression. An SCP can be visualised as a train journey, where different stations and tracks are available. The patient starts the journey at one station and stops on different stations depending on the plan and the journey. At any given point, the train may change tracks at a specific station based on specific needs.

3.1.2 Patient-centered care pathways (PCCPs)

Patient-centred care pathways (PCCPs) are recommended by EU policy to ensure quality of care through the cancer trajectory; from screening and diagnosis, through treatment, to long-term monitoring and support in survivors and end-of-life care (25). Patient-centred care is a broad approach that considers both the person and the disease with attention to the individual's values, needs, resources and preferences. In this approach the main focus is the person living with and or beyond the disease (cancer). The Patient's individual health needs in addition to the anti-cancer needs (treatments) are the driving force.

3.1.3 MyPath- digital Patient Centred Care Pathways (dPCCP)

In MyPath the focus is to design, test and implement Patient Centred Care Pathways (PCCP) – using digital or electronic technology to support the delivery and organisation of care that is tailored personally to patient needs. The use of dPCCPs aims to facilitate the real-time retrieval of information, ensuring individualized care is guided by the incorporation of the “patients’ voice” into the clinical consultation and the decision-making processes using ePROMs to elicit the patients’ perspective and guide the MyPath consultation and ongoing management and care. Thus, the ultimate project objective is to improve the content and delivery of high-quality patient-centred care to European cancer patients during the entire disease trajectory. Importantly, the dPCCPs are to be implemented alongside the anticancer treatment that may or may not be administered for a given patient. Hence, the two will complement each other to improve comprehensive care.

At the MyPath launch meeting (held in September 2022) consortium members worked in small groups to brainstorm ideas around what the pathways might look like and how they might be incorporated into the care of patients. Figure 4 provides examples of ideas generated and reflects the challenge and complexity of conceptualising the pathways.

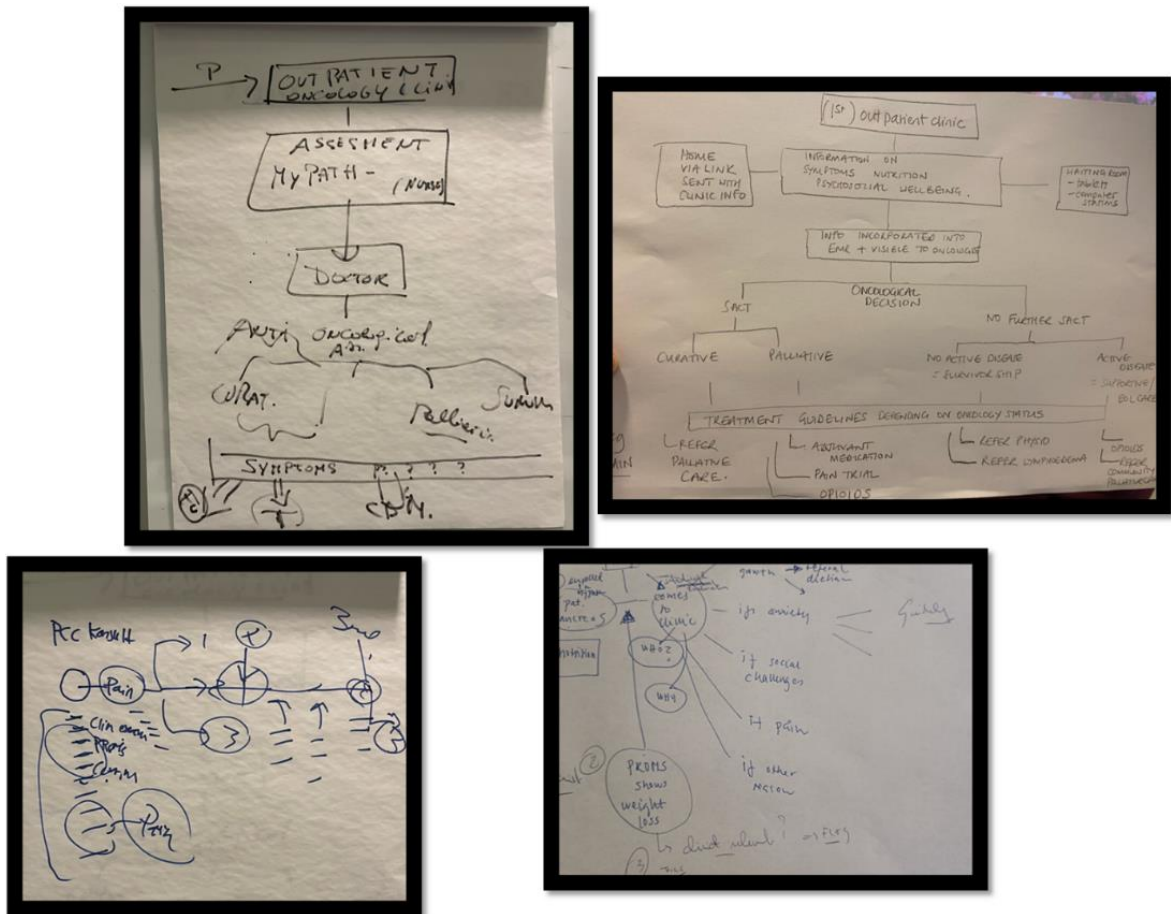


Figure 4: Examples from MyPath launch meeting brainstorming activity on the design and structure of digital Patient Centered Care Pathways (dPCCPs)

Since the launch meeting the core understanding of the MyPath dPCCPs has been refined to an overall architecture consisting of the three main elements (see Figure 5):

- **Onboarding:** Includes the steps leading to the inclusion and enrolment of eligible patients digitally entered into MyPath.
- **Diagnostic pathway:** The aim is to create the patient-centred assessment of problems/issues (single/multiple) based on PROMs completed through the EIR system, a structured clinical consultation (that may be conducted by various HCPs) and further complementary tests as required. This will lead to a diagnosis of particular conditions (e.g., using ICD-11 for pain) and provide specific treatment or care recommendations.
- **Treatment pathway:** the classification will lead to the activation of specific treatment/care recommendations (or tracks) within a given pathway with the content and ongoing follow-up tailored to the patient need.

Three key points are fundamental to understanding the purpose and function of MyPath dPCCPs.

1. **Depending on the patient, different tracks or pathways can be activated at the same time** for example a head and-neck cancer patient may experience pain, malnutrition and problems with psychological functioning/emotional distress secondary to curative radiotherapy treatment, as such, they will simultaneously follow the pain and malnutrition and emotional distress MyPath pathways.

2. **MyPath diagnostic and treatment/care pathways do not refer to anticancer diagnostic procedures/ treatments**, but to the management of problems with pain, fatigue, nutrition, physical and social function, and psychological distress. However, MyPath pathways will function in parallel to the anticancer treatment pathways that patients across different cancer groups and settings undergo.
3. The ultimate goal is that the **MyPath approach can be adapted for use with all cancer patients**; e.g., across all cancer groups and those with a suspicion of cancer, newly diagnosed patients, patients undergoing anti-cancer treatment, patients receiving survivorship care and patients with relapsed or incurable disease.

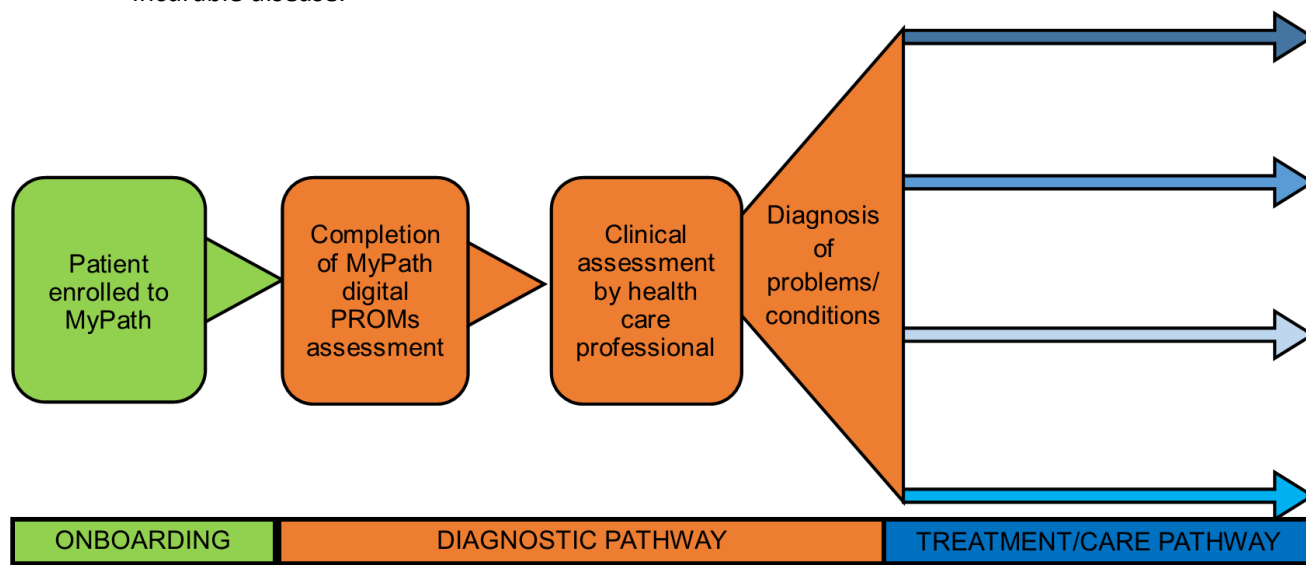
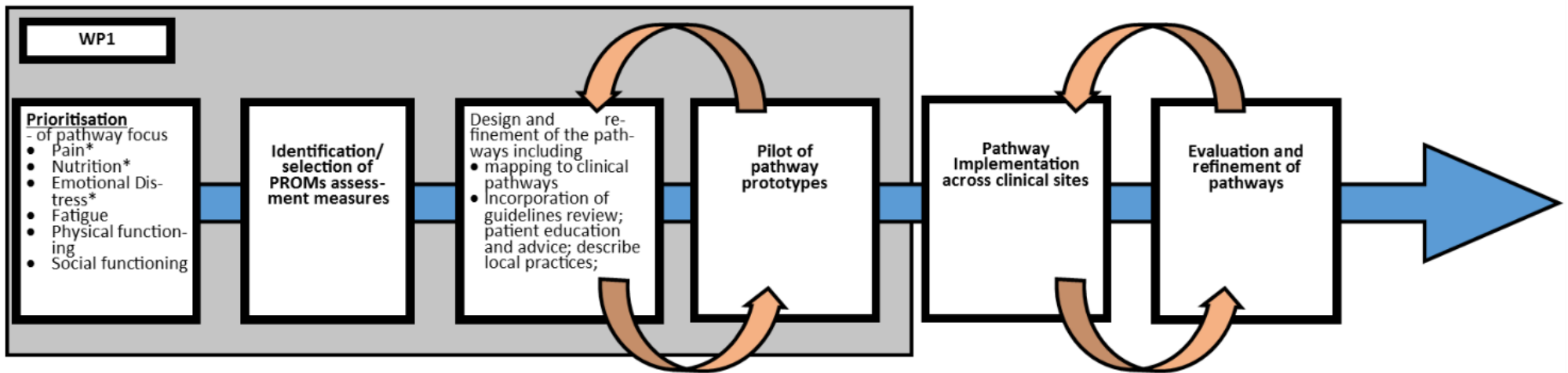


Figure 5: Overview of MyPath dPCCP elements

3.2 Developing MyPath dPCCP – A step wise approach exemplified with the pain pathway.

The initial focus for Work Package 1 has been to develop the generic template for the underlying structure that the development of the different dPCCPs will follow. The content of the pathways follows consensus-based guidelines and recommendations for the specific symptom or condition. Thus, the pathways aim to be specific enough to guide patient care and at the same time be flexible enough for adaptation to the needs of the individual patients. Further, the dPCCPs and their use will be adjusted to attend the needs of the groups in the different consortium sites and countries involved in MyPath piloting and implementation.

The general overview of the pipeline to pathway development and steps to be taken towards implementation are summarised in Figure 6.



*Initial prioritised pathways

Figure 6: Overview of MyPath pipeline to pathway development



MyPath is funded by the European Union (grant no. 101057514) and supported by Innovate UK and the Swiss State Secretariat for Education, Research and Innovation (SERI). Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HADEA). Neither the European Union nor the granting authority can be held responsible for them.

Based on the clinical expertise within the consortium and the availability of well-established international guidance, we have first focussed on planning the content and structure of the dPCCP for pain.

The approach to MyPath dPCCPs development is taking the following main steps:

1. Assembly of scientific lead and expert team (from across MyPath consortium and wider external expertise as needed).
2. Preparation of initial on-boarding documentation including an overview of MyPath project, definition of dPCCP.
3. Preparation of:
 - a. A patient scenario to help exemplify pathway process;
 - b. Available evidence-based recommendations and guidelines embedded in the different steps of the diagnostic pathway that will lead to diagnostic classifications.
4. Conduct first expert team meeting covering:
 - a. Creation of common ground
 - i. Shared understanding of MyPath dPCCPs;
 - ii. Overview of structure of MyPath consultation, including introduction to EIR as the software that will retrieve PROMs;
 - iii. How and when the pathway will be initiated;
 - iv. Target HCPs involved in pathways/care.
 - b. Agreement on the overall structure of MyPath.
 - c. Discussion of evidence-based content to be included in each step of pathway.
5. Ongoing iterative development and refinement of pathway (following an agile process), including:
 - a. Smaller group work;
 - b. Further refinement of the pathway incorporating items discussed in previous meetings and further discussion via email;
 - c. New pathway proposal to be discussed/refined at further meetings until final prototype to be programmed into the MyPath software is agreed;
 - d. Pilot testing of dPCCP.

4 Summary and plans for next steps

This deliverable presents summary results from previous work related to patient-centred care, examples of the diverse digital solutions that have been designed and used in oncology settings to date and the way forward for the MyPath project. A number of stakeholders from across the consortium have contributed with knowledge and expertise to guide the MyPath dPCCPs conceptualisation. Further work throughout the MyPath project will involve different stakeholders both regarding the scientific evidence base, ICT and technology experts, professional and lay organizations and all end-users (HCPs, patients, and administrators). Through the regular project working meetings, knowledge and ideas are being continuously exchanged and evolving around pathway development both with our collaborating ICT organization (DNV Imatis), who is building and programming the underpinning MyPath digital system, and those leading implementation activities in Work Packages 2 and 3.

Following completion of the prototype content and structure of the MyPath pain pathway, the next priorities will be following similar processes to develop the nutrition and psychological functioning pathways. Once pathway prototypes are finalised engagement activities with the MyPath consortium will be taking place as part of ongoing refinement of content and structure for the different clinical settings and sites where MyPath will be implemented. Piloting of the prototypes is planned for summer 2023 and European Society for Medical Oncology (ESMO) will be supporting the delivery of a series of stakeholder workshops from September 2023.

References

1. Nguyen H, Butow P, Dhillon H, Sundaresan P. A review of the barriers to using Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) in routine cancer care. *J Med Radiat Sci.* 2020.
2. Warrington L, Absolom K, Conner M, Kellar I, Clayton B, Ayres M, et al. Electronic Systems for Patients to Report and Manage Side Effects of Cancer Treatment: Systematic Review. *J Med Internet Res.* 2019;21(1).
3. Velikova G, Absolom K, Hewison J, Holch P, Warrington L, Avery K, et al. Electronic self-reporting of adverse events for patients undergoing cancer treatment: the eRAPID research programme including two RCTs. Programme Grants for Applied Research. Southampton (UK)2022.
4. Warrington L, Holch P, Kenyon L, Hector C, Kozłowska K, Kenny AM, et al. An audit of acute oncology services: patient experiences of admission procedures and staff utilisation of a new telephone triage system. *Support Care Cancer.* 2016;24(12):5041-8.
5. Warrington L, Absolom K, Holch P, Gibson A, Clayton B, Velikova G. Online tool for monitoring adverse events in patients with cancer during treatment (eRAPID): field testing in a clinical setting. *Bmj Open.* 2019;9(1).
6. Holch P, Warrington L, Potrata B, Ziegler L, Hector C, Keding A, et al. Asking the right questions to get the right answers: using cognitive interviews to review the acceptability, comprehension and clinical meaningfulness of patient self-report adverse event items in oncology patients. *Acta Oncol.* 2016;55(9-10):1220-6.
7. Holch P, Warrington L, Bamforth LCA, Keding A, Ziegler LE, Absolom K, et al. Development of an integrated electronic platform for patient self-report and management of adverse events during cancer treatment. *Annals of Oncology.* 2017;28(9):2305-11.
8. Absolom K, Gibson A, Velikova G. Engaging Patients and Clinicians in Online Reporting of Adverse Effects During Chemotherapy for Cancer The eRAPID System (Electronic Patient Self-Reporting of Adverse Events: Patient Information and Advice). *Med Care.* 2019;57(5):S59-S65.
9. Absolom K, Warrington L, Hudson E, Hewison J, Morris C, Holch P, et al. Phase III Randomized Controlled Trial of eRAPID: eHealth Intervention During Chemotherapy. *J Clin Oncol.* 2021:JCO2002015.
10. Holch P, Absolom KL, Henry AM, Walker K, Gibson A, Hudson E, et al. Online Symptom Monitoring During Pelvic Radiation Therapy: Randomized Pilot Trial of the eRAPID Intervention. *Int J Radiat Oncol Biol Phys.* 2023;115(3):664-76.
11. Krogstad H, Sundt-Hansen SM, Hjermstad MJ, Hagensen LA, Kaasa S, Loge JH, et al. Usability testing of EirV3-a computer-based tool for patient-reported outcome measures in cancer. *Support Care Cancer.* 2019;27(5):1835-44.
12. Krogstad H, Brunelli C, Sand K, Andersen E, Garresori H, Halvorsen T, et al. Development of EirV3: A Computer-Based Tool for Patient-Reported Outcome Measures in Cancer. *JCO Clin Cancer Inform.* 2017;1:1-14.
13. Hjermstad MJ, Aass N, Andersen S, Brunelli C, Dajani O, Garresori H, et al. PALLiON - PALLiative care Integrated in ONcology: study protocol for a Norwegian national cluster-randomized control trial with a complex intervention of early integration of palliative care. *Trials.* 2020;21(1):303.
14. Barbera L, Moody L. A Decade in Review: Cancer Care Ontario's Approach to Symptom Assessment and Management. *Med Care.* 2019;57 Suppl 5 Suppl 1:S80-S4.
15. Cancer Care Ontario. Patient-Reported Outcomes and Symptom Management Program Strategic Framework 2016-2019. Available from <https://www.cancercareontario.ca/en/cancer-care-ontario/programs/clinical-services/patient-reported-outcomes-symptom-management/strategic-framework>.
16. Montgomery N, Howell D, Ismail Z, Bartlett SJ, Brundage M, Bryant-Lukosius D, et al. Selecting, implementing and evaluating patient-reported outcome measures for routine clinical use in cancer: the Cancer Care Ontario approach. *J Patient Rep Outcomes.* 2020;4(1):101.
17. Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care.* 1991;7(2):6-9.
18. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multicenter study comparing two numerical versions of the Edmonton Symptom Assessment System in palliative care patients. *Journal of pain and symptom management.* 2011;41(2):456-68.

19. Barbera L, Lee F, Sutradhar R. Use of patient-reported outcomes in regional cancer centres over time: a retrospective study. *CMAJ Open*. 2019;7(1):E101-E8.
20. Barbera L. PROs by mandate: Lessons learnt from province wide implementation. ASCO Annual meeting. 2018.
21. Basch E, Barbera L, Kerrigan CL, Velikova G. Implementation of Patient-Reported Outcomes in Routine Medical Care. *Am Soc Clin Oncol Educ Book*. 2018;38:122-34.
22. Howell D, Li M, Sutradhar R, Gu S, Iqbal J, O'Brien MA, et al. Integration of patient-reported outcomes (PROs) for personalized symptom management in "real-world" oncology practices: a population-based cohort comparison study of impact on healthcare utilization. *Support Care Cancer*. 2020;28(10):4933-42.
23. Barbera L, Sutradhar R, Seow H, Mittmann N, Howell D, Earle CC, et al. The impact of routine Edmonton Symptom Assessment System (ESAS) use on overall survival in cancer patients: Results of a population-based retrospective matched cohort analysis. *Cancer Med*. 2020;9(19):7107-15.
24. European Pathway Association European Pathway Association. <https://e-p-a.org/care-pathways/>. Accessed February 26, 2023.
25. Kaasa S, Loge JH, Aapro M, Albreht T, Anderson R, Bruera E, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. *Lancet Oncol*. 2018;19(11):e588-e653.