european cancer organisation

The Time to Act is Now

Action Report from Covid-19 & Cancer Workforce Special Network Meeting





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Principal Authors

Matti Aapro, President of the European Cancer Organisation Andreas Charalambous, President-elect of the European Cancer Organisation, Co-Chair of the Workforce Network Miriam Crul, Co-Chair of the Special Network on the Impact of Covid-19 on Cancer and of the Workforce

Mirjam Crul, Co-Chair of the Special Network on the Impact of Covid-19 on Cancer and of the Workforce Network

Mark Lawler, Co-Chair of the Special Network on the Impact of Covid-19 on Cancer Geerard Beets, Co-Chair of the Workforce Network

Coordinators

Agnese Abolina, Communication and Community Manager Richard Price, EU Affairs Policy Manager, European Cancer Organisation Norbert Couespel, Policy and Research Officer, European Cancer Organisation

Contributors

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Executive Summary

The ongoing Covid-19 pandemic has brought about a number of challenges to cancer care and management. These require timely and firm policy responses, backed up by robust intelligence and active campaigns, to ensure that services are not only more resilient to future challenges but also built back better than before.

Cancer patients and citizens, healthcare professionals, policymakers and health system leaders must not hold back from tackling cancer, despite all the disruption brought about by the pandemic. As such, cancer must remain at the top of everyone's agenda, as the backlog of cancer cases is addressed and access to services, free of Covid-19, is maintained.

Key issues that emerged as the pandemic unfolded include the lack of early cancer detection, disruption to multidisciplinary and coordinated care, and the halting of clinical trials. These have been accompanied by increasing stress among patients and citizens, and higher rates of burnout among healthcare professionals as the pressures on systems mounted.

Comprehensive data on the impact of the pandemic is needed to understand and tackle these problems and make sure that they are not repeated. There is a need for greater access to speciality training to help healthcare professionals deal with evolving clinical realities, and the workforce shortages and often difficult working conditions that have been exacerbated by the pandemic need to be addressed.

Alongside the difficulties, the Covid-19 pandemic offers opportunities for rebuilding cancer services, but this cannot be achieved without clear policy recommendations and a deep understanding of the current situation. Above all, the Time to Act is now.

Introduction

By Matti Aapro, President of the European Cancer Organisation

The European Cancer Organisation's Workforce Network and Special Network on the Impact of Covid-19 on Cancer have both published timely and important policy papers in recent months that set out the key challenges resulting from the ongoing Covid-19 pandemic.

These Reports are accompanied by firm policy recommendations, backed up by robust intelligence and active campaigns, to address these challenges and ensure we not only overcome the problems caused by the pandemic, but also seize the possibilities to rebuild our cancer care systems and make them more resilient.

Some of these challenges are common to both Networks, such as workforce shortages and difficult working conditions, as is the opportunity to build back better from Covid-19. This includes the greater deployment of digital solutions to streamline care and reduce the risk of errors.

To examine these challenges and opportunities, achieve synergies in the activities of the two Networks during 2021, and obtain mutual support for their policy objectives, the European Cancer Organisation called a Covid-19-Workforce Special Network meeting.

Held on 28 April 2021, the World Day for Safety and Health at Work, the joint meeting updated Member Societies, Patient Advisory Committee members and other stakeholders on the latest activities of the <u>Time To Act campaign</u>, which was launched internally with European Union Health Commissioner Stella Kyriakides on 7 April, 2021.

The campaign urges cancer patients and citizens, healthcare professionals, policymakers and health system leaders not to let Covid-19 stop them from tackling cancer, despite all the disruption brought about by the pandemic. Cancer must remain at the top of everyone's agenda, with particular emphasis on addressing the cancer backlog and ensuring that cancer services keep going and stay free of Covid-19.

To achieve that, the European Cancer Organisation is collaborating with national societies, patient organisations, charities and the healthcare industry to develop a toolkit that has been translated into over 30 European languages and launched on 11 May, 2021. Participants at the meeting were then invited to share their experiences of the impact of the Covid-19 pandemic on cancer care, and exchange ideas on the key priorities for building back services and ensuring healthcare systems are robust enough to face future challenges.

Key themes that emerged from the discussion included the lack of early cancer detection, and disruption to multidisciplinary and coordinated care, as well as to clinical trials. These have been accompanied by rising distress in citizens and in cancer patients, and higher rates of burnout among healthcare professionals.

The need for comprehensive data to understand the impact of the pandemic on cancer care was underlined, alongside the need for greater access to speciality training to allow healthcare professionals to adapt to the evolving clinical realities brought about by the pandemic, alongside novel strategies to ensure the ongoing provision of care.

Finally, the Workforce Network presented its consensus paper <u>Working Against Cancer</u>. <u>Giving Professionals the Right Tools for the Job</u>¹ which was launched on 7 April 2021. This sets out the key workforce challenges in the context of implementing Europe's Beating Cancer Plan, with particular emphasis around workforce shortages, professional mobility, working conditions, and educational and developmental opportunities, all of which have been disrupted by the Covid-19 pandemic.

To resolve these difficulties, the paper, written in close consultation with European Cancer Organisation's Member Societies, Patient Advisory Committee members and other invited expert stakeholders, sets out a series of clear policy recommendations, as well as the next steps required to make sure they become a reality for the cancer workforce all across Europe.

Overall, the meeting was an excellent opportunity for participants to exchange ideas and the result was a series of extremely positive inputs that gave us all clear direction for rebuilding cancer services. Above all, it underlined that the Time To Act is now. In the words of the campaign:

Don't let Covid-19 stop you from tackling Cancer.

Special Network on the Impact of Covid-19 on Cancer

In the first part of the meeting, Mirjam Crul and Mark Lawler, Co-Chairs of the Special Network on the Impact of Covid-19 on Cancer, introduced participants to the Network and the Time To Act campaign, the key message of which is not letting Covid-19 get in the way of tackling cancer. It emphasises that, "for all the disruption the pandemic has brought, now is the time for you to act and tackle your concerns about cancer".

Lawler explained that the campaign was internally launched with European Union Health Commissioner Stella Kyriakides and high-profile MEPs from the Special Committee on Beating Cancer on 7 April, 2021. This was followed by a consultation with the cancer care community during April, and a call for collaboration from national stakeholders, national societies, patient organisations, charities and the healthcare industry. In parallel, cancer intelligence is being gathered at European level to develop key messages that will bolster the Time To Act Campaign.

There is currently a toolkit under development that brings together key elements of the <u>Covid-</u> <u>19 & Cancer Hub</u>, the <u>7-Point Plan to Address the</u> <u>Urgency and Build Back Better</u>,² and the <u>European</u> <u>Code of Cancer Practice</u>.³ This has been translated into over 30 European languages and launched at a virtual event with the Special Committee on Beating Cancer on May 11, at TimeToActCancer.com. It will be followed by national launches in a number of countries in late May and June.

Crul set out the key messages of the campaign, which are directed at cancer patients and citizens, healthcare professionals, policymakers and health system leaders. To patients and citizens, the message is: *Don't delay*. The campaign urges patients to see their doctor if they have warning signs of cancer, to keep screening and treatment appointments and be reassured that cancer services are safe.

The message to healthcare professionals is: *You are not alone*. They are encouraged to share experiences, information and examples of what has worked and what has not during the Covid-19 pandemic, for the benefit of patients and the cancer community.

Finally, the message to policymakers and health system leaders is: *Cancer must be at the top of the agenda*. This means that they must act now to address the cancer backlog, keep cancer services going and ensure they are free of Covid-19, all coordinated to help save lives.

Figure 1. Time to Act: Campaign Messaging



Cancer Patients and Citizens:

Don't Delay: See your Doctor if you have Warning Signs of Cancer. Keep your Screening and Treatment appointments. Re-assurance that cancer services are safe.



Healthcare Professionals:

You are not alone. Sharing experience, information and examples of what has worked and what hasn't for the benefit of our patients and community.



Policy-makers and Health System Leaders:

Cancer must be at the top of the agenda. Act now to address the cancer backlog. Keep cancer services going and free of Covid to save lives.

The campaign strapline and key messages are currently being translated into over 30 languages, and will be accompanied by a shot video, Crul explained.

Lawler continued that the campaign will be backed up by a data intelligence project, the aim of which is to build an evidence for the message. This is centred around the latest statistics on the Covid-19associated backlog in cancer screening, diagnosis, referral and treatment, the estimated excess cancer deaths linked to the backlog and the impact of the pandemic on different tumour types and on inequalities.

To achieve this, the European Cancer Organisation has entered into a partnership with IQVIA in two stages. The first is information acquisition and an initial analysis based on IQVIA's existing multi-wave survey, public data sources of population and prevalence estimates, a brief literature of the published literature and interviews.

This will be used to build a model that can be extrapolated to the EU27 countries and the UK. Understanding of the impact of the pandemic will then be broadened and refined to allow a more rigorous analysis. This will be backed up by a focussed qualitative survey and investigations into specific therapy areas, starting with breast, lung and colorectal cancer.

The need for such a detailed and in-depth datadriven approach, Lawler underlined, is because the Covid-19 pandemic has amplified existing inequities faced by cancer patients across the European region.

Key Learnings from the Covid-19 Pandemic

In the second part of the meeting, representatives of Member Societies, Patient Advisory Committee members and other invited expert stakeholders were asked to share their experience of how the Covid-19 pandemic has affected cancer care and services to identify commonalities, as well as the diversity of views.

From this wide-ranging and open discussion, a number of key themes emerged. One of the most important was the lack of early detection, with patients presenting at later stages and with more advanced disease. There has also been disruption to multidisciplinary and coordinated care, as well as to clinical trials, the effects of which will be felt for years to come. The disruption has been accompanied by rising cancer distress in patients and higher rates of burnout among healthcare professionals.

Participants underlined the need for comprehensive data to understand the impact of the pandemic on cancer care and the issues facing services, as well as how to clear the backlog of cases. There also needs to be greater access to speciality training to allow healthcare professionals at all levels to take on new roles and adapt to the evolving clinical realities brought about by the pandemic, alongside novel strategies to ensure the ongoing provision of care.

Kicking off the discussion, Jamie Wilkinson, from the **European Pain Federation** (EFIC), said the pandemic and the subsequent shutdown of cancer services highlighted the need for more specialised education and training for healthcare professionals in pain management, especially in cancer.

Jolanta Kunikowska, President of the **European** Association of Nuclear Medicine (EANM), said access to doctors was interrupted by Covid-19, right from the general practitioner level. This had a huge impact on cancer staging, with more patients presenting with more advanced and extensive disease rather than at the beginning of their cancer journey.

From the perspective of nuclear medicine, a survey conducted by EANM showed that the biggest impact on services was in March, April and May 2020, although the situation is now more stable. Initially, cancelled flights affected radioisotopic delivery for treatment, meaning that some forms of treatment were impossible. However, imaging services were less affected. A more detailed assessment of the impact of Covid-19 on nuclear medicine will be published as an editorial in the European Journal of Nuclear Medicine.

Csaba Dégi, Director of the **International Psycho-Oncology Society** (IPOS), emphasised that access to cancer care is a basic human right. He stressed that the development of cancer care plans is not just a medical question but a societal one. Mental health is a central aspect of that, especially as cancer distress is so often overlooked. Moreover, societal factors associated with poor mental health, such as social isolation, reduced access to services, job losses and financial distress, were exacerbated by the pandemic.

On the healthcare professional side, burnout is increasingly prevalent, with already present insecurities and distresses worsened by Covid-19. This was underlined by a survey of UK healthcare professionals, which highlighted concerns that the full impact of the pandemic is yet to be fully realised.⁴

Mary Coffey, from the **European Society for Radiotherapy and Oncology** (ESTRO), agreed that specialist training, including in radiotherapy, is increasingly important, particularly as the Covid-19 pandemic meant that staff at all levels, especially radiation therapists, took on additional responsibilities.

One positive that came out of the pandemic is that novel, shorter, fractionation regimens were explored right across Europe, with benefits to patients from having fewer hospital visits without compromising the quality of care. However, radiation therapists often did not have the specialist education to be able to adapt clinical care to the new realities.

An often overlooked consequence of the pandemic was that ubiquitous and constant mask wearing made it difficult to communicate with patients. This exacerbated the sense of isolation engendered by patients not being able to take people along with them to their appointments. For a treatment such as radiotherapy, this only served to increase the stress experienced by patients and their families.

Sarah Collen, from the **European Association of Urology** (EAU), echoed the comments on access to training, adding that the increasing need for multidisciplinary care underscores the potential role of inter-specialty training.

She also underscored comments made by Mark Lawler earlier in the meeting (see Special Network on the Impact of Covid-19 on Cancer) on the role of data, saying that the Covid-19 pandemic has shone a light on the need for better use of data in cancer care, with real-world and real-time evidence.

A key concern for the EAU is the reduction in the early detection of cancers during the pandemic, which was a very prominent issue for prostate cancer. This went right through to primary care, with general practitioners feeling the pressure to identify patients earlier on in their cancer journey. The question then becomes how to work with and better support primary care to introduce an early detection programme that can function even in these challenging circumstances.

Anna Mislang, from the **International Society of Geriatric Oncology** (SIOG), explained that older people with cancer have been heavily impacted by the pandemic, due to not only the complications of the disease itself but also the disruption to multidisciplinary care they require, in both the hospital and community setting. Older patients do not necessarily have the reserve to wait for the opportune time for treatment, so the timing of diagnosis and treatment must be weighed against the risk of toxicities and the ongoing threat of the pandemic.

While telemedicine has allowed clinicians to conduct assessments and continue treatment planning, not everyone has access to the internet or digital devices, or knows how to operate them, particularly when carers may not be present to due lockdown.

In addition, the coordination of care, which is essential to avoid fragmentation and miscommunication, has been limited and disrupted, and strategies and platforms need to be developed to deliver services safely and effectively. Educational sessions could alleviate patients' anxiety and fears, address their concerns and correct misconceptions, and screening for distress, depression and anxiety should be encouraged.

Mehmet Ungan, immediate past President of **WONCA Europe**, said that they have put together a knowledge base of Covid-19 resources for general practitioners and family doctors,⁵ covering primary care in general but also cancer care and care homes.

Their work has shown that a major problem was the postponement of care, while in certain areas the workload of primary care doctors has shifted to the hospital. Nevertheless, a survey of WONCA Europe members on the impact of the pandemic on the functioning of healthcare and primary care also showed how services have adapted and redesigned themselves in response.

Next, Jacqueline Daly, Ken Mastris and Paulina Gono from the **European Cancer Patient Coalition** (ECPC) reiterated previous comments that cancer services are still catching up over late diagnoses, and that the pandemic had caused a huge toll on mental health. The delays in screening have caused anxiety, while many patients have experienced an increased sense of isolation during the pandemic.

In addition, human papillomavirus (HPV) vaccination was put on hold in many countries, and a cause of concern for patients was that many clinical trials were postponed or interrupted, potentially negatively impacting cancer care for years to come.

The ECPC published a joint letter in April 2021,⁶ supported by 324 organisations, including the European Cancer Organisation, that launched a global campaign to ensure patients can access diagnosis and treatment safely, identify the impact of the pandemic on cancer services and design services to mitigate it, and resource cancer services properly and safely for the long term.

In 2020, ECPC published international recommendations for patients with cancer during the Covid-19 pandemic,⁷ translated into 23 languages, which was followed up in 2021 by guidelines on Covid-19 vaccinations for cancer patients.⁸ Later this year, the ECPC will share the results of a survey on the use of telemedicine. However, preliminary findings have already showed that, while cancer patients had experience of telemedicine during the pandemic, technical limitations were a notable feature, and many said they preferred personal contact.

Zorana Maravic, Acting CEO of **Digestive Cancers Europe**, said that an example of the reality of screening delays due to the Covid-19 pandemic is that patients with positive faecal tests have been unable to undergo endoscopy, which was extremely stressful for patients and their families. Even now, screening has not picked up in some European countries.

Others at risk have also expressed fears over going to see their general practitioner, while those already diagnosed and undergoing treatment have seen their surgical procedures delayed as they were considered non-urgent. Yet there is no such thing as non-urgent surgery in this patient population. In some countries, patients with, for example, stoma have not received proper advice, management and support, further contributing to patient stress, as they cannot deal with it on their own.

Carers have been unable to go with cancer patients to the hospital, which has added to the distress patients experience. This underlines the need for greater referral to patient organisations to offer them more information, and the role of patient support groups. All cancer patients, she stressed, not just those undergoing chemotherapy, should also be vaccinated against Covid-19 as a priority.

Katie Joyner, Patient Advocacy Programme Manager at **Myeloma Patients Europe**, said that two surveys, one with patients and the other with member organisations, are currently underway to understand the impact of Covid-19 on care.

What is known is that, similar to other diseases, myeloma patients have experienced delays in diagnosis, the long term impact of which is currently unknown. They also have ongoing anxiety about visiting the hospital and getting their healthcare needs met.

The most commonly reported delays in care in this patient population are those around stem cell transplants. The impact varies by country, with those hardest hit by the pandemic typically experiencing the most delays, potentially related to the availability of intensive care beds.

Issues over telemedicine have also been expressed, especially as myeloma patients tend to be older and more reliant on in-person support groups to address their concerns. There are ongoing reports of depression and anxiety, and telemedicine, even if accessible, is not as effective in tackling those issues.

Peter van Dam, from the **European Society of Breast Cancer Specialists** (EUSOMA), said they are collating Europe-wide data on the impact of the Covid-19 pandemic on breast cancer care but national data from Belgium indicates diagnoses were down by 11% in 2020 compared to previous years. Whether this translates into patients presenting later stages remains to be seen, as disease progression is slower than that for lung cancer, for example.

Breast cancer care has tried to adapt to the situation, with novel regimens allowing the shortening of adjuvant radiotherapy courses being rapidly implemented in response to the pandemic.

A Covid-19 vaccine trial in breast cancer patients is also currently underway, with preliminary results suggesting that it is very well tolerated, with no increase in adverse events even in those currently receiving treatment. However, it appears that antibody levels are lower in patients with some haematological cancers, and further results are awaited.

Roberta Ventura, from the **Advanced Breast Cancer** (ABC) Global Alliance, said that their primary focus is clearing the backlog of cancer patients by addressing the interruption of referrals and services, and how that will affect the number of cancer cases further down the line. Another concern is how the disruption to clinical trials will worsen cancer outcomes now and in the future. She echoed previous comments that telemedicine has both positive and negative aspects and physicians and healthcare professionals need training on how to communicate remotely. ABC Global Alliance has also conducted webinars and education sessions for patients on Covid-19 to pose their questions to experts, which revealed a lack information around whether it was safe to be vaccinated and the impact of the vaccine on treatment.

Barbara Wilson, Founder and Director of **Working** with Cancer, said that the Covid-19 pandemic has been affecting people who continue working while having a cancer diagnosis, with concerns around shielding at home and employers not setting boundaries, especially as video calls have sometimes given the impression that patients are well when they are not. The pandemic has consequently left patients having to cope with isolation and being cut off from their community, work colleagues and employer, who often does not understand their concerns.

Sushmita Sen and Cheryl Law, from **Roche**, said they have launched a three-phase Covid-19 and Cancer project. The first phase is coordinated with the European Cancer Organisation's Time To Act campaign and is looking at how to increase rates of screening, especially for high-risk individuals, as well as restoring public trust in healthcare systems.

Phase two will tackle the lack of guidance in some of the more urgent areas of the cancer backlog, including treatment, with healthcare professional, patient and stakeholder cooperation as a key priority. They are also collating further local and national level data to examine, for example, to what extent dosing schedules are changing as a result of the pandemic. It is vital that best practices in cancer care during the Covid-19 era are captured and quickly disseminated.

Lucy Dance, from **AstraZeneca**, reiterated the concern over the backlog of cases, and said they are working to ensure that patients come forward and re-present to oncology services. They have launched campaigns in several countries to drive public awareness, as well as offer support for local campaigns.

The need for this has been highlighted by reports of the later presentation of patients following a year of shielding and being worried about coming forward with symptoms. This has been a particular concern for lung cancer. One of the most important ways of helping with this is to gather data to understand the extent of the problem in different cancer populations.

Another important focus is the home-based delivery of treatment to meet the needs of patients,

and they are working with regulators to ensure that medications have the correct licences.

Jose Luis Gomez, from **BD**, underlined that the catch-up in cancer services following the pandemic should be achieved while protecting the safety of patients and healthcare professionals. While the training of more doctors and nurses is a medium-term solution, the deployment of technology and digitisation is a vital part of the solution in the shorter term to improve efficacy and patient safety.

The automation of medication management, which is already being trialled in leukaemia and lymphoma, is one approach, while self-sampling could be one way of tackling the screening backlog. Technology can also be used to reduce treatment delays.

Although these solutions can be implemented to help tackle these issues during the Covid-19 pandemic, they will remain in place once it is over and help prevent the delays that were present before the pandemic, and thus offer significant long term benefits.

Harriet Doig, from **MSD**, said that, regarding the diagnosis of cancers at later stages, the question is

whether the services are available, in terms of staff, beds and medicines, to treat these patients, as they will require more complex management than if they were diagnosed earlier on.

Another aspect is that cancer charities and patient associations have suffered a drastic loss of income due to lockdown, which has been a major issue for patients and their support.

Looking specifically at individual diseases, head and neck cancer and lung cancer are examples of the Covid-19 pandemic exacerbating pre-existing inequalities, as they are typically associated with lower socioeconomic status. In Ireland, rates of head and neck cancer are higher in Irish traveller communities, a group that has been further marginalised by the pandemic.

Summarising the discussion, Mark Lawler thanked all the participants for their excellent input and said it provided a number of ideas and approaches that can be incorporated into the Time To Act campaign. One of the most important learnings was that data intelligence is key and he urged participants to share data intelligence from their particular organisations with the European Cancer Organisation secretariat.

The Right Tools for the Job

In the final part of the meeting, Andreas Charalambous and Geerard Beets, Co-Chairs of the Workforce Network, emphasised that the European Code of Cancer Practice enshrines the right of patients to have access to specialised multidisciplinary care.³

Europe's Beating Cancer Plan,⁹ published earlier this year, underlines that high-quality cancer care also depends on having a high-quality workforce, and that the European Commission will launch an inter-specialty cancer training programme in 2021 to deliver a more skilled and mobile workforce.

However, the Workforce Network, in its consensus paper Working Against Cancer: Giving Professionals the Right Tools for the Job,¹ has identified four key challenges, all of which have been exacerbated over the past 14 months by the Covid-19 pandemic.

These are resolving the difficulties caused by workforce shortages, reducing unnecessary barriers to professional mobility, improving occupational conditions to protect healthcare professionals and enhancing educational and developmental opportunities.

To achieve that, the paper sets out a series of policy recommendations to tackle each of the key challenges, such as adding a section on the promised Cancer Inequalities Registry dedicated to measuring patient access to cancer professions, and initiating a cancer-related skills partnership under the European Commission Pact for Skills strategy.¹⁰

Other recommendations include harmonising education and training requirements and increasing the mobility of skills and experience in cancer control across Europe. It also recommends conducting a study on the use of the European Union directive on the recognition of professional qualifications to improve access to high-quality multidisciplinary cancer control.¹¹

The paper recommends addressing the exposure of healthcare workers to cytotoxic products and radiation to protect healthcare professionals' wellbeing, and mandating the European Agency for Safety and Health at Work to focus on the occupational health and safety concerns of the cancer workforce as part of the European Union's collective efforts in tackling cancer.

Among other measures, it recommends that the inter-specialty cancer training programme of Europe's Beating Cancer Plan to include all professions and specialties involved in cancer control, and the inclusion of digital and other cross-professional skills in professional curricula, qualifications and requirements for continuous education.

Figure 2. The Next Steps

Direct outreach to decision-makers e.g.

- Inter-disciplinary training programme
- OSHA-EU; HERA

Wider promotion

- Events e.g. European Cancer Summit
- Social media
 material
- Journal publication

Inter-Network cooperation e.g

- Covid-19
- Inequalities
- Survivorship & Quality of Life

To achieve all that, the Workforce Network is calling for direct outreach to decision makers, wider promotion of the recommendations via events such as the European Cancer Summit, social media and journal publications, and cooperation with the European Cancer Organisation's Special Network on the Impact of Covid-19 on Cancer, <u>Inequalities</u> <u>Network</u>, and <u>Survivorship and Quality of Life</u> <u>Network</u>.

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Participants in the Workforce Network

Member Organisations Part of this Patient Organisations Part of this Network Network RSE European Association DIGESTIVE CANCERS (of Urology RAIN TUMOUR N ON 400 Lung Cancer Europe **Charities and Foundations Part of** this Network European EMANUELE Society of MALTA Pathology EST<u>RO</u> Community 365 INITIATIVE OF THE EUROPEAN CANCER ORGANISATION essc EUSOMA To view the latest list of the participants to the Workforce Network, visit our website. If you would like to find out more about the INTERNATIONAL SOCIETY OF GERIATRIC ONCOLOGY Workforce Network, please contact us at: info@europeancancer.org

Participants in the Special Network on the Impact of Covid-19 on Cancer

Member Organisations Part of this Network



Patient Organisations Part of this Network





To view the latest list of the participants in the Special Network on the Impact of Covid-19 on Cancer, visit our <u>website</u>.

If you would like to find out more about the Special Network on the Impact of Covid-19 on Cancer, please contact us at: 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.

european cancer organisation

Rue d'Egmont 13 B-1000 Brussels, Belgium

+32 2 775 02 00

europeancancer.org

