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MyPath: the roadmap to implementing patient-centred care

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Abstract

Globally, healthcare systems are grappling with economic and human resource struggles. The ageing of the population and the rising prevalence of cancer are some of the main drivers of healthcare expenditure. If these challenges are not properly managed, the quality of the cancer care provided can deteriorate. Moreover, people with cancer struggle with physical, psychological, and social problems that are not routinely addressed despite overwhelming evidence of the benefits of the systematic assessment and management of symptoms. Based on the evidence that the delivery of patient-centred care (PCC) with active anticancer treatment improves most clinical outcomes and satisfaction with care, international consensus and guidelines revisions recommend the delivery of PCC as an integral part of anticancer treatment. Unfortunately, PCC is not implemented routinely, and patients do not receive the care they need. Funded by the EU, the MyPath project aims to assess whether PCC can be integrated into clinical practice using patient-centred care pathways supported by health information technology. At the core of the project is implementation science. Understanding what is required to successfully implement PCC will facilitate the uptake of evidence-based medicine across the continuum of routine cancer care, from active treatment to palliative care, to ensure that patients receive the care they need, when they need it. The purpose of this article is to present the methodology to be used in the MyPath project to implement PCC routinely. This study will be performed in nine European cancer centres. After its completion, we will assess if the proposed solution is successfully implemented.

Keywords: *patient-centred care, implementation, patient-centred care pathways digitalisation*

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1. Introduction

Patient-centred care (PCC) involves the systematic assessment and management of symptoms, functions, and experiences. Clinical studies have shown that a PCC approach improves clinical outcomes such as symptom burden, anxiety, quality of life, overall survival, and

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reduces costs in cancer [1] care. However, its routine implementation in clinical practice remains a challenge. In a European Union (EU)-funded project, we are developing a novel approach, with standardised care pathways (SCPs) as the basic structure supported by a new health information technology (HIT) system. Using implementation science methodology, we will evaluate current clinical practices and needs and design the SCPs and the development of the HIT support system. This approach aims to restructure and optimise routine clinical practice and implement PCC into routine clinical care.

Healthcare systems worldwide are struggling with economic and human resources. The number of people working in healthcare in Europe is rising. The number of new medical graduates has nearly doubled in the last 20 years in Organisation for Economic Co-operation and Development (OECD) countries, and for every doctor, there are, on average, 2.5 nurses [2]. However, the increased demand for healthcare due to the growing ageing population with complex comorbidities has extended the treatment trajectory and the steady growth in health spending threatens the sustainability of healthcare systems. The only way to address these challenges is through innovative strategies in healthcare policies, improved work organisation, and the increased use of new technologies, which all need to converge on an appropriate strategy to ensure the quality of care [3].

Cancer is a driving force in healthcare expenditure due to its high prevalence, the human capital loss, and its high treatment costs [4, 5]. More patients are being cured of cancer, and significantly more live longer with the disease, as cancer has become a "chronic disease" in many cases. The treatment costs derive from the use of advanced treatments, multiple lines of anticancer therapy, and high numbers of immediate and long-term adverse effects, particularly when used in older adults and in populations with a high number of comorbid conditions. These costs rise significantly at the end of life (i.e., the last 6 to 12 months), often driven by the high use of futile aggressive diagnostics and treatments, visits to the emergency department, and longer hospital stays [6]. However, early and timely palliative care is associated with lower hospital costs, especially by reducing aggressive interventions with low chances of benefit [7–9]. Innovative strategies supported by appropriate policy changes are needed to ensure that the quality of cancer care does not deteriorate [4].

While the number of patients living with or being cured of cancer increases, so does the number of people facing substantial psychological, physical, existential, and social problems [10, 11] resulting from the disease, its treatment, or its late effects. These issues often go undetected and untreated, causing unnecessary suffering. However, the systematic assessment and management of symptoms, along with early access to palliative care lead to increased patient and family satisfaction with care [12], improved symptom management [13], quality of life (QoL) [14], overall survival [15], resource utilisation, and fewer hospital readmissions [16]. Routinely assessing the patient's symptoms and needs and active patient involvement in treatment and care decisions are essential parts of PCC, defined as "providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions" [17]. PCC comprises methodologies such as shared decision-making and advance care planning that answer today's patients' demands to be active partners in their own care and treatment decisions. Underpinning effective PCC is the careful assessment of the patient from the physical, emotional, existential, and social aspects. Based on the aforementioned evidence, international consensus and guideline revisions recommend the delivery of PCC as an integral part of anticancer treatment [18, 19]. It is paramount to differentiate PCC from personalised medicine. Both advocate for individualised care; however, personalised medicine achieves this within a biomedical framework, while PCC has a more holistic view focused on caring [20].

In this article, we present the methodology of MyPath, a EU project. MyPath seeks to address known challenges to PCC implementation by applying implementation science methodology with iterative adaptations of the clinical and digital development components of the project, while supporting necessary changes in clinical practice. We will assess whether the proposed solution can be successfully implemented in nine participating cancer centres and sustain its use beyond the project's duration.

2. Challenges and opportunities for the implementation of patient-centred care

Despite the available evidence and international recommendations, the implementation of PCC does not happen routinely. The immediate focus of patients during an oncology consultation is the status of their cancer and cancer treatment. Time constraints and varying degrees of implementation of systematic symptom assessment, among others, can lead to insufficient symptom management. Studies show that more than 80% of patients with solid tumours report moderate to severe symptoms, e.g., malnutrition and emotional, social, and existential distress [21]. Furthermore, palliative care providers are involved in the treatment of less than 50% of patients with incurable disease, and in the treatment of less than 20% of patients with curable disease, even though the symptom burden may be as high as in those with incurable disease [21, 22]. Futile anticancer treatment in the last months of life is associated with higher acute side effects, lower QoL, higher costs, and no survival benefit [23]. Nevertheless, up to 40% of patients still receive systemic anticancer treatment in the last 30 days of life [24]. Many factors drive this approach, including society's demand for continuing cancer treatment, and the continuous development and marketing of innovative medications [25]. The barriers to the implementation of PCC include attitudes, misconceptions, insufficient training, and increasing administrative burdens [1].

The disease trajectories for most patients with cancer are complex, independent of the anticancer treatment intention. Care planning requires the involvement of several healthcare providers, either in parallel or in sequence. A seamless "journey" requires coordinated efforts across professions and healthcare levels. The patient's "journey" within the healthcare system can be understood as a process from A to B to C. Hence, process analysis and organisation using the standardised care pathway (SCP) methodology can be applied. SCPs are well-organised, multidisciplinary, and detailed individual care plans. The development and implementation of care pathways aim to streamline care delivery and improve efficiency and quality of care [26]. The European Union (EU) policy recommends the use of SCPs to ensure quality care and PCC [27].

HIT can support SCPs [28], tailor them to patients' needs, and facilitate the re-allocation of resources to implement PCC. However, past experiences show that top-down decisions to develop HIT,

without involving patients, clinicians, and other end-users, result in digital solutions that are poorly implemented and which do not meet the requirements [29]. The content and implementation of today's electronic patient record systems have only improved care processes to a limited extent, but at a high cost [30]. It is paramount to consider the complex functioning of the healthcare organisation in which the SCPs is intended to work, the clinical workflow, and clinician's and patients' needs, as well as the channels of the information flow. To our knowledge, an integrated system combining the SCP approach with HIT systems has not been developed for PCC.

The uptake of HIT and evidence-based practice in routine healthcare is challenging. A major barrier is the need to change human behaviour [31]. This challenge is evident from the many randomised controlled trials showing that PCC works in the context of a study but is not implemented in routine care once the trial is closed. Implementation science has gained increased attention in the past years, focusing on bridging the gap between research and clinical practice. Implementation science is "the scientific study of methods to promote the systematic uptake of research findings and evidence-based practices into routine practice". Learning from the analyses of implementation scientists of what often goes wrong and how this can be mitigated is an obvious start when planning an implementation project. Insightful advice will help drive the project design and draw on analyses of why and how the implementation of HIT and PCC have failed or how they can work [32]. Clearly, a functional and mutually respectful partnership between all those involved in delivering patient care and those wishing to introduce HIT-delivered PCC is fundamental.

3. MyPath—a possible solution to implement patient-centred care

The EU project MyPath [33], under the Horizon Europe topic HORIZON-HLTH-2021-DISEASE-04 Tackling diseases (2021) and Europe's Beating Cancer Plan, aims to understand and overcome existing barriers and implement PCC in routine cancer care. The project relies on the development of SCPs supported by HIT to ensure that PCC is delivered systematically according to patients' needs in a cost-effective manner. It is hypothesised that introducing a systematic approach to identifying individual needs with appropriate management options will help to achieve PCC. Additionally, implementation science guides the project and aims to develop an implementation strategy for the uptake of the digitalised SCPs.

However, as an implementation project, MyPath's ultimate goal is to assess whether PCC can be integrated into routine clinical practice. Understanding what underpins adoption and sustained use is key when seeking to maximise the potential benefits of MyPath. Different settings have different healthcare systems, cultures, and patient needs that are likely to shape attitudes, uses, and adoption patterns. Implementation science will help us to understand contextual differences, use cases, and implementation and adoption trajectories. We will achieve this through conducting a real-time systematic theory-based formative mixed-methods implementation science study.

The MyPath project was initiated in 2022 and consists of three periods: the design phase (September 2022–August 2024); the implementation phase, during which the solution will be implemented in nine European cancer centres with iterations of content and implementation strategy (September 2024–August 2026); and the evaluation phase (September 2026–August 2027). As part of the implementation study, we will (a) quantitatively and qualitatively assess the MyPath digital solution and its implementation strategies; (b) further refine the MyPath structure and content, along with implementation strategies, which will contribute to sustainability in all cancer centres; and (c) assess scalability beyond the participating cancer centres using mixed-methods data on success or lack thereof. Further information regarding the implementation study and methodology to assess if the proposed solution is successfully implemented is explained elsewhere (manuscript in preparation).

MyPath is a complex intervention project in terms of its content, use of healthcare resources, and HIT involvement. It requires competence and involvement from stakeholders from different backgrounds, e.g., cancer care, palliative care, supportive care, social sciences, computer technology, nutrition, pain specialists, psychology, patients, and informal caregivers. To achieve its goals, MyPath relies on the coordination and interplay of all the relevant stakeholders through co-creation and agile methodology. Particularly, a complete side-by-side collaboration between academics, clinical healthcare, and patients along with companies providing HIT solutions is needed.

3.1. Development of standardised care pathways to deliver patient-centred care

SCPs represent a "set" of detailed steps covering the organisation of care processes within a care plan for a well-defined group of patients during a specific period. They are particularly useful for guiding complex care procedures and multidisciplinary decision-making processes [34]. SCPs support the integration of clinical guidelines into national and local clinical practice, ensuring the implementation of evidence-based medicine and the provision of standardised care for specific patient populations. In a sense, the SCPs represent a custom-made roadmap for each patient, defining what needs to happen at a given point in time for a specific patient (i.e., defines how to go from A to B to C, and so forth). For a large patient cohort, it will result in thousands of individual SCPs based upon the best available evidence. Patients can enter an SCP based on well-defined diagnostic criteria with decision-tree thinking translated into digital algorithms (e.g., if-then-else logic). Hence, in MyPath, we will develop an SCPs supported by HIT into digital patient-centred care pathways (dPCCPs) as our approach to implement PCC.

In MyPath, the use of Patient-Reported Outcomes (PROs) retrieved digitally (ePROs) will facilitate the patient's voice directly into the consultation. PROs can be defined as "any report of the status of a patient's health condition that comes directly from the patient" [35]. The systematic use of PROs and ePROs in clinical practice is recommended [36] since they are associated with improved symptom control, physical function, QoL, and survival [37]. In MyPath, the information collected through ePROs will provide an immediate overview of the patient's current symptoms, nutritional and functional status, and social and emotional distress, with symptom development tracked over time on the same screen.

These PROs will guide the clinical consultation and assessments (e.g., by nurses, physicians, dietitians, physiotherapists, further laboratory tests, etc.). A clinical assessment based on international

guidelines is structured; it standardises the core elements of the assessment and can be digitalised as one of the steps of the PCCP. HIT can automatically provide a classification or diagnosis-based PROs and a clinical assessment paired with a summary of evidence-based suggestions tailored to each centre's local resources and national guidelines. Based on shared decision-making, the clinician will develop personalised evidence-based care plans that include appropriate ePROs in the follow-up assessment.

3.2. Implementation science, co-creation, and agile methodology

Implementation science is key when developing new methodologies supported by HIT to address the human factors, information and communication technology (ICT) factors, and project management issues, among other barriers to implementation [32]. Some recommendations for integrating new HIT in a working environment include flexible HIT. This allows for local adaptations and involvement and engagement with the adopters early in the process, empowering the local organisation to drive changes [32]. Therefore, MyPath relies on agile methodology [38] and co-creation, in which relevant internal and external stakeholders and users are involved at different stages, redefining, improving, and adapting the product to the end-users' needs (**Figure 1**). This begins at the level of each centre in the study but includes the exchange and sharing of knowledge between the nine international centres as the study progresses.

The co-creation in MyPath involves patients, caregivers, healthcare professionals (HCPs, e.g., oncologists, psychologists, nurses, social workers, palliative care specialists, surgeons, physiotherapists, and dietitians), researchers, and ICT experts from all centres. By actively soliciting feedback and integrating insights into the project's development, the final solution aims to both meet the content requirements and be technically sound and responsive to the needs and preferences of its end-users.

As aforementioned, changing behaviour is complex and challenging. New practices are unlikely to be implemented without any assistance when it requires a change in the clinician's routine or behaviour. In addition to engaging and aligning the end-users early in the process, we need to identify barriers and facilitators and develop an implementation strategy to successfully achieve change. Moreover, the local management needs to be involved and empowered to perform the required organisational changes. The researcher or implementer's insight, self-awareness, and emotional intelligence can enhance collaboration with end-users. Conversely, a lack of these qualities can create barriers, indicating that the researcher plays a crucial role in the success or failure of the implementation. Arrogance in this type of research that can lead to ignoring the pressures, demands, and clinical complexities faced by the clinical team will almost certainly lead to failure.

3.3. "Tying everything together"—MyPath working methodology

The working methodology in MyPath involves international multidisciplinary steering groups and "local groups" at every centre in which MyPath will be implemented.

The international steering groups comprise experts from different backgrounds, who have, based upon the latest evidence, focused on developing the structure and content of the dPCCP, the design and programming of the digital solution, and the implementation activities. The work of these groups was shared and updated with the whole consortium and presented to local groups for retrieving end-user feedback, and, when possible, with external relevant stakeholders. Examples of the latter include a collaborative workshop with 14 ESMO-designated centre leaders [39] on PCC and the use of HIT to facilitate its implementation, or the review and endorsement of the nutrition assessment used in MyPath by world experts in the 7th Cancer Cachexia Conference [40].

Local groups consisted of the local Principal Investigator (PI) and research group, the clinicians (or end-users) that would implement MyPath, and, when appropriate, other relevant stakeholders (e.g., organisation leaders, management, local ICT groups, patients, and informal caregivers). Using semi-structured interviews, focus groups, and informal meetings, the work from these groups mapped current practices; prior experiences with PRO, PCC, or other HIT interventions; the clinicians' views of the project's aim; and the structure and content of the solution. These activities

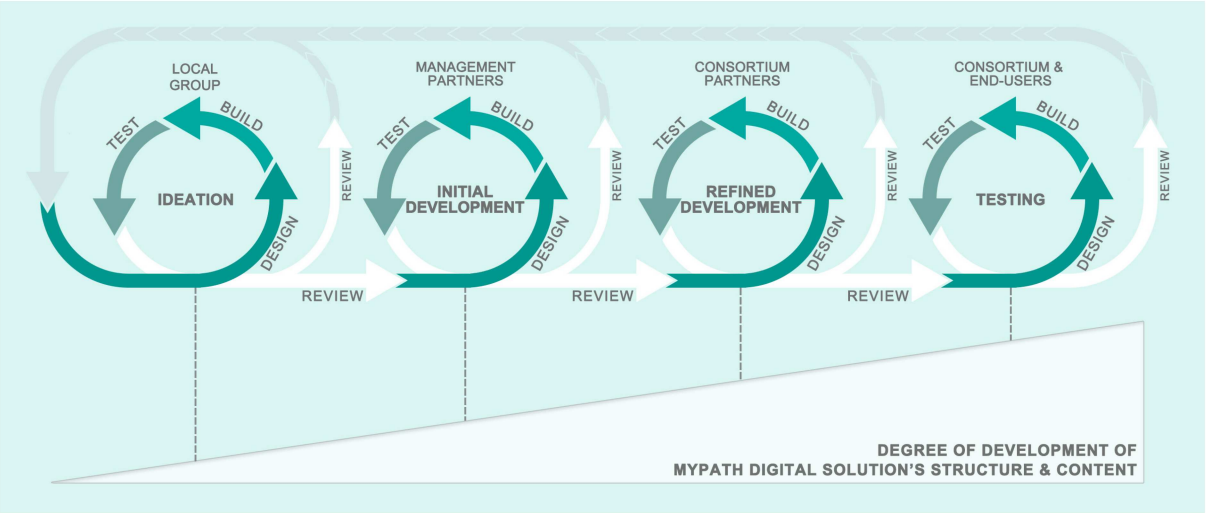

Figure 1 • Working methodology in MyPath. The development of the content and structure of MyPath relies on iterative processes and co-creation: initially, a local group will produce the first suggestion which will subsequently be presented, refined, tested, and adapted based on feedback and contribution from all relevant stakeholders.

aimed at identifying facilitators of and barriers to implementation, collecting end-user feedback regarding the content, structure, and digital interface, and outlining how MyPath would be used at their specific centre. These interactions also allowed a collaborative relationship to form around MyPath, establishing an ongoing honest dialogue, which is fundamental to potential success.

The development of a single tool that fits different patient populations, local clinical practices, guidelines, and cultures is not feasible. From this evolved the need to make the MyPath Digital Solution configurable, offering versatility to adjust to local needs and practices.

4. The structure of MyPath—how will MyPath work in clinical practice?

4.1. Overarching architecture

The overarching architecture of MyPath consists of three different stages: onboarding, assessment of patient's needs, and the management plan. How each stage is initiated and managed will depend on the individual cancer centre; however, each centre will have a clear systematic strategy in place. In order to ensure the sustainability of MyPath, it is important to adapt the intervention to the specific organisation and workflow of the centre.

(1) Onboarding. Eligible patients, regardless of where they are in the cancer trajectory (i.e., patients with new cancer diagnoses, those currently undergoing treatment, survivors, and patients who have relapsed, as well as patients who are no longer receiving anticancer treatment), who fulfil the pre-defined inclusion criteria at each centre will be approached by a clinician explaining the purpose of MyPath. After signing the informed consent form and being included in the project, patients will receive instructions on how to proceed with onboarding and inclusion in the MyPath digital solution.

(2) Patient-centred care assessment. Once the patient is included in the system, the next step involves a comprehensive assessment of the patient's needs, current symptoms, and preferences. This includes a combination of PROs, information from the clinical assessment, and complementary data, resulting in a classification of certain problems. All of the aforementioned issues combined will aid the clinician significantly in their final diagnostic formulation/s. Suggested management strategies for all the commonly occurring problems will be provided as described below.

(3) Patient-centred care management. Based on the assessment and clinical diagnostic formulation, the digital solution will provide tailored evidence-based suggestions. The clinician, together with the patient, will identify what needs should be addressed and ultimately establish a management plan to handle them, specifying when, how, and by whom. The management plan will include a follow-up plan consisting of ePROs in most cases and additional clinical meetings when needed.

4.2. Clinical steps

These stages involve different steps that will occur before the scheduled consultation, during the patient-centred consultation, and after the consultation (**Figure 2**).

(1) Before the scheduled consultation. Onboarded patients will receive a reminder to fill in the PROs using the digital application before a scheduled consultation at the cancer centre (usually 48 h in advance). A summary information of the completed assessment will be available to HCPs at their workstation, providing a clear snapshot of the patient's current needs and issues before the patient comes to the clinic. Each centre will establish a functional system to review and address the PROs. Based on the local practices and resources, who reviews this information and how a PCC consultation to handle the

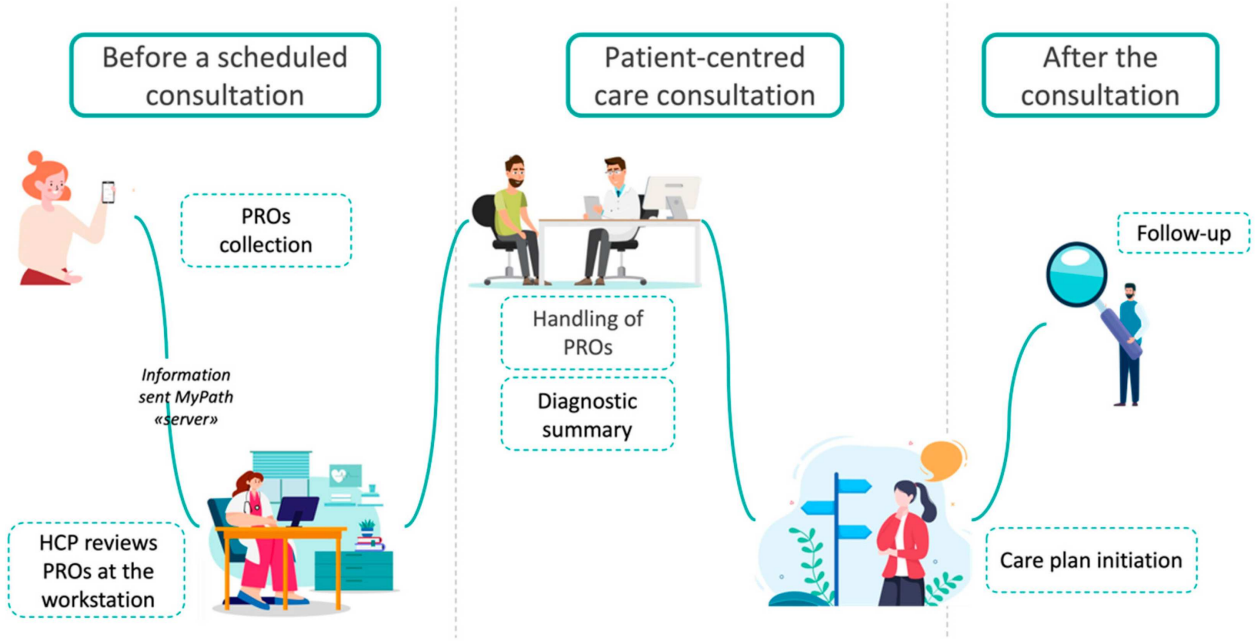

Figure 2 • MyPath clinical steps. HCP: healthcare professional. PROs: Patient-Reported Outcomes.

PROs is facilitated will vary. This information can be used to inform and plan, or adapt, the scheduled consultation.

(2) Patient-centred care consultation. When and how the PCC consultation will take place will vary between centres and patients. For some patients, the PROs identified at a clinically significant level will be addressed during the "normal" oncology consultation in parallel with tumour-centred issues. Other patients may require further assessments by HCPs from other disciplines for specific care.
Regardless of the organisation, the PROs collected prior to the PCC consultation will guide meetings with the patient. In order to ensure that the patient needs are addressed systematically, the digital solution will provide guidance for clinicians during these meetings, indicating which information needs to be added in the system to complete the assessment. The combination of all the information available will contribute to a summary diagnosis. Based on this, the digital solution suggests evidence-based care options, which include self-management support, non-pharmacological and pharmacological interventions, among others. These options will be discussed with the patient, and the final management plan will be initiated.

(3) After the consultation. After meeting the clinician, the patient initiates the agreed management plan and appropriate follow-up by completing the ePROs assessments. Patients will also have the possibility to initiate "need-based" ePROs registrations as necessary. This information will be submitted to the hospital in real time. To warrant safety, patient education is key to ensure they use the right channels and services in the event of clinical changes or new symptoms of concern. Moreover, the ePROs can provide reminders on when to use the established emergency services. Further, if a symptom intensity exceeds a pre-specified threshold, an alert can be sent to clinicians. The information retrieved from the ePROs and clinical consultations will further refine the assessment and the management plan, ensuring the care provided is responsive and adapted to the patient's current status.

5. MyPath challenges, lessons learned, and next steps

Given the project's complexity, some challenges were foreseen, and others have arisen as the project progressed, involving the digital solution development and its end-users, i.e., clinicians and patients (**Figure 3**). Another significant challenge are the researchers' knowledge and skills when planning the implementation of a new technology. All of these challenges have clearly demonstrated the need for continuous communication between the research partners in the consortium and the early involvement and engagement of the clinicians. Perhaps the most challenging need was understanding the iterative nature of the project and the unlikelihood of developing a fully functional and integrated solution from the beginning.

As the implementation phase will soon begin, invaluable insights will be gained and contribute to the iteration, development, and improvement of the solution to meet identified needs and challenges.

6. Conclusions

The routine implementation of patient-centred care is challenging. MyPath proposes a digital solution based on patient-centred care pathways that include systematic assessments with linked management suggestions underpinned by HIT support. We hypothesise that MyPath will facilitate the necessary clinical changes for the systematic provision of patient-centred care in cancer care. The primary aim of the MyPath study is to assess if we can implement MyPath into routine cancer care.

Domain	Challenges	Opportunities and lessons learned
Digital solution	• Understanding the clinical needs • Compromise between ICT possibilities and clinical needs. • Complexity of developing an adaptive and iterative solution • Integration with existing electronic journals • Paper-based recording in some settings	• Increase trans-collaboration among all partners • Focus on iterative development
Clinicians work	• Changing behaviour • Limited resources • Time constraints • Digital literacy	• Reallocate resources and responsibilities • Avoid duplication of work and enhance multidisciplinary collaboration • Need for local configurations and adaptability
Patients	• Ensuring safety - equipoise • Digital and health literacy • Digital toxicity	• Patient and caregivers' involvement in co-creation • Understanding patients' perspectives and needs

Figure 3 • Challenges, opportunities, and lessons learned. ICT: Information and Communication Technology.

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Author contributions

Conceptualization, A.C. (Augusto Caraceni), M.J.H., T.L., D.A., A.C. (Andres Cervantes), L.D., G.P.K., N.L., N.M., S.O.D., C.P., G.V., M.F. and S.K.; writing—original draft preparation, A.U., A.C. (Augusto Caraceni), M.F. and S.K.; writing—review and editing, A.U., A.B., A.C. (Augusto Caraceni), M.J.H., T.L., D.A., A.C. (Andres Cervantes), L.D., G.P.K., N.M., S.O.D., C.P., M.F. and S.K.; funding acquisition, M.F. and S.K. All authors have read and agreed to the published version of the manuscript.

Conflict of interest

The authors declare no conflicts of interest.

Data availability statement

Data supporting these findings are available within the article, at https://doi.org/10.20935/AcadOnco7566, or upon request.

Institutional review board statement

The co-creation sessions with relevant stakeholders and the MyPath Implementation study will be conducted in accordance with the Helsinki declaration. Each of the nine participating centres have applied for ethics approval from their respective Institutional Review Board or Ethics Committee.

Informed consent statement

Informed consent will be obtained from all patients participating in the implementation study, as well as the stakeholders taking part in the co-creation sessions, when required, in accordance with the Helsinki declaration.

Supplementary materials

The supplementary materials covering detailed information about the MyPath Consortium are available at https://doi.org/10.20935/AcadOnco7566.

Additional information

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