



Survivorship and  
Quality of Life  
Network



Quality Cancer Care  
Network



# Cancer Care Needs in the Community Setting

**ACTION REPORT**



## Survivorship and Quality of Life Network



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The Survivorship and Quality of Life Network is one of the European Cancer Organisation's Focused Topic Networks, and was launched in May 2020.

More information is available on our website.

Contact us at: [info@europeancancer.org](mailto:info@europeancancer.org)

## Quality Cancer Care Network



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[info@europeancancer.org](mailto:info@europeancancer.org)

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### Community 365

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# Acknowledgements

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We thank all those who provided their time and expertise for the preparation and execution of the Roundtable, who gave comments and suggestions towards the completion of this summary, and who continue to support the work of the European Cancer Organisation in achieving high-level discussions and actions on cancer care needs in the community setting.

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Thanks are due to all who participated in the Cancer Care Needs in the Community Setting 2022 Roundtable, including speakers and those providing comments during and after the session. We also thank all member societies and patient organisations who contributed to the review of this paper during the Policy Approval Pathway<sup>b</sup> process.

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- a. European Cancer Organisation's Policy Decision Making Process. <https://www.europeancancer.org/2-uncategorised/24-policy-decision-making>
- b. Community 365 is a group of charity, philanthropy, and industry contributors to the Focused Topic Networks of the European Cancer Organisation. Community 365 provide ideas, guidance, practical support, and resources for our work in convening stakeholders and building consensus in the European cancer community. Community 365 contributors do not have a decision-making role in our policy work. Rather, policies of the European Cancer Organisation, such as those represented in this document, are agreed by our Board after consultation with our Member Societies and Patient Advisory Committee, via

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## Executive Summary

This meeting brought together leading policymakers, politicians, patient advocates, oncology experts and primary healthcare professionals (HCPs) to discuss EU policy developments related to cancer care needs in the community setting. This Roundtable demonstrated how the rights of cancer patients to quality cancer care can be met and delivered by a fuller utilisation of care opportunities in the community setting.

Twelve key themes emerged in the policy recommendations developed and discussed during the meeting:

1. **Better data collection** on outcomes for people living with cancer, with a recurrence of cancer, or with metastatic cancer must be facilitated. Collecting quality data and turning it into cancer intelligence, applying the lessons learnt from the Covid-19 pandemic is essential. This includes ensuring that Europe's cancer registries are reorientated to capture standardised data about cancer recurrence and cancer metastasis going forward.
2. **Unmet needs** for those living with cancer include the need for better care coordination and support for psychological and emotional effects of cancer.
3. **The European Code of Cancer Practice**, including its right to reintegrate into society must be implemented across Europe, in particular the right to return to work. This should be delivered with the support of additional legislation as required.
4. **Primary healthcare professionals** must be supported to play a greater role in caring for those living with cancer.
5. **Cancer care to underserved communities** must be improved by diversifying traditional approaches to treatment and care, as well as through accelerated use of standardised data intelligence and access to innovative digital technologies.
6. **Electronic patient reported outcomes (ePROs)** must be used to assess and address patient needs for those living with cancer, preferably as part of routine care, within the community setting.
7. **Careful planning and integration** for digital health technologies must be implemented in ambulatory care hospitals to avoid data silos, reduce inequalities, and avoid roadblocks to implementation
8. **Digital infrastructure and skills** must be invested in by health systems to improve patient safety and health system efficiency, reduce administrative burden on healthcare professionals and thus increase face-to-face interaction.
9. **A digital, longitudinal, and accessible patient-centred record**, integrated into a National Cancer Control Programme (or other similar national system), must be delivered to support safe and effective cancer care in the community setting.
10. **Collaboration between national and EU policymakers** must be facilitated to ensure that local, regional, and national health data systems are interoperable, and ensure healthcare professionals in the community setting have appropriate access to provide effective cancer care in the community.
11. **High-level policy frameworks** such as Europe's Beating Cancer Plan, the EU Research Mission on Cancer, and the European Health Data Space must be exploited to provide opportunities to strengthen the European Health Union, including cancer care in the community setting.
12. **Broad and senior clinical leadership** must be ensured within health systems for the digitalisation of health services and practices, including across different care sectors.

# Introduction

Kathy Oliver, Co-Chair, ECO Patient Advisory Committee; and founding Co-Director, International Brain Tumour Alliance (IBTA), and Mirjam Crul, ECO Board Member; Co-Chair, ECO Special Network on the Impact of Covid-19 on Cancer and Workforce Network; and Vice-President of the European Society of Oncology Pharmacy (ESOP).

With advances in cancer prevention, detection, treatment, and care, an increasing number of cancer survivors, numbering over 20 million in Europe, are living beyond a cancer diagnosis.<sup>1</sup> Alongside this, there is a desire to treat and care for patients in locations more convenient for, and less disruptive to, their daily lives. There are lessons to be learnt from our experience during the Covid-19 pandemic, as well as with advances in innovative digital technologies. These factors place an increasing focus on how we can better care for patients in the community setting, and support their caregivers, families, and friends.

The October 2022 Community 365 Roundtable event on Cancer Care Needs in the Community Setting sought to provide a spotlight on a range of policy needs associated to providing enhanced quality of care for cancer patients outside of the hospital setting.

The Roundtable also aimed to demonstrate how cancer patients' rights to quality care, (as articulated in the *European Code of Cancer Practice*), can be met in the community setting. This includes the right to Quality of Life, Supportive and Palliative Care, Survivorship and Rehabilitation, and Reintegration. The event also builds upon the 2019 publication, *ECCO Essential Requirements for Quality Cancer Care: Primary Care*. The Roundtable brought together policy makers, healthcare professionals, patient advocates, and interested stakeholders to develop a series of recommendations which were subsequently reviewed and approved by the European Cancer Organisation membership and Patient Advisory Committee for formal adoption as a policy mandate.

Figure 1. Why this Roundtable?



## Why this Roundtable?

- To achieve and ensure successful long-term management of cancer in the community setting
- To identify and implement the roles of primary care and allied healthcare professionals in long term management of cancer
- To learn from the experiences of those working with cancer
- To explore new forms of treatment and care for those living with cancer in the community setting.

## FIND OUT MORE

- **Essential Requirements for Quality Cancer Care**  
[europeancancer.org/2-content/8-erqcc](https://europeancancer.org/2-content/8-erqcc)
- **The European Code of Cancer Practice**  
[europeancancer.org/code](https://europeancancer.org/code)



# Living With cancer. The Metastatic Breast Cancer Case Study

## SUMMARY

- Data collection for people living with cancer in the long-term, with a recurrence of cancer, or with metastatic cancer is currently lacking – across the globe
- Recent research has identified several key unmet needs for those living long-term with cancer, including the need to address the psychological and emotional effects of cancer and treatment
- Despite the development of the European Code of Cancer Practice, including its tenth right to Reintegration, EU-wide action on the right to return to work is also currently lacking
- Primary healthcare professionals are an underutilised resource within health systems, in particular for those living long-term with cancer

**Co-chaired by Fatima Cardoso, Director, Breast Unit, Champalimaud Clinical Center; and President, ABC Global Alliance, and Matthijs Van Meerveld, former Head of Global Public Affairs for Breast Cancer, Sanofi, and Global head of access policy & patient access, Menarini Stemline Oncology, in discussion with Tanja Spanic, President, Europa Donna Slovenia, Taylor Puhl, Manager, Health Policy & Insights, Economist Impact, and Barbara Wilson, Founder and Director, Working With Cancer.**

## The Fundamental Role of Primary Care Health Professionals in Cancer Care

To deliver high quality care in a seamless manner, a connection is needed between oncologists and primary care physicians. Healthcare professionals in the primary care sector have a fundamental role in all parts of cancer care: for prevention, detection, and treatment, but also for long-term care and survivorship. Homecare, and the coordination between the disciplines of oncology, general practice, and palliative care, up until the end of life, is one of the greatest challenges for any health system. Primary care professionals can also play a role in addressing non-cancer related diseases and symptoms for cancer patients, thereby freeing the oncologist for more highly specialised care.

*Cancer patients have the right to have other diseases.*

## Addressing Incomplete Data and Unmet Needs in Metastatic Breast Cancer

The needs of patients with metastatic breast cancer (MBC) require specific attention. A recent Economist

Impact study undertook specific research across a number of countries to better understand these unmet needs, and pinpoint recommendations for patients and caregivers. Historically, much attention has been placed on early-stage breast cancer, whilst sometimes overlooking the many unmet needs of patients with advanced and MBC.

*What should be done to make sure our healthcare systems and policies keep pace with innovation?*

The Economist Impact study, entitled *Rising to the metastatic breast cancer challenge: Current and future policy responses*, explores five different topics in relation to MBC, (the needs of people living with MBC, care delivery, healthcare workforce, financing and access policy, and data), across seven countries (the US, Brazil, Japan, United Kingdom, France, Germany, and Italy).

The report highlighted that currently, there are incomplete data collection concerning those living with cancer, those having recurrence of cancer, or those experiencing metastatic cancer. This lack of data collection limits development and improvement of care and enhancing outcomes, and the report makes several recommendations for better data collection:

- Identifying successful data capturing methodologies for de novo or recurrent breast cancer that follows patients throughout the system
- Better system integration and interoperability with various databases (e.g., cancer registries)

and electronic health records) within and across health systems

- Include the entirety of the data ecosystem in planning and execution (e.g., guidelines, infrastructure, financing, incentives) to ensure data collection, processing, and sharing is sustainable and consistent

*With so much emphasis placed on the more treatable, early-stage cancer, women with MBC often feel isolated, invisible and stigmatised.*

According to the report, metastatic breast cancer patients experience insufficient psychosocial support, are faced with inadequate health system resources and low rates of reimbursement for medications, poor access to personalised treatment, and have difficulty navigating investigational treatments. The report makes several recommendations to overcome stigma and improve quality of life, including recognising the non-clinical impacts of metastatic breast cancer, addressing limited access to multidisciplinary care, and improving access to palliative and supportive care. Specifically, the report found that major unmet needs for patients with metastatic across the countries studied, included support for the psychological and emotional effects, and better care coordination.

## Working with MBC

Health systems should aspire to achieve the level of patients' rights as outlined in The European Code of Cancer Practice, and in particular, those related to reintegration. Despite the existence of a *European Code of Cancer Practice*, and its tenth right (*The*

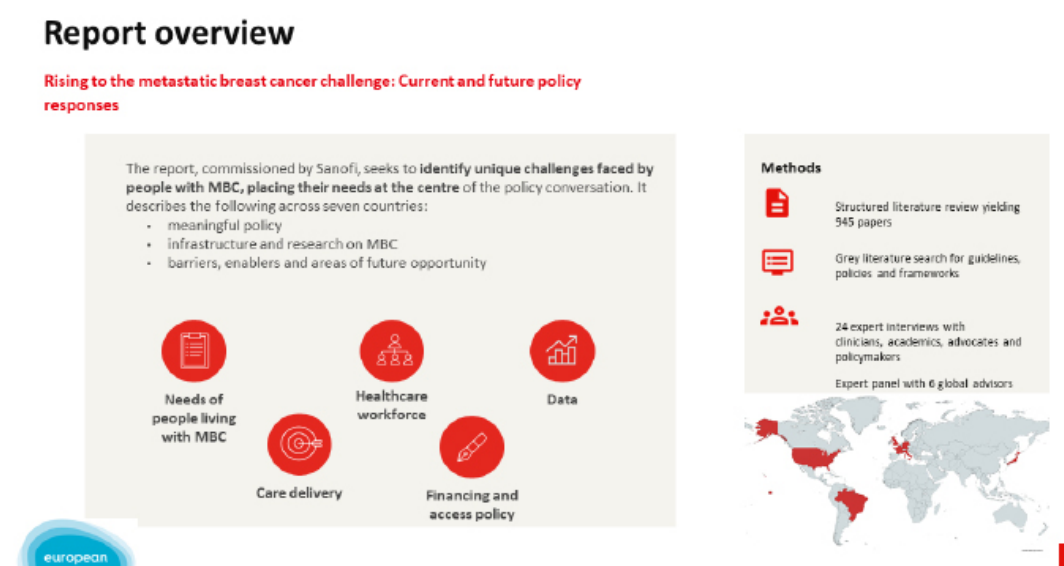
*Right to Reintegration*: be fully reintegrated into society and protected from cancer-related stigma and discrimination, so that, in so far as possible, you can return to a normal life), this right still does not exist in practice on an EU-wide basis. It does exist, however, in some countries, such as the UK where, since 2010, cancer patients have key employment rights and employers have a responsibility to support anyone who has a cancer diagnosis.

Patients with metastatic breast cancer experience several key challenges in relation to work. These include the physical and emotional impact of treatment, and its compatibility with work and the workplace environment. Another challenge includes the continuing stigma of cancer, where patients are faced with employers' or colleagues' ignorance and assumptions about life expectancy, wishes, and needs of those with advanced or metastatic breast cancer. Additionally, in a recent survey from the Institute of Employment Studies in the UK, it was found that those with breast cancer were more likely to report that the emotional impact of cancer was greater than the physical impact.

Being able to remain in or return to work, provides a very important sense of normality. As well as providing a sustained income, remaining in, or returning to work is a powerful source of social connection, *In returning, I was part of the work I loved doing once again, and work was also good for me. It distracted in the down times and was motivating and exciting in the good times.*

Returning to work whilst living long-term with cancer is not only an exercise in fundamental rights, but it also brings numerous intrinsic benefits. Two key

**Figure 2. The Economist Report Overview**





recommendations can be drawn to ensure those with advanced or metastatic breast cancer can successfully remain in, or return to the workplace. They include legislation and best practice guidance to support implementation. Specifically, the concept of the right to be remembered was highlighted as a facilitator for the return to work of those living with cancer in the long-term. In this case, this would ensure that the employer, colleagues, and anyone else involved in the return to work remembers that those living with cancer have rights and are provided with the support that they need.

## CASE STUDY

### The right to return to work in the UK

There are around 900,000 people of working age living with cancer in the UK. This number is expected to increase to 1,150,00 by 2030. For those affected by cancer, work is important. A job can restore a sense of normality and wellbeing as well contributing to financial independence, but many cancer survivors find returning to work a struggle as they deal with cancer's short- or longer-term side effects.

## General Practitioners Can Help Improve Quality of Life

General practitioners (GPs) play an important role supporting patients in both the early stages of cancer as well as those with metastatic cancer.

Thomas Frese, President-Elect of WONCA Europe, articulated the General Practice (GP) perspective of improving care for those with advanced breast cancer. WONCA Europe is the academic and scientific society for general practice and family medicine, who's vision is to improve the quality of life of people through fostering high standards of care in general practice and family medicine.

GPs are a crucial, familiar, and local resource for cancer patients when they leave the hospital, and this is especially the case in small towns or rural areas, where patients can often be more than 50 kilometres from their cancer treatment centre. This distance could equate to patients spending half or even a whole day travelling to their nearest cancer treatment centre. Patients who must travel longer distances also suffer a reduction in quality of life, and a loss of vital free time as a result of their travelling commitments. GPs are a resource that healthcare systems should better utilise to perform procedures or follow-ups closer to patients' homes and in their communities, subsequently linking back to their patients' cancer treatment centre.

Figure 3. Recommendations: Legislation supported by Best Practice Guide



## Recommendations: Legislation supported by Best Practice Guidance

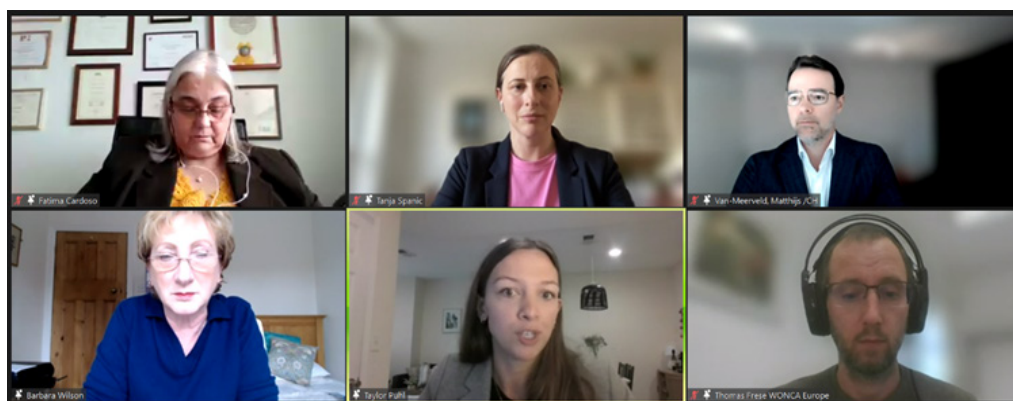
1. **Make returning to work after cancer a lifelong right for anyone who has had a cancer diagnosis. A 'right to be remembered'.**
  - Include as a minimum the rights to:
    - Phased return to work
    - Workplace adjustments
    - Time off work for medical appointments
    - Not to be discriminated against, victimised or harassed.
2. Employers should follow best practice guidance, ensuring employees with cancer are fully supported to continue working if they wish to do so.
3. Long term cancer care strategies which fully take into account the fact that cancer patients want or need to work.

Key areas that policymakers and healthcare systems should address include the dearth of data, the lack of understanding, unmet needs (including providing psychosocial support), better involvement of healthcare professionals in the primary care sector, and ensuring the right to work is implemented with best practices and legislation. Additionally, the need to ensure the correct use of terminology (e.g., advanced versus metastatic) was also identified as a critical consideration, as well as the need to address 'the patient' rather than 'the cancer'. This includes being aware of other co-morbidities, and how they interact with cancer and the cancer patients' quality of life.

Further work is needed to ensure that the recommendations from this Roundtable are

disseminated and discussed with European policymakers. Health systems and policymakers should strive to meet the dual aims of improving quality of care, whilst ensuring care is delivered close to patients, as this delicate balance of centralisation and care in the community improves the overall wellbeing of patients.

**Figure 4. Panellists of the first session of the Roundtable**



## KEY POLICY RECOMMENDATIONS

- To improve quality of care and health outcomes, better data collection for people living with cancer in the long-term, with a recurrence of cancer, or with metastatic cancer is needed, for example through registries
- To address unmet needs for those living long-term with cancer, better care coordination, including support for the psychological and emotional effects is required
- To overcome the key challenges for people living with cancer in the long-term, (for example, stigma), full implementation of the European Code of Cancer Practice, including its tenth right to Reintegration, across Europe, is essential
- EU-wide action on the right to return to work should be supported by both legislation and best practice guidance for implementation
- Primary healthcare professionals should be supported to play a greater role in caring for those living long-term with cancer

# Cancer in the Community Setting: Lessons from Covid-19

## SUMMARY

- The Covid-19 pandemic has disrupted cancer care across Europe, with wide-reaching affects for cancer prevention, detection, treatment, and survivorship
- Traditional approaches to treatment and care risk excluding or underserving specific communities
- The accelerated uptake and widespread use of digital technologies and data capture as a result of the Covid-19 pandemic, provides opportunities for advancement and improvement of cancer care in the community
- As these technologies continue to be used and rolled out further, careful integration is required to avoid creating and perpetuating data silos, inequalities, and implementation issues

Co-chaired by Mark Lawler, ECO Board Member; Co-Chair, ECO Special Network on the Impact of Covid-19 on Cancer; and Professor of Digital Health, Queen's University Belfast, and Faisal Mehmud, Head of Medical for International Developed Markets, Pfizer Oncology, in discussion with Federico Pratellesi, European Commission Official, 'Performance of National Health Systems' Unit, DG SANTE, Roger Wilson, Patient Advocate, Sarcoma Patients Advocacy Global Network (SPAGN), Rayna Patel, CEO and Co-Founder, Vinehealth, and Ülle Helena Meren, Lead Pharmacist, East Tallin Hospital.

## Data-Informed Policy Responses

There is tremendous value in using data to understand, respond to, and mitigate the impact of Covid-19, in particular where cancer is concerned.

*People are starting to fear a Covid-19 diagnosis more than a cancer diagnosis.<sup>2</sup>*

Research from the UK has shown that as a result of the disruption caused by Covid-19, seven out of ten people with suspicion of cancer were either not going to their GP or were not getting referred to cancer specialist centres, and four in ten cancer patients were not getting access to their chemotherapy at the appropriate time. This equates to between 7.000 and 18.000 excess deaths according to modelled predictions, deploying combined data from primary and secondary care settings.<sup>3</sup>

In fact, modelling work has revealed that even with conservative estimates, the disruption caused by Covid-19 could significantly affect five-year survival, and for some cancers (such as colorectal), the pandemic could set Europe back nearly a decade. In response to these alarming signals, the European Cancer Organisation set-up the *Special Network on the Impact of Covid-19 on Cancer*, and produced a *7-Point Plan to Build Back Smarter from Covid-19*. This led to development of the award-winning Covid-19 and *Time to Act Cancer* campaign, and to the *Time To Act Data Navigator*.

The *Time to Act Data Intelligence* study revealed that clinicians across Europe saw 1.5 million fewer cancer patients in the first year of the pandemic, 100 million cancer screening tests were not performed as a result of the pandemic, and 1 million cancer patients could be undiagnosed due to the presentational and diagnostic backlogs. The *Data Intelligence* study also revealed the pandemic's toll on the oncology workforce, with four in ten feeling burnt out and three in ten showing signs of clinical depression. Ultimately, the *Data Intelligence* study was presented to the European Parliament Beating Cancer Committee on 10 May 2021, with a demand that cancer be put at the top of the European health agenda.<sup>4</sup> This action resulted in recognition at the very highest levels of the European Commission, with President Ursula von der Leyen of the European Commission, and Health Commissioner Stella Kyriakides both referencing the Time to Act Data Intelligence findings in key speeches and events.

## Digital Innovation, Accelerating Access, and Care in the Community

Healthcare systems are likely to see a 'bolus' of patients presenting with signs and symptoms of cancer following the disruption caused by the pandemic. For example, there is now a 20% increase in presentation of brain metastases from patients with lung cancer and breast cancer. These phenomena have dramatic consequences for the type of data that are generated, and how we synthesise/present that data for clinicians and patients to aid treatment decisions and management. In relation to dosing intensity, patient outcomes are critically important in maximising treatment effectiveness and quality of life for patients, in particular in the community setting.

*The Covid-19 pandemic can pinpoint ways we can improve cancer care and make it more resilient. This includes amongst other things, accelerating digital transformation of healthcare, being more agile in innovation, and properly responding to underserved communities.*

To maximise cancer care in the community, three key actions are required:

### 1. Accelerating digital transformation.

Example: digitally enabled home blood self-monitoring for cancer patients.

### 2. A more agile approach to innovation

Example: implementing some of the same sense of urgency about innovation and new ways of working that made the Covid-19 vaccination programme so successful).<sup>4</sup> Improving access in underserved communities.

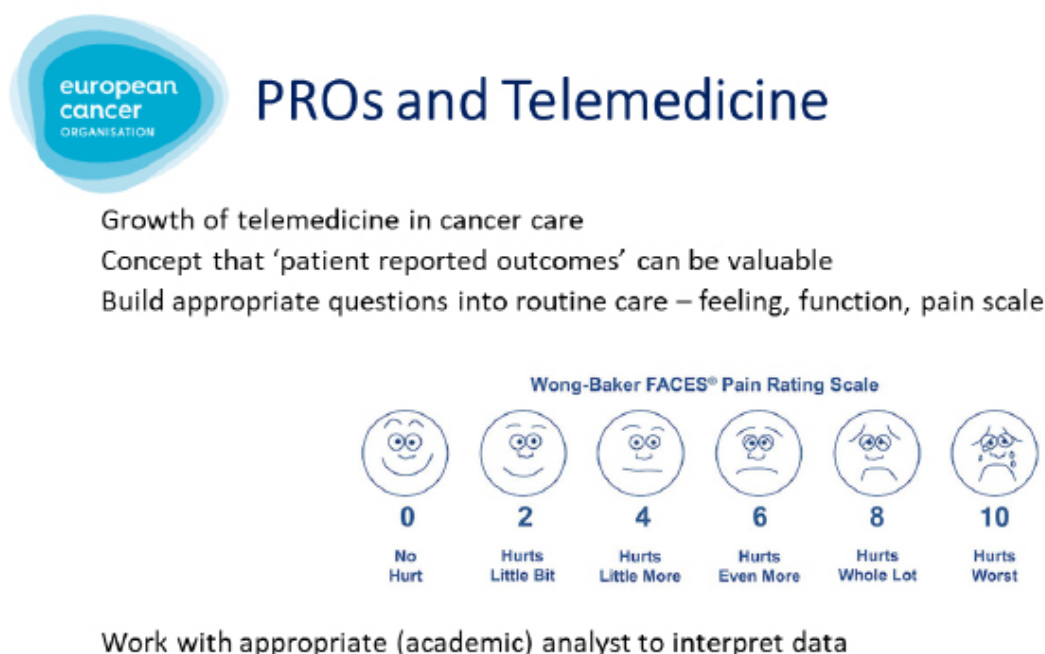
Example: ensuring greater diversity in clinical trial participation, and more proactive outreach programmes in the community for older citizens, ethnic minorities, and those in rural locations.

## Patient Reported Outcomes Can Complete the Picture

*You are always a survivor, right-up until the day you die.*

Too often in healthcare professionals and patient, opportunities are missed to understand what is really happening from the patient perspective. Patient reported outcomes (PROs) can help to provide some of the answers needed, with more information collected, and a fuller picture gained. That said, there is still room for improvement with PROs, as traditional methods of data collection for PROs (such as the EORTC QLQ-C30), contain multiple questions that require (sometimes lengthy) consideration by the patient. From a patient perspective, answering a shorter number of questions would be preferable, for example,

Figure 5. PROs and Telemedicine



## CASE STUDY

In 2018, over 1,000 cancer patients and their healthcare professionals contributed to developing the *UK Top 10 Living with and Beyond Cancer Research Priorities* project. The research priorities identified included generic, tumour group specific, and individual needs, as well as psychological, nutritional, and physiotherapy needs. These needs should all be addressed individually, as well as in the individual patient context.

as part of routine care Following the Covid-19 pandemic there has been a growth in telemedicine in cancer care. This provides an opportunity to build appropriate questions into routine care (for example; feeling, function, pain scale). A critical aspect of collecting data via PROs is to ensure that not only is it collected, but that it is also appropriately interpreted. Collection and interpretation of feedback from patients can also play a role in ensuring correct and differential diagnosis (and avoiding misdiagnosis).

### Electronic Patient Reported Outcomes Offer Even More Opportunities

Prior to the Covid-19 pandemic, digital health innovation remained relatively nascent in cancer care in the community setting. However, Covid-19 has dramatically increased the application of digital technology in healthcare and is here to stay, with such technology having both patient-facing and clinician-facing applications. Since the pandemic, online consultations are now more common in both primary and secondary care settings.

Despite these changes to clinical practice, there is still a gap in data, interpretation and understanding across healthcare, drug development and research, on what actually affects patients the most. For example, symptom burden, medication adherence, treatment outcomes and quality of life are often poorly understood, with a scarcity in relevant data intelligence. To understand these issues, symptom reporting, and other factors need to be captured remotely, from the community setting where patients spend their most time. Additionally, research suggests that clinician-reported symptoms are underreported by up to 76%. Data from the Memorial Sloan Kettering Cancer Center demonstrated that routine collection of ePROs led to a seven percent reduction in admission to Accident and Emergency departments, a median

survival of five months longer, patients able to stay on chemotherapy longer, and a better quality of life.<sup>5</sup> As such, the next advance needed in the domain of PROs is to fully embrace electronic PROs (ePROs). The effective implementation of ePROs is also required to ensure effective uptake, including helping patients to understand the benefits and outcomes of submitting their data via PROs.

### Technology alone is not a magic bullet.

Caution is needed however to ensure that the uptake and implementation of digital technologies is performed appropriately and integrated into European health systems accordingly. The effect of Covid-19 has also led to the rapid adoption of digital health technologies in months, rather than over years as per pre-pandemic. This has led to potential data silos, lack of clinical integration, technology outpacing policy development, and issues over data access, quality, security, and reimbursement for digital health technologies. The rise of use and implementation of digital technologies in healthcare also requires an examination and appreciation of the digital inequalities that may be associated with their use, in particular, avoiding widening of existing gaps in access and equality.

### State of Health in the EU – A Key Source of Health Information in the EU

The 'State of Health in the EU' project aims to make health system information, expertise, and best practices easily accessible to policymakers and stakeholders who help to shape health policies. This information can be used to identify areas to focus on, such as the need to address the disruption of non-Covid care services during and after the pandemic.

The State of Health in the EU project is managed by the European Commission and is delivered with cooperation from the Organisation for Economic Cooperation and Development (OECD), and the European Observatory on Health Systems and Policies. Key findings from the most recent round of data collection indicated that there were major disruptions in cancer care due to the Covid-19 pandemic.

Key takeaways from the 2021 Companion Report for State of Health in the EU include:

1. Understanding the far-reaching health impacts of the Covid-19 pandemic
2. Locking-in the advantages of digital innovation in healthcare delivery and public health



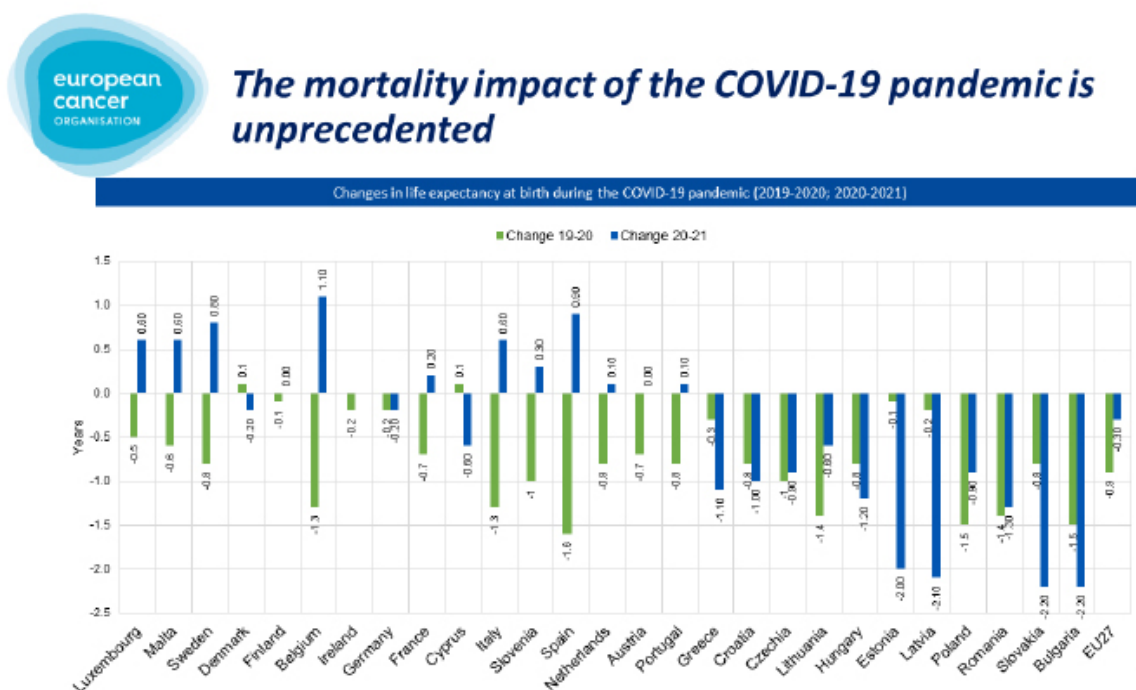
### 3. Rethinking healthcare workforce strategies and planning after the Covid-19 pandemic

Prior to the pandemic, life expectancy was generally on the rise within the EU. However, from 2020, this trend has now reversed with a reduction in life expectancy in all countries except two, with the EU average declining by almost one year. Existing variances in health workforce capacities across the EU were exacerbated as a result of the pandemic and resources were allocated away from non-Covid related activities in the health system. Consequently, this has increased unmet needs across the EU, with one of the most critical areas of care affected being cancer care. Healthcare systems across the EU still face a yet unquantified burden from 'long-Covid', as well as other risks such as antimicrobial resistance, the war in Ukraine, the health effects of climate change, and health workforce labour shortages.

## Conclusions

There is still a significant lack of data standardisation and integration across technologies, within health systems, and throughout Europe itself, which prevents the potential benefits of new technologies being fully realised. The integration between primary care (e.g., GP records), and secondary care (e.g., specialist / hospital records), remains largely absent. Applying lessons learnt from Covid-19, especially with respect to care in community settings, health systems should utilise new digital tools to ensure that patients are always at the centre of care. Additionally, the importance of shared decision making between healthcare providers and patients should not be underestimated, and can be facilitated by adoption of new technologies and practices such as ePROs.

Figure 6. The Mortality Impact of the Covid-19 Pandemic



## KEY POLICY RECOMMENDATIONS

- Data, research, and lessons learnt from the Covid-19 pandemic must be applied, including the demand to put cancer at the top of the European health agenda
- Cancer care to underserved communities should be improved, and can be achieved by diversifying traditional approaches to treatment and care, as well as through accelerated use of innovative and digital technologies
- Patient reported outcomes (PROs) should be used to assess and address patient needs for those living long-term with cancer. Preferably, as part of routine care, within the community setting, and electronically (ePROs). Use of such practices should also be encouraged to better facilitate shared decision making in cancer care
- The introduction and use of digital health technologies should be carefully planned and integrated to avoid data silos, to reduce inequalities, to ensure that regulation and reimbursement keeps pace with innovation, and that the full benefits of real-world data/evidence (RWD/E) are realised
- Ensuring data standardisation can facilitate the use and benefits of new technologies for cancer care in the community, including in underserved communities

## FIND OUT MORE

- **Special Network on the Impact of Covid-19 on Cancer**  
[europeancancer.org/topic-networks/16:impact-of-covid-19-on-cancer.html](https://europeancancer.org/topic-networks/16:impact-of-covid-19-on-cancer.html)
- **7-Point Plan to Build Back Smarter from Covid-19**  
[https://bit.ly/ECO\\_7PointPlan](https://bit.ly/ECO_7PointPlan)
- **This is Living With Cancer platform and app**  
[thisislivingwithcancer.com/living-with-app](https://thisislivingwithcancer.com/living-with-app)
- **UK Top 10 Living with and Beyond Cancer Research Priorities**  
[bit.ly/PSP-research-priorities](https://bit.ly/PSP-research-priorities)

# Caring For Cancer Patients In The Community Setting: Using Digitalisation To Ensure Safety And Efficiency

## SUMMARY

- The digitalisation of health systems is still work in progress across Europe. There are a number of valuable experiences at both the national and EU-level that can be shared as best practices, and can be applied as lessons learnt
- There is an acute need to improve patient safety and healthcare professional wellbeing, particularly in the post Covid-19 pandemic context
- Several high-level policy frameworks such as the Beating Cancer Plan, EU Mission on Cancer, and European Health Data Space, could be used to strengthen cancer care in the community setting
- As health systems rollout digital innovations, end users (patients and healthcare professionals) are in a prime position to provide valuable feedback to help their development and implementation

**Co-chaired by Gilly Spurrier-Bernard, Vice-Chair, ECO Patient Advisory Committee; and Vice-president of Melanoma Patients Network Europe, and George Valiotis, Executive Director, European Health Management Association (EHMA), in discussion with Grant Carroll, National Cancer Information System Chief II Pharmacist, National Cancer Control Programme, Kyriacos Hatzaras, Programme Officer, EU Policies of Unit H3 – eHealth, Wellbeing and Ageing, Directorate-General CNECT, European Commission, and Nicolás González Casares MEP, Member, Committee on the Environment, Public Health and Food Safety (ENVI).**

Many patients feel a disconnect with health systems once they reach the community setting. However digital tools have great potential to improve both cancer outcomes, as well as the functioning of health systems (such as the linkage between hospital and community settings, addressing the disconnect that currently exists). This issue is further compounded by health systems across Europe which are facing serious capacity and personnel shortages. As such, the need for digital solutions and infrastructures has never been greater.

## Digitalisation of Health Systems, Including Medication Management, Means Improved Health Systems

Health managers can play a role in achieving the goals of increasing patient centredness, supporting the workforce to respond better to crises, and

improving patient safety, for example, using digital technologies to reduce medication errors and harm. It is estimated that one person per million dies every day due to a medication error, with more than half of this occurring in the community care setting.<sup>7</sup>

*Almost half of the medication harm to patients is estimated to be occurring in the community and ambulatory care setting. How can we improve? Better medication management is an important element.*

Comprehensive data on harm to patients from medications used in the community care setting are lacking across Europe. Harm can also be caused by interruptions to continuity of care as a result of medicines shortages and disruptions to supply.<sup>6</sup> Additionally, visibility, traceability, and accurate data on medication stock and supply are lacking across Europe, which also has consequences for medication use and safety. There are low levels of digital medication management pathways across Europe. In the Roundtable it was highlighted that the Netherlands is presently the only EU country to have implemented a nationwide programme using barcodes for medication traceability.<sup>6</sup>

*If we're going to be serious about real world evidence and real time data, we need strong systems of digitisation to support it.*

**Figure 7. Scaling Up and Implementing Digital Innovations for Medication Management Will Enhance Cancer Care**



## Scaling up and implementing digital innovations for medication management will enhance cancer care



- Patient harm and healthcare professional risk reduced
- Reduced administrative burden, increased satisfaction and productivity, and reduce risk to healthcare professionals' (second victim).
- Generate real-world evidence and real-time data
- Eliminate data silos and provision of critical data
- Personalisation, precision medicine and AI implementation

Better use of data and use of digital innovations for medication management will enhance cancer care, including for patients in the community setting. It is estimated that approximately 40% of nurses' time is spent on administrative tasks.<sup>8</sup> However, the use of digital innovations in medication management can not only reduce the administrative burden (by more than three hours a day), but also can increase healthcare professional satisfaction, productivity levels and reduce the risk of medication errors.<sup>9</sup> Every hour of reduced administrative activity is a potential additional hour of patient-facing time for the healthcare professional – and the healthcare system.

Health systems can improve medication management and supply systems by ensuring the implementation of interoperable digital medication management systems and tools that collect real-time data and the use of personalised, precision medicine and AI technologies. Additionally, digitalisation of medication data can assist in better managing medicine shortages, including improving having access to real-time and accurate information on the demand and inventory of medicines. Investing in digital infrastructure and skills for patient safety can improve patient outcomes, staff wellbeing, and the efficiency of healthcare settings.

### **A National Cancer Information System Inspired by a National Cancer Control Programme**

In Ireland, the evolving National Cancer Information System (NCIS) aims to facilitate a patient-centred, longitudinal, and accessible care record, within

and across hospitals, making the right information available at the right time, and in the right place. The aim of the NCIS is to ensure safe and effective chemotherapy prescribing and administration and data sharing. The NCIS has been driven by the National Cancer Control Programme (NCCP) in response to requirements identified by medical oncology consultants and healthcare professionals delivering cancer care, with the NCIS currently deployed to 7 of the 26 hospitals providing systemic anti-cancer treatment, with rollout ongoing. Additionally, the NCIS is complemented by the Sláintecare reform programme and the Health and Service Executive National Service Plan 2022.

Via this system, multi-disciplinary meetings are facilitated in different parts of Ireland, without the need for either patients or their health data to move between treatment centres. The system integrates medication management and record keeping systems. The technical integration of the shared treatment record supports the longitudinal cancer care record through cross-referencing and linking of demographic data from disparate hospital systems. Data that are captured through the system are useful both in the direct provision of treatment and care to the patient, as well as for research and reporting purposes.

There are however challenges in implementing and using the NCIS, such as: navigating the complete health IT landscape; no 'functional' health identifier for patients; the need for standardisation of laboratory inputs and reporting; the standardisation of practice; and issues relating to privacy and access.



Tangible results from the NCIS include:

- Access to information at point of care
- Legible prescriptions
- Automated calculations
- Closed loop administration
- Documentation and communication

In terms of future plans for the NCIS, as well as provision of care closer to home, a patient portal will also be established and a more seamless information flow between primary and secondary care is foreseen.

### Linking Local, Regional, and National Systems Together

In Estonia, eHealth records, as well as a computerised physician order entry (CPOE) and pharmacy modules specialised for oncology, act as facilitators in achieving a number of improvements in patient safety brought about by digital innovations, including a decreased risk of medication error during prescribing and production.

The eHealth record in Estonia is a centralised national database which includes X-rays, ePrescriptions, and a national eBooking system, amongst others. To support this, a system of automatic and digitalised documentation is

available that reduces the burden of administration for HCPs and therefore, increases the amount of patient-facing time. Further improvement is needed however, to link local and regional systems for cancer care to national systems, including to eHealth records. Additionally, a gap exists where community pharmacists are currently not able to access to such eHealth records.

### The EU as a Facilitator for Digital Innovations in Healthcare

The European Commission is working on a comprehensive strategy to advance digital technology and infrastructure, as well as the interoperability of data and systems, and data and patient access. There are a large number of EU initiatives currently underway to support a strong environment for uptake of digitisation across many areas of healthcare, including cancer care. The policy framework includes Europe's Beating Cancer Plan,<sup>10</sup> the EU Mission on Cancer,<sup>11</sup> the proposed regulation for a European Health Data Space, and the Commission Communication on Digital Transformation of Health and Care.

The respective elements of the policy framework feed into a broader aspiration for a strong European Health Union, supported at the highest political levels of the European Commission. Key ongoing actions include initiatives utilising tools such as artificial intelligence in healthcare, pharmacogenomics, exchange of electronic health records across Europe, and initiatives to facilitate patient access to healthcare data, among others. There are also efforts underway to facilitate deployment of the technical infrastructure at national levels to support primary and secondary use of data across the EU. Beyond the core policy framework, work is also underway with the *Proposed Draft Regulation for Artificial Intelligence*, and the *Data Governance Act* promoting data altruism and donation.

From a political perspective, the European Parliament now has an increased role in driving the use of digital innovations in healthcare, especially in the context of the ongoing work of the European Health Data Space and applying lessons learnt from the Covid-19 pandemic. Digitalisation can be beneficial in addressing medicines shortages, for example, with digital communication between supply chain actors on stock levels to mitigate shortages, with the European Health Data Space expected to create a European Shortages Monitoring Platform by 2025.

### CASE STUDY

The National Cancer Information System (NCIS) is a clinical information system that supports the care of oncology and haemato-oncology patients (including the provision of SACT) across Ireland. The system will be used in the designated cancer centres, satellite centres and other locations where medical oncology and haemato-oncology patients are receiving SACT treatment.

Access to the patient's cancer treatment record will be available through the NCIS. This will ensure that all relevant healthcare providers will have access to the patient's data in an appropriate and timely manner.

NCIS has a number of key functionalities which will be used by various health care professionals including prescribing, electronic medication administration records, support for aseptic compounding, Multi Disciplinary Meeting (MDM), documentation and reporting.



Digitalisation and the use of digital tools for health can also improve access to healthcare for patients in rural communities. Patients must be involved and engaged in not only the use of these tools, but their design and implementation to ensure they are fit for purpose, as the ultimate end-users. This is particularly relevant given the higher burden of cancer in the over 60's demographic of society, who may also be less digitally literate.

The EU can be a facilitator in the significant changes that are needed, for example, via the European Health Data Space. The Health Data Space will be established as a platform for the future, which will facilitate the primary and secondary use of data for treatment for patients, but also to facilitate and stimulate research and innovation in health, including for cancer care in the community. There is also a role for digitalisation to play for cancer, for example in the context of the Comprehensive Cancer Centres as part of Europe's Beating Cancer Plan.

*Speaking as a nurse, I can also say that this is a great opportunity for healthcare professionals, in particular in the context of the post Covid-19 pandemic measures to improve healthcare system resilience,* said Nicolas González Casares MEP.

## Conclusion

In order to achieve the aspirations and full benefits of the digitalisation of cancer care, and care for those living with cancer, an effective legal framework is required alongside dedicated funding to support uptake and implementation. Examples at an EU level include: the European Health Data Space; the Artificial Intelligence Act; EU4Health; Horizon Europe; and the EU Recovery and Resilience Facility. All provide support to achieving the political commitment of the EU to support the digital transition of health systems. For example, additional funding has been made available for preparatory actions for capacity building activities in Member States that will materialise in specific projects as progress is made with the negotiation, adoption, and implementation of the European Health Data Space.

Broad clinical and management leadership is critical to guaranteeing that digital innovations are designed, adopted, and implemented in practice, and avoiding collection of poor-quality data, or no data collection at all. Training users of digital innovations should also be integrated alongside their development and implementation, to facilitate their effective uptake and use in practice

**Figure 8. EU Policy Priorities Update: Digital Health & Cancer**



## Overview

- **comprehensive strategy: advanced digital technology and infrastructure, interoperability of data and systems, data and patient access**
- **policy framework:**
  - Europe's Beating Cancer Plan, EU Mission on Cancer (research)
  - **European Health Data Space** proposed regulation
  - COM Communication on Digital Transformation of Health and care
- **Key ongoing actions:**
  - **Federated European infrastructure for cancer images**
  - **1+MG (1 + million Genomes)**
  - **EEHRxF – the European Electronic Health Record Exchange Format**
  - **EUDI / eID Wallet – the European Digital Identity Wallet**
  - **EDITH CSA fostering an inclusive ecosystem for virtual twin modelling in healthcare**

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## KEY POLICY RECOMMENDATIONS

- Health systems should invest in digital infrastructure and skills for patient safety and health systems efficiency. This should include a focus on interoperable IT systems in healthcare setting to reduce administrative burden on healthcare professionals and increase their patient-facing time
- A digital, longitudinal, and accessible patient-centred record, integrated into a National Cancer Control Programme (or other similar national policies), can support safe and effective cancer care in the community setting. However further collaboration is still required between primary and secondary care providers
- Collaboration is needed between national and EU policymakers to ensure that local, regional, and national health data systems are interoperable, and to ensure healthcare professionals in the community setting have appropriate access to provide effective cancer care
- High-level policy frameworks such as Europe's Beating Cancer Plan, the EU Research Mission on Cancer, and the European Health Data Space provide opportunities to strengthen the European Health Union, including cancer care in the community setting
- Health systems should ensure there is broad and senior clinical leadership involved in all digitalisation of health services and practices

## FIND OUT MORE

- **OECD: The Economics of Medication Safety: Improving Medication Safety Through Collective, Real-time Learning**  
[https://bit.ly/OECD\\_WP147](https://bit.ly/OECD_WP147)
- **Irish National Cancer Strategy 2017 – 2026**  
[https://bit.ly/Irish\\_NCS](https://bit.ly/Irish_NCS)
- **European Health Data Space proposal for a regulation**  
[https://bit.ly/EHDS\\_Proposal](https://bit.ly/EHDS_Proposal)
- **EU4Health**  
[https://bit.ly/EU4Health\\_Programme](https://bit.ly/EU4Health_Programme)

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## Concluding Remarks

Kathy Oliver, Co-Chair, ECO Patient Advisory Committee; and founding Co-Director, International Brain Tumour Alliance (IBTA), and Mirjam Crul, ECO Board Member; Co-Chair, ECO Special Network on the Impact of Covid-19 on Cancer and Workforce Network; and Vice-President of the European Society of Oncology Pharmacy (ESOP), and and Richard Price, Head of Policy at the European Cancer Organisation (ECO).

### Living with Cancer: The Metastatic Breast Cancer Study

Discussions during the first session revealed that data collection and their interpretation for people living with cancer in the long-term, with a recurrence of cancer, or with metastatic cancer are currently lacking across the globe. Furthermore, recent research has identified several key unmet needs for those living long-term with cancer, including the need to address the psychological and emotional effects of cancer and its treatment. Better data collection for people living with cancer, with a recurrence of cancer, or with metastatic cancer, (for example through registries), is needed to improve quality of care and health outcomes. Better care coordination, including support for the psychological and emotional effects, will address key unmet needs for those living long-term with cancer.

Another key point raised during the first session was that despite the development of the European Code of Cancer Practice, (including its tenth Right to Reintegration ), EU-wide action on the right to return to work is currently lacking. Stigma was also identified as one of the key challenges to overcome for people living with cancer. To address these issues, full implementation of the European Code of Cancer Practice, including its tenth right to Reintegration, across Europe, is essential. Furthermore, EU-wide action on the right to return to work, supported by both legislation and best practice guidance for implementation, will help facilitate this aspiration.

Finally, speakers and participants highlighted that primary care professionals are an underutilised resource within health systems, and health systems should strive to ensure that these healthcare professionals play a greater role in caring for those living long-term with cancer.

### Cancer Care in the Community: Lessons from Covid-19

From the second session, it is clear that the Covid-19 pandemic has significantly disrupted cancer care across Europe, with wide-reaching effects for cancer prevention, detection, treatment, and survivorship. As such, data, research, and lessons learnt from the Covid-19 pandemic must be applied to ensure Europe can build back stronger, more fit-for-purpose and resilient systems of cancer care.

There was broad consensus that traditional approaches to treatment and care risk excluding or underserving specific communities. The accelerated uptake (and widespread use) of digital technologies and data captured from the Covid-19 pandemic, provide opportunities for advancement and enhancement of cancer care in the community. Cancer care to underserved communities can be improved by diversifying traditional approaches to treatment and care, as well as through accelerated use of innovative technologies, including digital technologies. Patient reported outcomes (PROs) should be used as a minimum to assess and address patient needs for those living long-term with cancer, preferably as part of routine care within the community setting. Furthermore, speakers and participants called for the use of electronic PROs (ePROs) to better facilitate shared decision making in cancer care.

However, it was noted that as these technologies continue to be used and rolled out further, careful integration is required to avoid creating and perpetuating data silos, widening inequalities, and slowing implementation. Policymakers should ensure that regulation and reimbursement keep pace with innovation, and the full benefits of real-world data/evidence (RWD/E) must be realised. Making sure data are standardised can facilitate the use and benefits of new technologies for cancer care in the community, including in underserved communities.

### Caring for Patients in the Community Setting: Using Digitalisation to Ensure Safety and Efficiency

In the final session, speakers and participants noted that despite recent progress, the digitalisation of health systems is still work in progress across

Europe. However, there are a number of valuable experiences at both national and EU-levels that can be shared as best practices, and lessons learnt. For example, health systems should invest in digital infrastructure and skills for patient safety and health systems efficiency, including for reducing administrative burden on healthcare professionals and thus increasing their patient-facing time. A digital, longitudinal, and accessible patient-centred record, integrated into a National Cancer Control Programme (or other similar national policies), can support safe and effective cancer care in the community setting, however further collaboration is still required between primary and secondary care providers.

There was strong agreement that collaboration is needed between national and EU policymakers to ensure that local, regional, and national health data systems are interoperable and ensure healthcare professionals in the community setting have appropriate access to provide effective cancer care. Several high-level policy frameworks such as Europe's Beating Cancer Plan, the EU Research Mission on Cancer, and the European Health Data Space provide opportunities to strengthen the European Health Union, including cancer care in the community setting.

Finally, speakers and participants emphasised that as health systems rollout digital innovations, end users (patients and healthcare professionals) are in a prime position to provide valuable feedback to help their development and implementation. Health systems should ensure there is broad and senior clinical leadership involved in any digitalisation of health services and practices, to maximise its impact for the benefit of patients.

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# Participants in the Survivorship and Quality of Life Network

## Member Organisations Part of this Network



## Patient Organisations Part of this Network



## Charities and Foundations Part of this Network



# Participants in the Quality Cancer Care Network

## Member Organisations Part of this Network



## Patient Organisations Part of this Network



To view the latest list of the participants to the Survivorship and Quality of Life Network or to the Quality Cancer Care Network, visit our website.

If you would like to find out more about the Quality Cancer Care Network, please contact us at: [info@europeancancer.org](mailto:info@europeancancer.org)



As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community.

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