Cancer/Covid-19 Research Summit

12 November 2020

The pandemic has highlighted the importance of research and has made it clear that it is an integral part of a well-functioning healthcare system. There are numerous lessons to learn about how cancer-related research is conducted and how findings are translated into practice to aid crisis responses.

The aim of this meeting was to bring together researchers who are involved in projects on Covid-19's impact on cancer to:

- Identify key research themes or questions around Covid-19's impact on cancer prevention, early diagnosis and screening that we should continue to monitor/research.
- Establish if there are any significant gaps in our understanding of Covid-19's impact on care pathways and cancer patients that need to be addressed and how existing and new strands of research might be used to understand these issues.
- Raise other areas of concern we need to focus on to mitigate the impact of Covid-19 on cancer patients through effective research in this area.

This paper summarises the discussions and key research questions that were raised by the participants. While members of CRUK, PHE & NCRI facilitated the main discussion and breakout sessions, the views represented in this meeting summary do not necessarily represent the views of their organisation.

Knowledge and communication of cancer patients' risks associated with Covid-19

The pandemic highlighted a clear vulnerability in our understanding of infection risk in cancer patients, how we respond to these types of infections and communicate evolving knowledge. Policies and mitigation strategies, such as shielding advice and alterations to treatment pathways, were too broad and at times based on assumptions that lacked evidence. There need to be more solid criteria to support decision making, particularly to inform how referral and treatment should be managed for different patient groups. Faster and more extensive population-based screening in response to widespread infections was also deemed important to determine prevalence of infection among certain populations and enable accurate risk assessments. There is a huge opportunity to understand how people perceive and manage risk and how that impacts care.

Participants raised the need to develop a better understanding of how the risk of Covid-19 to a cancer patient is impacted by:

- Cancer type
- Treatment and polypharmacy - what elements of cancer treatment/progression influence the likelihood of infection and severe morbidity/mortality?
- Co-morbidities / pre-existing conditions / multiple long-term conditions
- Immunological factors - How does cancer impact the immune response to infection?
- Social inequalities

- Age - evidence has emerged that while absolute survival is worse in older cancer patients, the impact of cancer on survival is greater in younger cancer patients. Why is this and how does this impact an individual's risk?
- Sex - Data suggests that men and women are equally likely to acquire Covid-19, but men have a higher risk of severe illness and death. Why does sex matter? What differences in the endocrine background play a role here and how can this knowledge be used to help with risk stratification, both for Covid-19 and in response to other infections? How does this impact risk mitigation in the context of cancer?

Capturing the impact of Covid-19 on diagnostic and care pathways through health service research

Covid-19 caused a major disruption across cancer screening, diagnosis, treatment and follow-up/long-term care pathways. To fully understand the impact on patients and the healthcare system, the following areas need to be addressed:

- What changes in the patient pathway have occurred as a result of the pandemic and what has been the actual impact? Covid-19's impact on screening, referral, survival/stage, etc. has been largely based on modelling/estimation and there is a need to capture real/actual impact and over the longer term.
- How did primary care activity change during lockdown and the recovery period (e.g. symptom presentation, new diagnostic tests, urgent referrals) and how did this impact on stage of diagnosis? Anecdotally, clinicians have been seeing more advanced cancers.
- What gaps in service could be filled with pilot/research projects/innovation? What innovations were rapidly introduced that now need to be systematically evaluated to determine their benefits and limitations (e.g. telemedicine)?
- The number of two-week-wait referrals dropped during the first wave compared to the same period last year and there is concern that there may be a limited ability to catch up on the referrals that were not made. It was suggested that there may be a number of missing cancer cases as a result of this. What happened to the cases that would ordinarily have been diagnosed this year?
- Was the screening backlog caused by disruptions in service delivery or public attitudes e.g. fear of visiting primary and secondary care? What is the impact on screening uptake over time?
- Can uptake of innovations to address the screening backlog be accelerated e.g. HPV self-sampling, risk stratification? These would need to be introduced in a systematic way and appropriately evaluated to inform their usefulness during the pandemic and under normal circumstances.
- There has been, and in parts continues to be, a major impact on access to imaging and radiology services, which means that routine surveillance/secondary prevention is a major concern and this links to patient concerns about missed recurrences. It is also having an impact on clinical trials as the limited radiology capacity is prioritised for routine care. Are there examples of best practice where effective and efficient use of imaging was maintained during the pandemic that can be learned from? What opportunities for additional research are presented by the huge volumes of lung imaging data that has been collected in the National COVID-19 Chest Imaging Database (NCCID)[1]?

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[1] https://www.nhsx.nhs.uk/covid-19-response/data-and-covid-19/national-covid-19-chest-imaging-database-nccid/

- Endoscopy services were particularly disrupted, and some diagnosable and treatable cancers were not detected. What is the impact of the resulting stage shift for colorectal cancer and on cancer care pathways generally? How can such services be sustained during subsequent waves or pandemics?
- What has been the impact of changes or delays to standard cancer treatment regimens during Covid-19 on patient outcomes for different cancer types? Who was/is making the decisions to postpone or change treatment and how is the impact of those decisions being assessed? Is there a subgroup of patients that may have benefitted from the widespread off-label use of therapies during the height of the pandemic when standard treatment options were not readily available for many patients?
- Are people trying to self-manage symptoms using over the counter medication and other means of treatment or support?
- Covid-19 has highlighted many inequalities with regards to care across the country, for example access to diagnostics, treatment and support. Have people from ethnic minority backgrounds have been particularly affected in the context of cancer care? How are inequalities in care addressed and what additional support is needed?
- The pandemic has brought to light a troubling lack of preparedness in the healthcare system coupled with insufficient flexibility and capacity to sustain established care pathways in response to a major disruption. What lessons can be taken from the experiences during the pandemic and what contingency plans need to be put in place to manage future crises? What care pathways or procedures demonstrated higher resilience and could learnings from these inform measures to mitigate future disruptions in other parts of the system? How can sudden unexpected changes in patient pathways be managed more effectively?

Behaviour changes in response to a pandemic and factoring these in for the effective provision of cancer care

The pandemic and the measures implemented to manage it have had a profound impact on peoples' behaviour, particularly with respect to their health and accessing health services. There is a need to continue to develop a better understanding of attitudinal and behavioural changes in response to the pandemic and how these impact health and interaction with the healthcare system. This is not just important in the context of Covid-19 but will also inform strategies and guidance during future crises. There is a cross-cutting behavioural aspect to research studies on Covid-19's impact on cancer and it was suggested that it would be valuable to build a behavioural science framework or toolkit to support future studies. Several outstanding questions remain that need to be addressed:

- How much of the effect of COVID-19 on health services was due to deliberate system changes, changes in policy or changes in behaviour of public/patients/healthcare professionals? What role did unintentional changes play and to what extent were these known about and controlled for?
- How much did the COVID-19 pandemic and continual policy changes (i.e., social distancing rules and lockdowns) impact health behaviours of the public/patients?
    - Smoking, alcohol consumption, diet, physical activity
    - Attendance at screening
    - Compliance with medication
    - Visiting the GP & attendance at hospital/other healthcare settings
- Are there differences in changes to these behaviours in different groups due to a higher/lower perceived risk of severe Covid-19 and other factors?

Understanding the impact of the pandemic on the Quality of Life of patients and carers

Covid-19 infection can have far-reaching consequences for the individual, which can be greater for people with co-morbidities such as cancer. The pandemic also indirectly impacts the quality of life of cancer patients and those involved in cancer care and research. It is hoped that through more detailed monitoring of the patient experience, service delivery can be improved and negative effects on quality of life mitigated. To achieve this requires a better understanding of the impact of covid-19 on the following areas:

- What were the effects on the quality of life of:
    - Patients (see CRUK Cancer Experience Survey)
    - Caregivers
    - Those shielding
    - People with potential signs/symptoms of cancer (i.e. worry, access to services/screening etc)
    - Researchers
    - NHS Oncology Workforce (see COVID-NOW Study)
- What are the broader impacts on patients? Mental health and wellbeing is getting some focus, but what about financial impact, social impact, etc
- What are the effects of Covid-19 on the cancer population over time? This includes the potential long-term effects on Covid-19 positive cancer patients (Long Covid).

Importance of collecting and sharing data rapidly across disease areas and treatment modalities

The importance of collecting high-quality health data and sharing it for research, clinical and policy decision-making was brought to the forefront by the pandemic. There have been many exemplars of good practice and regulatory flexibility to enable fast and secure access to data. However, the pandemic has also highlighted limitations of the current system that need to be addressed. Collaboration is essential to capitalise on progress made in the health data space in response to Covid-19 and address the following areas:

- There is a need for new evidence (on say treatment efficacy; risk factors) to reach / be acted upon by the decision-makers responsible for the Covid-19 mitigation policy & guidance (practices, advice, instructions etc.). Some insights from data collected during the 1st wave were not translated into guidance to patients or changes to design and delivery of services in preparation for the 2nd wave. How is this data/policy disconnect managed to enable informed decisions on changes to healthcare provision and guidance?
- What can be learned about the translation of research and data into practice?
    - During emergencies
    - In normal circumstances
- Lots of different social determinants impact Covid/cancer outcomes, but this information is spread across many different platforms. There need to be improvements in the collection and sharing of data, as well as sharing of data resources, across the UK.
- Important to bring together Cancer/Covid data across the cancer pathway and across the disciplines. A Trusted Research Environment (TRE) is a good way to achieve this and efforts to establish these for health data need to be joined up to make the most of the existing data.

- There is a need for better signposting of what data is available, where and how it can be accessed. The Health Data Research UK (HDR UK) Innovation Gateway is being developed as a common entry point to discover and enquire about access to UK health datasets for research and innovation. There is a need to encourage and support researchers to share metadata in this way as this will be hugely important to highlight what data is available to inform research and policy.
- Covid-19 has also highlighted the need for data to be made available in real-time to support decision making and research.

Learning from the pandemic to build a better future for cancer research and care

The pandemic has raised public awareness of the importance of research and made it clear that research is an integral part of a well-functioning healthcare system. There are numerous lessons that can be learned from the pandemic about how cancer-related research is conducted and how findings are translated into practice. While this is by no means an exhaustive list, here are some of the suggestions that were made:

- The outstanding speed with which some of the academically led Covid-19 research studies and trials were initiated, set up and reported demonstrated that the constraints and challenges normally encountered can be overcome. Granted, in the case of Covid-19 all other research efforts were largely set aside to focus resources, capacity and infrastructure on a single goal and building a large collaborative effort, but it is important to understand what barriers were overcome to improve how research is usually conducted. For example, what can be adopted to improve clinical trials under normal circumstances? To what extent does there need to be more coordinated prioritisation of clinical studies or essential elements of individual studies to enable cancer research to progress at pace through to clinical implementation?
- In the context of Covid-19 it was important to understand how infection affects people with cancer and there have been examples of multidisciplinary efforts to characterise the interaction of Covid-19 and cancer. Could these be adopted to inform multimorbidity research across diseases and disciplines? How can working across disciplines be improved to gain a broader understanding of disease interactions?
- Research funding is a major concern, particularly for cancer research going forward due to the impact the pandemic has had on cancer charities (see here for more information). There is a need for more rapid response mode funding calls in the cancer domain to support innovative fast-paced research. There is also a need for a more coordinated and joined up approach by government, industry, third sector organisations and charities to better align their cancer research funding strategies so that support is provided along the research pipeline, as well as along the various stages of a researchers career pathway.
- Decisions about research are being interpreted in different ways and made locally – clinical research is linked to the healthcare system in such a way that when the health service comes under threat research gets pushed aside. It is essential to understand how to embed research in a way that it is seen as a core and indispensable function of the healthcare system.
- A system that supports complexity in clinical research and trial protocols that vary from standard care is required – there is a pressure to make protocols as simple as possible to limit strain on the system but we need to be clear that more complex

and experimental trials are needed to really shift the needle – these also need to be effectively prioritised and protected in times of crisis and driven forward through coordinated and collaborative efforts.

- “There is too little resilience in the system - We don’t have enough space on the board to move around the pieces when something goes wrong” - There needs to be a focus on protecting health services, as well as improving them. There was a clear inability to adapt or to be imaginative in order to protect vital cancer services. It is hoped that the experiences from the pandemic trigger a more considered re-design of services. How can data on service /patient impact be used to add to the case for more systems capacity – particularly for screening, surgery and potentially health improvement services (i.e. the case for resilience)? What long term resilience/preparation needs to be put in place?
- “Infectious disease doctors were somewhat prepared for this and had contingency plans in place, so they reacted rapidly, but I am struck by our inability to react to this sort of crisis in cancer care and to protect vital research efforts so not to lose years of progress” - What can be learned from colleagues working in infectious diseases? How can collaborations and infrastructure built in response to Covid-19 be leveraged to identify, support and progress vital research in other disease areas? What can be learned for the future from what is known now?

Next steps

It is important we work together across cancer research, care and beyond to address some of the key questions raised during this Cancer/Covid Research Summit and take forward what has been learned to ensure our ambitions for cancer prevention, early diagnosis and treatment can be realised.

CRUK, NCRI and PHE NCRAS will share this summary with colleagues and wider external networks. These research questions will inform the external research we monitor and the research we manage/initiate within our relevant departments. We will look to build on this meeting and bring the community together around some of the key areas outlined above.

We want to thank all the researchers that participated in the Cancer/Covid-19 Research Summit for their contributions and for keeping the UK at the forefront of research even in these trying times.