

Thursday, 10 December 2020 - updated

## INTRODUCTION

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As the COVID-19 crisis impact continues and worsens in many countries around the world, we as Chief Executive Officers, Chairs, and Presidents of nine global cancer coalitions and alliances, representing 750 patient advocacy and cancer organizations working on behalf of over 14 million patients around the globe, reaffirm our call for a plan of action to meet the challenges of this pandemic. This plan of action should draw on the experiences of the first wave and implement evidenced-based practices that have been proven to be effective, and include:

1. **Establishing COVID-19-free centres** where cancer patients can be treated at much lower risk of contracting the virus. Cancer patients, and their families, must be confident that they can safely access services. We also need safe options for access to general practitioners for cancer patients, or those experiencing cancer symptoms, that require in-person consultation.
2. **Implementing strategies, pathways, and practices and, where necessary, new infrastructure to enable cancer services to continue to operate** at the highest level of capacity possible - including screening, diagnostic, and treatment services.
3. **Providing ambulatory services** to deliver, where practical and safe, treatments or tests at a patient's home.
4. **Making the best use of tele-medicine services** to maintain consultations between clinicians and patients and decrease the need for in-person hospital visits, for example, for routine follow-up appointments. We also advocate for the use of technology to allow family and carers to participate in consultations where patients may not be allowed to bring anyone with them.
5. **However, it is also essential that patients have access to in-person consultations** with clinicians, where physical examinations are required, or where face-to-face consultations are necessary to maintain a strong patient-clinician relationship.
6. **Supporting patient advocacy organizations that are working on the front-line** providing invaluable information and support to those living with a cancer diagnosis as well as their families and carers. These organizations often complement or replace health care services that have been displaced by the pandemic. Emergency funding must be made available to these organizations to enable them to continue to provide this support.

Since our last Statement, published in July 2020, the dramatic downward trend in the number of clinical trials that are open to participants and the reduced number of patients recruited to trials that have been able to remain open has continued. For basic and translational research, it is crucial to ensure that cancer researchers are given access to the facilities and resources needed to resume their work.

At the same time, there have been some positive lessons learned during the pandemic, for example the benefit of decreasing the administrative burden and constraints on investigators and patients (i.e. decreasing the number of visits to the hospital and allowing the use of tele-medicine for some follow-up visits). Going forward, these positive lessons should be adopted as standard practice.

## BACKGROUND TO THIS CURRENT CALL TO ACTION

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### SOME FACTS AND FIGURES

In our initial joint statement, we outlined our concerns about the impact of COVID-19 on cancer services around the world, including the impact of the widespread suspension of screening and diagnostic services, cancellation and/or deferrals of life-saving treatments, changes in treatment regimens and interruption of vital research and clinical trials.

Six months on, and as of the date of this Statement, we now have concrete evidence of the devastating impact that COVID-19 has had on cancer services worldwide.

- More than **80,000 diagnoses** of five common cancers in the United States may have been delayed or missed in the first three months of COVID-19<sup>i</sup>
- A delay of just four weeks in cancer treatment can increase the risk of death by six and 13 percent<sup>ii</sup> (based on a systematic review and meta-analysis of seven cancers)
- Around **2.4 million people** in the United Kingdom are waiting for cancer screening, further tests or cancer treatment<sup>iii</sup> and it is estimated that across the United Kingdom, compared to a similar time frame last year 50,000 fewer people have been diagnosed with cancer<sup>iv</sup>
- In the United States, during the pandemic, the weekly number of newly identified cancer patients declined by 46.4%<sup>v</sup> (for six cancers combined)
- **38% of cancer surgeries** globally have been postponed or cancelled due to COVID-19<sup>vi</sup>

**ENSURING SUSTAINABILITY OF CANCER PATIENT ADVOCACY ORGANISATIONS**

**Front-line charities and not-for-profits that play a vital role supporting cancer patients continue to suffer acutely in the wake of COVID-19.** Surveys of our own coalition and association member organizations consistently highlight extreme levels of concern about their ability to continue to support patients, raise awareness, and fund research. One survey found that just 5% of cancer patient advocacy organizations were confident of their financial position with 80% projecting an average fall in income of almost 50% over the course of the coming year.<sup>vii</sup>

Our surveys of member organizations have also shown that patient advocacy organizations experienced significant increases in demand with 45% of calls and emails due to the pandemic. Most (63%) reported that they created new information resources relating to COVID-19. These organizations offer exceptional value and outstanding services – their loss would be immeasurable.<sup>viii</sup>

**COVID-19 – SECOND WAVE**

**COVID-19 has already had a catastrophic effect on cancer services and will impact survival rates for years to come.** More worryingly, many countries have entered further waves of the pandemic – with many starting their winter flu seasons at the same time.

We are extremely concerned about the ability of healthcare systems to respond to the virus’s resurgence and about the threat of further setbacks for cancer patients and future survival rates. Cancer services are already strained with the backlog of patients who have not been screened, investigated, or treated during the pandemic. Healthcare professionals are exhausted and many people living with cancer or experiencing cancer symptoms remain anxious about their wellbeing and access to safe health services.

**CANCER RESEARCH**

**COVID-19 has disrupted almost every aspect of cancer care, including research that drives critical advances in cancer outcomes.** Because of COVID-19 restrictions, important scientific activities including clinical trials have been delayed or suspended, research laboratories closed or reassigned to COVID-19 research activity and research materials (including specimens) lost and unlikely to be recovered.

In addition, the research community relies heavily on funding from the charitable sector. As highlighted above, patient advocacy organizations have experienced significant reductions in income which has meant that most have had to scale back funding of research. Our survey of coalition members<sup>ix</sup> found that:

- **75%** reported that research activities were affected at the time of the survey
- **A third** expressed concern about the viability of their current projects (30%)
- **30%** of those involved in research expected to reduce the amount of funding they can supply, or undertake in the future

The short-term disruption of research is worrying – the medium-long term impact has the potential to be disastrous for survival for hundreds of thousands cancer patients worldwide

In closing, the undersigned group of global cancer coalitions and alliances believe we must act swiftly to implement the above calls to action to avoid further set-backs in cancer care and survival and ensure that it does not take many decades to return to pre-pandemic levels.

*Advanced Breast Cancer Global Alliance*

*Lymphoma Coalition*

*Global Lung Cancer Coalition*

*World Bladder Cancer Patient Coalition*

*Global Colon Cancer Association*

*World Ovarian Cancer Coalition*

*International Brain Tumour Alliance*

*World Pancreatic Cancer Coalition*

*International Kidney Cancer Coalition*

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<sup>i</sup> Three Months of COVID-19 May Mean 80,000 Missed Cancer Diagnoses - Medscape - May 05, 2020

<sup>ii</sup> Hanna Timothy P, King Will D, ThibodeauStephane, Jalink Matthew, Paulin Gregory A, Harvey-Jones Elizabeth et al. Mortality due to cancer treatment delay: systematic review and meta-analysis BMJ 2020; 371 :m4087

<sup>iii</sup> Cancer Research UK, Over 2 million people waiting for cancer screening, tests and treatments, 01 June 2020, <https://scienceblog.cancerresearchuk.org/2020/06/01/impact-of-coronavirus-on-cancer-services-revealed-over-2-million-people-waiting-for-screening-tests-and-treatments>

<sup>iv</sup> Macmillan Cancer Care, 'The Forgotten C', The Impact of COVID-19 on Cancer Care, October 2020, <https://www.macmillan.org.uk/assets/forgotten-c-impact-of-covid-19-on-cancer-care.pdf>

<sup>v</sup> [Harvey W. Kaufman, MD<sup>1</sup>](#); [Zhen Chen, MS<sup>1</sup>](#); [Justin Niles, MA<sup>1</sup>](#); et al, Changes in the Number of US Patients With Newly Identified Cancer Before and During the Coronavirus Disease 2019 (COVID-19) Pandemic, JAMA Netw Open. 2020;3(8):e2017267. doi:10.1001/jamanetworkopen.2020.17267

<sup>vi</sup> Dmitri Nepogodiev, Omar M Omar, James C Glasbey, et al, Elective surgery cancellations due to the COVID-19 pandemic: global predictive modelling to inform surgical recovery plans, BJS Society Journal, 2 May 2020, <https://doi.org/10.1002/bjs.11746>

<sup>vii</sup> The Impact of COVID-19 on Cancer Patient Organizations, June 2020, World Ovarian Cancer Coalition, World Pancreatic Cancer Coalition, Lymphoma Coalition. World Bladder Cancer Patient Coalition, ANC Global Alliance

<sup>viii</sup> ibid

<sup>ix</sup> ibid