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Review

Integrating patient-centred and tumour-centred cancer care: the EU-MyPath implementation project offers an innovative digital solution with care pathways

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***Abstract*:** Cancer is one of the leading causes of mortality, with new cases expected to rise. Medical advances increase cure rates and prolong patient lives, but survivorship involves high symptom burden, loss of function and emotional distress. Improving patient-centred care (PCC) and quality of life throughout the care process is essential. Key to this improvement are systematic use of patient-reported outcome measures (PROMs) and patient-centred care pathways (PCCPs).

Despite established benefits, current cancer care focuses on tumour-centred care approaches often neglecting the patient perspective. Evidence-based PCC guidelines fail to be routinely incorporated into clinical practices. The Horizon 2020-funded European MyPath project aims to address these gaps by developing, implementing and evaluating digital PCCPs with PROMs. MyPath will be tailored to enhance the organisational contexts of cancer centres across Europe through the application of implementation science strategies. This paper describes the current state of applying PCC in routine cancer care and presents a forward-looking perspective on how the MyPath project can successfully adopt and implement digital PROMs across countries. A literature search was conducted to provide the state-of-the art.

Keywords: implementation science, medical oncology, patient care planning, patient-centred care, patient-reported outcome measures, psycho-oncology, quality of life

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General introduction

Cancer care is a major public health issue. In Europe, about 4 million people were newly diagnosed with cancer in 2020,[1,2] with 1.9 million dying from it.[3,4] Cancer is the leading cause of death among those under 65 there,[3,4] and its associated death toll is expected to rise across all age groups over time.[4] The number of cancer survivors, that is, people who have had cancer in the past, is growing, with an estimated 12 million in Europe today.[4] Differences in national economies, resources and implementation of cancer plans contribute to geographical variations in cancer incidence and mortality rates.[5] In response to this, medical advances with new therapies for more effective anticancer treatments are continuously being developed, coupled with the implementation of innovative technologies for early detection and prevention.[6] However, major investments in anticancer treatments are mainly focused on treating the disease (tumour-centred care, TCC), curation and life prolongation and are determined by economic and political factors rather than social factors.[7]

Medical advances improve cure rates and life expectancy, but cancer's chronic nature leads to prolonged symptom burden and late effects.[7,8]

This highlights the need for better patient-centred care (PCC), which includes patient and family carer perspectives.[6,9] PCC focuses on respecting of and responding to patient preferences, needs and values,[10] aiming to provide the best possible care as perceived by the patient.[11,12] PCC should be an inherent part of all cancer care, alongside with TCC, encompassing the entire continuum from diagnosis and treatment to palliative care in all its forms, ranging from supportive care to end-of-life care.[7] Evidence shows that PCC approaches, such as systematically using patient-reported outcome measures (PROMs), patient-centred communication and patient engagement, enhance patient quality of care and health outcomes.[8,13,14] PROMs are patients' self-report of symptoms, problems and preferences for care.[15,16] Digital collection of PROMs (ePROMs) enhances data quality, enables early detection of problems, improves symptom control and increases patient empowerment.[17] Despite the benefits of PCC, including ePROMs, it is not routinely integrated into existing healthcare practices and contexts.[8,18,19] Successful implementation requires tailored strategies, guided by implementation science.[20]

The Horizon 2020-funded European MyPath project (2022–2027) aims to integrate PCC and TCC through a digital solution that facilitates communication between patients, family carers and healthcare professionals. MyPath will develop, implement and evaluate digital patient-centred care pathways (dPCCPs) with PROMs by using implementation science strategies. dPCCPs are digitally standardised, multidisciplinary plans of care outlining the sequence and timing of interventions for a specific patient population. This approach will address issues early, providing insights into financial, sociocultural, structural and ethical preconditions. The digital solution will be systematically adapted. By doing so, MyPath will translate the proven concept of PCC into a practical reality in various cancer care settings across Europe.

The purpose of this paper is to provide a comprehensive overview of the current state-of-the-art in the application of PCC in routine cancer care and present a forward-looking perspective on how the MyPath project can serve as a promising solution for the successful adoption, implementation and adaptation of dPCCPs with incorporated PROMs across diverse cancer care settings. To establish the state-of-the-art, a thorough literature search was conducted. The structure of the is designed to clearly articulate the MyPath project, with each section of the literature search directly linked to the MyPath project's approach.

Consequences of cancer and anticancer treatments

People with (advanced) cancer who are undergoing anticancer treatments as well as those in remission, experience a decline in their quality of life (QoL) throughout the course of the disease.[21–26] Treatments and care pathways are mainly focused on the disease. Less attention is paid to the patient perspective, symptom relief and QoL. The management of late and long-term effects of the treatment is often insufficient. For example, there is lack of attention towards prehabilitation and rehabilitation programmes aiming to improve patients' functioning, lifestyle, health and QoL before and after definitive anticancer treatments. Additionally, there is often poor coordination and communication among the various professional carers involved in patient care.[27,28]

The confrontation with cancer and its treatments, the treatment trajectory and long-lasting symptoms after being cured represent multiple challenges for all people involved, that is, the patients, their families and professional carers.

Consequences in people with cancer

People with advanced cancer experience a high symptom burden, loss of functions, low satisfaction with care and psychosocial distress.[22–26] They often have long-term and unmet palliative care needs, which may be physical (e.g. pain and fatigue), psychological (e.g. emotional distress, anxiety and depressive symptoms), social (e.g. reduced social interaction and loneliness) or spiritual (e.g. dignity). Economically, cancer results in increased hospitalisations and medical costs.[29] Cancer care also takes a psychological toll on family carers who report increased mood disturbances, psychosocial distress and a decline in QoL due to inadequate preparedness for the caregiving responsibilities.[30]

Consequences in cancer survivors

The impact of cancer and its treatments extends beyond the active treatment period.[31] Many cancer survivors face complex health challenges that negatively affect their ability to perform daily activities. Survivors experience physical symptoms such as pain, fatigue, sterility, loss of sexual function and sleep disruption[32] as well as psychological problems such as fear of recurrence or a new cancer diagnosis, depression and cognitive limitations.[33,34] The extent of these symptoms might hinder the return to work life, and in the last decade, financial toxicity is frequently reported.[31] Family carers may experience persistent problems such as depression, anxiety and sleep disturbance as well.[33,34] These problems in survivors and their families vary in intensity and duration and may persist long into survivorship.[35]

MyPath's patient population

Considering the impact of cancer and anticancer treatments, MyPath aims to improve the QoL and reduce health burden for people with the most common types of cancer (breast, prostate, lung, gastrointestinal, testicular, head and neck) at all stages, as well as cancer survivors and their families. MyPath will focus on the hospital setting, and more specifically adult outpatients aged 18 years or older.

Importance of PCC in people with cancer

Evidence on the impact of PCC interventions

Evidence shows that PCC approaches improve quality of care and health outcomes in patients with all stages of cancer, including those undergoing curative treatment, palliative care or who are cured but living with ongoing treatment-related problems, including psychosocial.[36–38] PCC is in itself not palliative care, but fundamental in it.[8] For example, several randomised controlled trials (RCTs)[39–42] focusing on palliative care for people with cancer have demonstrated modest yet statistically significant benefits over standard care. A Cochrane review concluded that, despite small effect sizes, timely palliative care provides meaningful benefits for both patients and their families.[9] Advantages include improved symptom relief, well-being, psychosocial distress, satisfaction with care, survival time, quality of care and QoL.[9,39–44] Timely palliative care can also positively impact family carers' and communities' well-being, psychosocial distress, burden, satisfaction with care, quality of care and QoL. Finally, at health service and society level, it has also been shown to be beneficial for caregivers' satisfaction with care[9,39,40,41,42] and reducing healthcare costs through shorter hospital stays and fewer admissions.[29,45]

A pre-treatment programme aiming to optimise patients' physical functioning, nutritional status and psychological well-being is likely to benefit the treatment outcomes, in terms of higher tolerance to treatment, improved QoL and even prolonged survival.[46,47] For example, pre-treatment programmes for pancreatic cancer patients improve postoperative outcomes.[46] These programmes can be as self-managed, enabling patients to handle long-term symptoms health challenges.[35]

Ongoing challenge of integrating PCC and TCC

PCC is not routinely integrated into clinical practice and not provided alongside TCC,[8] highlighting a need for improvement.[48] Commercial, financial, professional and attitudinal barriers hinder PCC and TCC integration,[7] including disproportionate funding, inadequate infrastructures and an apparent lack of standardisation and coordination. Cancer care is often managed in silos,[8] impeding the multidisciplinary team approach and efficient coordination and communication within and across levels of care. This contributes to patient complaints and unmet needs.[48] Taken together, this underscores the urgent need to shift from solely TCC to a combination of TCC and PCC, with an integration of supportive, survivorship, palliative care and end-of-life care in clinical practice. Notably, this also calls for a shift in policymaking at multiple levels.[8]

The PCC focus of MyPath

MyPath aims to integrate supportive, palliative, end-of-life and survivorship care and TCC, with respecting of and responding to individual patient preferences, needs and values. MyPath will systematically use PROMs focussing on six core areas (pain, fatigue, nutrition, physical function, social function and psychological distress) and facilitate shared decision-making between patients and professional carers.

PROMs as a means to improve PCC

Systematic use of PROMs is a prerequisite for the patients' voice to be heard and serves as a guidance of real-time PCC.[36,37] PROMs encompass a range of domains, including nutrition, pain, fatigue and psychosocial well-being.[15,16]

Numerous guidelines, such as those provided by the European Society for Medical Oncology, outline key recommendations regarding the integration of PROMs in cancer care.[49]

Paper-based PROMs

PROMs are traditionally assessed by using paper-based, validated questionnaires with or without support of a researcher or trained professional carer. These forms are often lengthy and cumbersome to use, which may hamper the data quality.[50] Further, their use is not routinely implemented into clinical cancer care.[39–42] Given the limitations of paper-based PROMs, routine integration of PROMs via digital and technological systems may be effective and sustainable in improving systematic symptom assessment, thereby improving PCC.[14,51]

Digital collection of PROMs

Recently, in the domain of PCC for people with cancer, the focus has shifted from paper-based PROMs to a ePROMs and its integration into routine cancer care.[17] ePROMs provide numerous advantages such as a more complete data capture, faster and higher-quality information transfer at scale and reduced costs compared to paper-based versions. Recent RCTs[14,52] focusing on the use of ePROMs showed that these can facilitate early detection of problems or complications. With or without the integration of automated alerts, the use of ePROMs enables more appropriate and timely healthcare interventions which prevents a more severe development of symptoms.

Another major benefit is the direct availability of patients' responses prior to physical or digital consultations. This makes it possible to set-up a more focused and individual care plan. The use of ePROMs improves symptom control, reduces emergency visits and hospitalisations, increases patient empowerment, promotes patient–clinician communication and clinical decision-making and improves satisfaction and patient survival.[50,53] A systematic review that provides an overview of the perceived benefits of ePROMs, showed that most end-users preferred digital administration of PROMs over paper administration and are satisfied by completing these.[50] The preference for using ePROMs is enhanced by the generally positive attitude towards these tools (e.g. to find it easy to learn and to use). To further improve PCC, ePROMs can also be integrated with PCCPs[14,50,51] including individual and tailored treatment and care plans.[54]

MyPath will use ePROMs

MyPath will use ePROMs as the keystones of PCC, containing information about the patients' symptom burden, functional level and care preferences. The ePROMs will be used adaptively and dynamically to meet the changing needs of patients. For the design, MyPath will build on previous work conducted by consortium members. The existing Eir software,[55,56] a computer-based symptom assessment tool for cancer, will be further optimised and adapted.

Implementation of ePROMs and dPCCPs in cancer care

Challenges of implementing ePROMs in cancer care

Despite the evidence supporting the potential of ePROMs and dPCC solutions in enhancing PCC, routine implementation of ePROMs remains sparse. There is an increase in the development of commercial and academic software packages supporting PCC in cancer care, but many of these often fail to realise their full potential.[8,18,19] The literature on digital health information systems reveals numerous challenges associated with the adoption of ePROMs, that is, deciding and learning to use these, and implementation of ePROMs, that is, using these in daily practice.[8,18,19] Additionally, obstacles are identified in the context of dPCCPs in cancer care.[57,58]

Several lessons can be learned from this literature. The list of challenges below describes the structure of the Technology, People, Organisations and Macroenvironmental (TPOM) framework by Cresswell et al.[59]

Technological challenges. Technological challenges associated with the implementation of ePROMs may include technological functioning, usability and the integration with existing health information infrastructures. Current Information and Communication Technology (ICT) solutions often lack responsiveness and are cumbersome to use.[18,60] Standalone solutions may not readily integrate into existing health information infrastructures, limiting their potential benefits (e.g. if clinical decision support cannot be integrated with patient information). Lack of availability of timely information and duplicate data entry may present (patient) associated safety risks.[60] It has repeatedly been found that systems are more readily adopted and implemented if they are intuitive, responsible and effectively integrated with existing digital systems. An ICT solution of PCC is therefore ideally integrated as part of the electronic medical record (EMR) system. This allows information exchange across systems and care level and facilitates the incorporation into the dynamics of the clinical consultation.[18,61]

Social/human challenges. At an individual level, the beliefs and expectations of end-users (e.g. professional carers, patients) and other stakeholders can influence adoption decisions and therefore also the implementation processes. Professional carers may not perceive ePROMs or PCC solutions as clinically relevant, may experience system usability issues, can have competing priorities, may experience increased workloads, or may not want to change their behaviour in terms of routines of work for other reasons (e.g. fear of increased visibility of actions).[62] Professional carers may also be worried about potentially adverse consequences for the clinician–patient relationships and patient safety. Professional carers may not want to change their existing clinical work practices when they perceive limited individual or patient benefits.[62–64] These concerns can lead to the development of both formal and informal workarounds involving using paper and other software systems as intermediaries.[65] Patients often fail to complete ePROMs due to insufficient awareness of their purpose, lack of knowledge on how to complete them, low confidence in using technology, perceptions of the tool as non-user-friendly and/or time-consuming, physical or cognitive impairments and limited digital literacy.[18,50,61,62,66] It is important to consider that the implementation of digital tools may contribute to increased inequity across patient groups or social levels. For example, people with low digital literacy could be disadvantaged because they lack the necessary understanding and knowledge (capabilities) and also even access.[67] Early engagement and involvement of the end-users,[48] system usability and professional carer and patient education, training and promoting awareness are therefore important prerequisites for a successful implementation.[54] This will build end-users capacity and confidence with the ePROMs system.[18]

Organisational challenges. ePROMs may not seamlessly integrate with existing workflows perpetuating existing silos in the organisation of cancer care. Furthermore, organising dPCCPs requires appropriate resources, for example for training, internet connectivity, hardware and software, and specialist IT and implementation staff.[50] It is important to recognise that organisations vary significantly in the level of digital maturity. Organisational readiness to implement a new digital system can be promoted by consistent high-level support and designated leadership.[68] Here, implementation strategies – the way the intervention is introduced – need to pay particular attention to training, organisational resources, organisational leadership, engagement, buy-in and support.[18,66] Implementation strategies must be adjusted accordingly and tailored to local needs to promote the adoption and implementation of ePROMs.[18,66] The implementation strategy should consider both bottom-up and top-down components to ensure buy-in of users and an organisational vision that various stakeholders can align with.

Macroenvironmental challenges. At a health system level, barriers for ePROMs in cancer care are related to strategies, policies and regulations. There is prevailing societal demand for more treatment-driven initiatives by pharmacology and technological improvements. This is further underscored by the disproportionate funding of these activities in contrast to the limited funding directed towards PCC initiatives.[7] Other factors such as macro-economic stability, interoperability, legal and ethical standards, governance, cybersecurity and compliance with personal health data protection rules to protect sensitive patient information also play a role.[69] These factors vary in line with health system contexts. ePROMs will only take off with sufficient capacity and capability building and if they are a political priority.

The need for (pre-)implementation studies

If health information technology innovations are not effectively adopted and implemented, these may create risks to safety, introduce new errors and increase the burden on the professional carers' team. Adoption and implementation of ePROMs in cancer care is not an easy task, and there is unfortunately no recipe for success. Factors that play an important role in this context are described in the paragraphs above.[17,48,50,54]

Implementation science can help embed new ePROMs and dPCCPs effectively into existing ways of working in cancer settings. Implementation science is a scientific field including theoretical frameworks to describe and evaluate the transfer from research and development towards daily life and clinical practice.[20] Next to help bridging the gap between research and practice, it helps to identify potential risks early on, and help to devise ways to address these proactively. Here, continuous and systemic evaluation of health information technology initiatives is needed, which involves evaluation and adaptation during each digitalisation phase (including design, development, implementation and optimisation). This can help to ensure that information technology initiatives meet existing practices and needs more effectively, and comply with existing infrastructures and socioorganisational contexts. Together this maximises the chances of successful adoption and implementation,[48,70,71] whilst minimising chances of introducing new risks.[71]

MyPath will be using implementation science strategies

MyPath is aimed at developing, implementing and evaluating dPCCPs. dPCCPs combine individual ePROMs with clinical data and other patient related characteristics. This combination will inform the best individual care at a given point in time. This will result in tailored care pathways that improve the shared decision-making between people with cancer/survivors and professional carers. MyPath is an implementation study, which means that it wants to integrate PROMs into routine cancer care with digital support. Furthermore, My Path will be integrated in the EMRs giving professional carers will have immediate access to the information. Besides aiming for behavioural change among patients and family carers, MyPath aims for behavioural change among professional carers and organisational change.

To achieve the above, MyPath includes a pre-implementation study (preparation and design), an implementation and evaluation study. The pre-implementation study will inform about the end-users' needs and expectations of the MyPath tool, potential barriers and facilitators to implementation, current work and organisation practices, existing technological/organisational infrastructures and political and cultural contexts. This information will be collected through general unit observations and semi-structured in-depth interviews with a wide range of staff and patients and family carers. Additionally, we will iteratively test the MyPath prototypes through co-creation sessions with the end-users. In the transition phase to implementation, we will provide education and training for all end-users. The implementation and evaluation study will make use of a comprehensive mixed-method implementation science research design using the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework. Throughout the entire implementation process, we will involve implementation scientists to ensure a science-based theoretical implementation process. This methodology should facilitate the translation of MyPath into practice and ensure its high functionality in 'real-world' settings.

Challenges of developing and implementing dPCCPs in cancer care across hospitals and national healthcare systems in Europe

Differences in supportive, palliative, end-of-life and survivorship care across countries

The organisation of supportive, palliative, end-of-life and survivorship care is different across hospitals and countries, which makes it challenging to successfully translate effective single-country health service interventions into meaningful clinician and patient care outcomes across countries.[72] Various other factors also play a major role in the provision of PCC: involvement of different stakeholders and contextual elements. Clinicians and other caregivers are important stakeholders (e.g. sociocultural factors such as knowledge, habits, beliefs and skills). Contextual elements can be related to the organisational setting (e.g. work processes, usage of a technology system such as the digital patient record) and the macroenvironmental setting (e.g. policy such as accessibility of palliative care, socioeconomic conditions shaping the security issues in digital health, funding models, PCC education).[29] Collaboration and coordination among different stakeholders, including professional carers, policymakers and technology vendors, across countries are necessary to overcome these challenges.[73]

MyPath will be using a systematic approach involving nine cancer centres across Europe

MyPath will be carried out in the following nine cancer sites across eight countries, representing different healthcare systems, cultures, traditions and beliefs within Europe: Oslo, Edinburgh, Leeds, Brussels, Valencia, Maastricht, Milan, Brasov and Copenhagen. Developing and implementing dPCCPs in the organisational models of different European cancer centres in countries provides insight into a wide range of aspects that can be compared and lead to the formulation of revised recommendations. MyPath will potentially deliver an implementation strategy and dPCCPs that are acceptable and universally useful across Europe.

Conclusion

There is an increasing body of research exploring the use of ePROMs in supportive, palliative, end-of-life and survivorship care. These studies indicate significant potential for positive impact on health outcomes for patients and their family carers. Nevertheless, routine implementation of ePROMs remain limited. To the best of our knowledge, there is no effective and sustainable digital system available for systematic measurement of ePROMs that also provide systematic and individualised patient care plans and also no specific technology delineating treatment and care options for supportive, palliative, end-of-life and survivorship care in cancer patients. With the Horizon 2020-funded European MyPath project (2022–2027), we aim to address the above gaps in research and practice and provide a potential solution. The ambition of MyPath is to improve the QoL for cancer patients by integrating supportive, palliative, end-of-life and survivorship care and TCC, with respecting of individual patient preferences, needs and values.

The main goal of MyPath is primarily to develop, implement and evaluate dPCCPs. These plans combine individual ePROMs with clinical data and other patient related characteristics, to inform the best individual care at a given point in time. This will result in tailored care pathways in terms of care plans that improve the shared decision-making between people with cancer and their professional carers. MyPath will collect information from the patient through digital questionnaires in six core areas: pain, fatigue, nutrition, physical function, social function and psychological distress.

The digital tool will be integrated in routine cancer care. Through a systematic approach involving nine cancer centres across Europe, we are deploying implementation science to ensure successful development, implementation and adaptation of the MyPath tool in diverse organisational contexts. By doing so, MyPath will translate the proven concept of PCC into an integrated practical reality in cancer care.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Author contributions

Anne-Lore Scherrens: Conceptualisation; Writing – original draft; Writing – review & editing.

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Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials

More information about the MyPath project can be found at CORDIS services with DOI (https://cordis.europa.eu/project/id/101057514) and the MyPath website (mypath-cancercare.eu).

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